Request for Further Evidence: Health, Social Care and Sport Committee Consultation on the Assisted Dying for Terminally Ill Adults (Scotland) Bill

7 November 2024

Thank you for the opportunity to give evidence on 5 November 2024 to the Health, Social Care and Sport Committee in relation to its consideration of the Assisted Dying for Terminally Ill Adults (Scotland) Bill. I provide this further evidence in response to a request for specific information from the Committee.

Further comments on the Scottish Bill

I was asked during the Committee session about my views on the Scottish Bill. My response highlighted a range of issues drawing on the submission I made with Professor Lindy Willmott to the Committee's consultation exercise. I commented on some of the issues in the session that we raised in that submission and I will not repeat what we have said in that submission. However, I will briefly make some key points:

- I support the Bill not specifically requiring a designated expected timeframe until death. This is a strength of the Bill for the reasons I mentioned at the session and those we raise in our written submission.
- We suggested consideration be given to regulating institutional objection in the Bill but as this was the subject of a separate question, I will address this further below.
- I mention again that if the Bill only allows self-administration, there is a risk of excluding people who are unable self-administer (depending on what methods of self-administration are permitted). I consider that the choice of voluntary assisted dying should be available to all persons who meet the eligibility criteria.
- Another issue I mentioned in the session (also addressed in our submission) is in relation to conscientious objection. We consider that individuals should be permitted to conscientiously object to participating in voluntary assisted dying but conscientious objectors should have some obligation to assist a patient to identify the next steps to take. At the very least, the objecting individual should be required to provide the patient with a document which provides information on how the patient can access information about voluntary assisted dying.
- One significant matter I did not address in the session is the reference in the definition of capacity to a person having capacity if they 'are not suffering from any mental disorder which might affect the making of the request.' For reasons we mentioned in our submission, this appears inconsistent with the usual approach to assessing capacity (including the presumption of capacity).

- I also mention support for two issues that Julian Gardner (Chair of the Victorian Voluntary Assisted Dying Review Board) raised in the session:
    - Waiting periods can cause access barriers and 14 days is longer than the timeframes we have in Australia (and those shorter waiting periods can be problematic here).
    - Residency requirements can also be problematic and if they are to retained, then the ability to seek exemptions in appropriate cases would be valuable.
- A final comment is to note I did not speak in the session about the need for policy deliberation on voluntary assisted dying to be evidence-based. Our submission sets out our position on this and I take this opportunity to draw the Committee's attention to our discussion of this.

Institutional objection

This issue is addressed in our submission and I will draw on that information here. I will also include the research we have done on this point as attachments.

We suggested that the Bill should regulate institutional objection to ensure patients are not deprived of access to voluntary assisted dying simply because of where they are receiving their care.

A threshold point to note is that there is emerging evidence of harm, to both patients and their caregivers, when institutions object to voluntary assisted dying. Research participants in a study of the Victorian system in Australia have described delays, emotional suffering and reduced patient choice that can result from institutional objection. The key study on this point and a two page research briefing summarising key findings are:

- Ben White et al, 'Harms to patients caused by institutions objecting to voluntary assisted dying', Research Briefing (2023)
- Ben White et al, 'The impact on patients of objections by institutions to assisted dying: a qualitative study of family caregivers' perceptions' (2023) 24 BMC Medical Ethics, Article number: 22.

It is important therefore that (a) regulation addresses these issues and (b) this regulation minimises the chance of such harm occurring.

Research from our team on the Canadian experience has also found institutional objection causes harms, including to health practitioners:

- Eliana Close et al, 'A qualitative study of experiences of institutional objection to medical assistance in dying in Canada: ongoing challenges and catalysts for change' (2023) 24 BMC Medical Ethics, Article number: 71.

We suggest it is therefore necessary to develop a framework that ensures institutional objection does not adversely affect an individual's access to voluntary assisted dying should that be their choice. We explore this issue further in:

- Ben White et al, 'Legislative Options to Address Institutional Objections to Voluntary Assisted Dying in Australia' (2021) University of New South Wales Law Journal Forum 1.

We note that the last four of the seven Australian jurisdictions which legalised voluntary assisted dying all chose to include some regulation of institutional objection, in recognition of the significance of this issue. We note in particular the models in Queensland and the Australian Capital Territory may be worth considering.

Regional access to voluntary assisted dying in Australia

I provide some information here in response to the request: ‘whether you have anything to add regarding challenges of rurality in Australia, for example in terms of face to face meetings and assessments’.

There can be challenges accessing voluntary assisted dying in regional areas in Australia (particularly given its size and the distribution of some regional communities). A particular complication for Australia is that Commonwealth law prohibits the use of telehealth and other forms of electronic communication for some parts of the voluntary assisted dying process. This Commonwealth law was not intended to apply to state voluntary assisted dying laws and efforts are underway to reform that legislation. That is a peculiar limitation in Australia which other countries do not have to navigate so I will put that aside for this discussion (but I acknowledge that any regional barriers are significantly further compounded by that Commonwealth law).

Different states have attempted to address regional access barriers through specified policy initiatives. We have done an analysis of the policy initiatives in Western Australia (the largest state by area in Australia and one of the largest subcountry divisions globally) to support regional access to voluntary assisted dying. Those initiatives include a Regional Access Support Scheme and Regional Access Standard. A second study then evaluated those initiatives through stakeholder interviews. I set out those studies below and also provide them as attachments.

- Willmott, Lindy, Haining, Casey, & White, Ben (2023) Facilitating regional and remote access to voluntary assisted dying in Western Australia: targeted initiatives during the law-making and implementation stages of reform. Rural and Remote Health, 23(1), Article number: 7522.
- Haining, Casey, Willmott, Lindy, & White, Ben (2023) Accessing voluntary assisted dying in regional Western Australia: early reflections from key stakeholders. Rural and Remote Health, 23(4), Article number: 8024.

A final point to make is that some Australian states have specific service capability to support access to voluntary assisted dying on a statewide basis. For example, in Queensland, the Queensland Voluntary Assisted Dying Support and Pharmacy Service has the capability to travel across the state to facilitate access to voluntary assisted dying where there is not local capacity. Likewise, New South Wales has established an Access Service which can travel to provide access to voluntary assisted dying across the State.

Other

I note the request for a forthcoming publication on the Australian experience of its medication protocol and would be pleased to forward this to the Committee when it is available.

Thank you for the opportunity to provide this further information to the Committee in relation to its inquiry into voluntary assisted dying. I would be pleased to provide any further information to the Committee if that would be of assistance.

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Harms to patients caused by institutions objecting to voluntary assisted dying

Delays, emotional suffering and reduced patient choice

What is this research about?

Victoria is the first Australian state to permit voluntary assisted dying (VAD). Health practitioners can conscientiously object to VAD but the law does not say anything about institutions (hospitals, palliative care units, and residential aged care facilities). In this Australian-first study, we gathered evidence on how objections by institutions affect patients seeking VAD.

What did we do?

We did 28 interviews with 32 family caregivers and one patient about the experience of seeking VAD in Victoria. 17 of those interviews discussed some experience with an institution objecting to VAD. We analysed what people said about institutional objection and its impact on patients.

What did we find?

The objections people described generally occurred in Catholic facilities or palliative care settings (e.g. palliative care units within hospitals).

Objections by institutions stopped some or all of the VAD process happening onsite. Most commonly patients were not allowed to:

- Have eligibility assessments (i.e. meet with a doctor to be assessed for VAD)
- Take delivery of the VAD medication from the pharmacy (when they were approved as eligible for VAD)
- Take the VAD medication or have it administered to them.

“They would not allow the state pharmacist representatives to come into the hospital at all.”

“Oh, sorry, … you’ll have to wait for [patient name] to come out of hospital.”

People described a range of harms that objections by institutions caused:

- Delays in patients being able to access VAD
- Patients transferring out of a facility to seek VAD
- Patients having to choose between continuing the VAD process or staying in a facility to receive palliative or other care
- Emotional suffering by patients and families
- Patients and families distrusting objecting institutions.

> **"It will always be a great sadness for me that the last few precious hours on Mum's last day were mostly filled with stress and distress, having to scurry around moving her out of her so-called 'home'."**

Some things made dealing with institutional objection easier such as:

- Supportive staff working at the facility, or
- Having an assertive family member who could advocate.

Some things made dealing with institutional objection more difficult such as:

- Facility staff being opposed to VAD, or
- Patients being so ill it was difficult to move to a more supportive facility.

What should happen next?

1. Objecting institutions should be aware of these harms to patients and try to avoid them. They should find ways to support patients' choice for VAD that avoid or minimise conflict with the institution's values. One option is to not participate in VAD but allow outside doctors and pharmacists access to institutions to undertake the VAD process for patients who make that choice.

> **"So allowing free access to VAD doctors to access patients, if that's what the patient wants, while they're in hospital. Because some people spend an awful long time in hospital..."**

2. Better regulation may also be needed. Victoria's VAD legislation does not deal with institutional objection – unlike the law in Queensland, South Australia and New South Wales. The Victorian Department of Health has a policy that guides how institutions can manage objections, but this is not binding. As a result, institutions currently have a lot of power to object to VAD. There is a strong argument to limit that power of institutions to object to VAD when this harms patients.

For more information

This research briefing is based on Ben P White, Ruthie Jeanneret, Eliana Close and Lindy Willmott, "The impact on patients of objections by institutions to voluntary assisted dying: a qualitative study of family caregivers' perceptions" *BMC Med Ethics* **24**, 22 (2023). More information about study limitations, research ethics and disclosures are available in the article: **https://doi.org/10.1186/s12910-023-00902-3**.

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RESEARCH **Open Access**

The impact on patients of objections by institutions to assisted dying: a qualitative study of family caregivers' perceptions

Ben P. White*, Ruthie Jeanneret, Eliana Close and Lindy Willmott

Abstract

Background Voluntary assisted dying became lawful in Victoria, the first Australian state to permit this practice, in 2019 via the *Voluntary Assisted Dying Act 2017* (Vic). While conscientious objection by individual health professionals is protected by the Victorian legislation, objections by institutions are governed by policy. No research has been conducted in Victoria, and very little research conducted internationally, on how institutional objection is experienced by patients seeking assisted dying.

Methods 28 semi-structured interviews were conducted with 32 family caregivers and one patient about the experience of 28 patients who sought assisted dying. Participants were interviewed during August-November 2021. Data from the 17 interviews (all with family caregivers) which reported institutional objection were analysed thematically.

Results Participants reported institutional objection affecting eligibility assessments, medication access, and taking the medication or having it administered. Institutional objection occurred across health settings and was sometimes communicated obliquely. These objections resulted in delays, transfers, and choices between progressing an assisted dying application and receiving palliative or other care. Participants also reported objections causing adverse emotional experiences and distrust of objecting institutions. Six mediating influences on institutional objections were identified: staff views within objecting institutions; support of external medical practitioners and pharmacists providing assisted dying services; nature of a patient's illness; progression or state of a patient's illness; patient's geographical location; and the capability and assertiveness of a patient and/or caregiver.

Conclusions Institutional objection to assisted dying is much-debated yet empirically understudied. This research found that in Victoria, objections were regularly reported by participants and adversely affected access to assisted dying and the wider end-of-life experience for patients and caregivers. This barrier arises in an assisted dying system that is already procedurally challenging, particularly given the limited window patients have to apply. Better regulation may be needed as Victoria's existing policy approach appears to preference institutional positions over patient's choice given existing power dynamics.

Keywords Assisted dying, Medical assistance in dying, Euthanasia, Assisted suicide, Institutional objection, Patient experience

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Background

There is an international trend to legalise assisted dying ("AD"), also known as medical assistance in dying, physician-assisted suicide and euthanasia [1]. Despite being lawful in many jurisdictions globally, AD remains controversial. Generally, health professionals can refuse to participate in AD through conscientious objection. While the appropriate scope of such objection remains contested, it is a well-recognised concept with protections in law and policy [2].

Healthcare institutions may also object to AD, yet how rights and obligations of objecting institutions are, or should be, conceptualised is less clear. While some analogies with individual conscientious objection are possible [3], there are important differences, including for example, the prospect of a wider access barrier for patients when an entire institution, as opposed to an individual health professional, objects to AD [4]. There may also be more diverse grounds for healthcare institutions to object.

Such objections are typically claimed by faith-based institutions, predominantly Catholic ones, which commonly provide a large proportion of end-of-life care [3, 5, 6]. But some argue institutions are incapable of holding a moral or ethical position based on conscience [3, 7]. An institution is a corporate organisation that, unlike an individual, cannot experience guilt or suffer moral injury from acting against its conscience. Others contend institutions may have a distinct mission and moral identity [6]. For example, Catholic institutions are centred on an "ethic of care" and Catholic values, an ethos which some argue is analogous to an individual's conscience [3, 6].

In a somewhat different vein, Shadd and Shadd skirt the debate about the existence of institutional conscience and instead contend institutions' right to object is a matter of self-governance, provided they have a "legitimate reason" for the objection, including moral or religious justifications [8]. Others respond that institutional objection must be curtailed and balanced against protecting patient interests, given the considerable harms such objections can cause [3, 9, 10]. This is important because patients seeking AD are often vulnerable by virtue of disease, illness, and/or frailty, and existing power asymmetry with institutions is more pronounced [9].

Despite bioethical engagement with institutional objection, there is limited empirical research on its impact on AD [10–13]. Studies report on objections by institutions to providing information about AD, eligibility assessments, and provision of AD medication onsite [12, 13]. In some cases, objections have resulted in forced transfers out of a facility for an AD assessment or provision, causing additional pain, suffering, and stress for patients and caregivers [10, 12–14]. In other cases, institutional objections have precluded access to AD because a transfer is unavailable or physically unbearable [4, 10, 13]. The literature also suggests broader impacts of institutional objection, including it being a risk factor for complicated grief [15], and "knock-on" effects of an institution's policy affecting the willingness of local healthcare professionals to participate in AD [12]. Existing findings about institutional objection have usually been included as part of wider reports about patients', caregivers', or health professionals' perspectives on AD more generally, and therefore the discussions of institutional objections are brief. As an increasing number of jurisdictions legalise AD, more research is needed to better understand how institutional objection can arise, the factors affecting patient experiences, and the impact of the particular regulatory context.

This article helps address this knowledge gap. It reports on institutional objection to AD in Victoria, Australia and draws on the country's first study of patient AD experiences, as reported by family caregivers. Victoria is examined as it was the first Australian state to legalise AD. Its *Voluntary Assisted Dying Act 2017* (Vic) has been operational for over three years. The Act's default method of AD is self-administration, where patients take the medication themselves (physician-assisted dying), but practitioner administration, where the medication is administered by a doctor (euthanasia) is permitted when patients are not physically capable of taking or digesting the medication [16]. Eligibility criteria include that a patient is terminally ill with doctors required to confirm that a patient is expected to die within 6 months, or 12 months for neurodegenerative conditions.

On the issue of institutional objection, the Victorian legislation is silent, an approach followed in the other states of Western Australia and Tasmania. By contrast, the legislation in South Australia, Queensland and New South Wales (the last three Australia states to legalise AD) specifically regulate institutional objection, with varying balances struck between ensuring patient access and respecting institutions' positions.

The legislative silence on institutional objection in Victoria led to regulation via policy. The Department of Health issued policy recommendations [17] and each institution manages its own institutional position and local policy development. The Department's policy guidance is permissive in that it suggests models of participation and possible steps, such as referrals to a statewide AD navigation service to facilitate access, but it does not require institutions take particular steps. Reflecting this, an analysis of publicly-available AD policies produced by objecting institutions demonstrated they contained little practical guidance that would assist patients to navigate those objections to AD [18].

This article reports on how institutional objection has manifested in practice, including the nature of objections expressed, practices institutions prohibited, views of employed staff, impact on patients, and mediating factors affecting patient experiences.

Methods

Research design

This study is part of a broader research project, involving interviews with patients, family caregivers, health professionals and regulators in Australia (as well as two case study countries, Canada and Belgium) [19]. The project seeks to understand participants' perspectives and experiences of decision-making about AD and how regulation is working in practice, to inform an optimal holistic model of regulation [20]. This article focuses on patient experiences of institutional objection while seeking AD, in the Australian state of Victoria, as reported by family caregivers.

We adopt a critical realist approach to this research, [21] and used Braun and Clarke's reflexive thematic analysis [22]. As noted below, our reflexive practice [22] included BPW and RJ conducting these interviews together, and debriefing after each interview as well as periodically discussing with the authorial team the initial analysis and interpretations of the data. A research journal was maintained and referred to throughout the data collection and analysis processes. All authors reviewed the final data collected and interpretations were shared and iteratively discussed to achieve a richer understanding of the data [23]. The method is reported according to the Consolidated Criteria for Reporting Qualitative Research [24].

Sampling and recruitment

For the wider study investigating patients' experiences of seeking AD in Victoria, Australia, participants eligible for inclusion were patients seeking AD in that state, and family caregivers who had or were supporting patients through this process. "Seeking AD" meant that the assessment process had started, but it did not have to be completed, nor did the person have to be approved for AD to be eligible to participate in this study. Participants had to be over 18 years of age.

As discussed further below, we were only able to recruit one patient in the broader study, and they did not experience institutional objection, hence this article is based solely on reports of patient experiences by family caregivers as proxy. While accounts directly from patients would have been preferable, to be eligible for AD in Victoria, patients must be terminally ill (within 6 or 12 months of death depending on their condition) and suffering intolerably, making this a challenging cohort to recruit. Many participants are too ill to participate in research once a terminal prognosis is established [25]. Challenges with recruitment of terminally-ill patients are well-recognised in end-of-life research, and after-death interviews with family caregivers are the next best way to explore patient experience [25, 26].

Recruitment occurred through social media (Twitter) and key patient interest groups Go Gentle Australia and Dying with Dignity Victoria (sharing study details via social media, newsletters, and direct emails). Initially relying on convenience sampling, we later used purposive sampling seeking a breadth of domains including patient age, sex, illness, location (metropolitan/regional), timing of seeking access, and patient experience of AD (self-administration, practitioner administration, sought AD but did not use or not approved). These later recruitment communications specifically stated the particular patient characteristics we were yet to collect data on, and this included direct emails from some of the patient interest groups noted above to potentially matching participants.

Data collection

An interview guide (Additional File 1) was developed based on our analysis of the Victorian legislation [16], previous interviews with doctors [27–29], and discussion within the research team. Key areas explored were: process of seeking AD including seeking information, eligibility assessments, and accessing and taking medication or having it administered; navigating the system; and overall perceptions of the system's operation. For cases when an institution objected to AD, discussion of this was often initiated by the participant in the course of explaining the patient's experience of the AD process. But a more general question was also asked if this issue was not specifically raised: "Did the facility facilitate access to AD or was it a barrier to access?". When an institutional objection was reported, follow up questions explored issues such as: the stage in the process where barriers arose (e.g. when AD was first raised, during eligibility assessments or at the medication stage); what the impact of the objection was; and the role of institution staff in implementing and communicating the objection.

Interviews traced the patient journey of seeking AD. Family caregivers were asked to report their perceptions of the patient's AD experience, but they also shared their personal views and experience. For example, when participants described the impact of institutional objection on them and family members other than the patient, these experiences were explored. Most of the caregivers interviewed had accompanied their family member patient throughout their AD journey, for example, caring for them at home and being present during medical appointments or clinical discussions in hospitals or other facilities, and so were able to draw on this shared experience.

Participants provided free and informed consent. For all family caregivers, the patient whose experience they were sharing had died, and so patient consent was not sought. Some interviews involved two participants at their request, for example, two children of a deceased patient. All interviews were conducted by two authors BPW and RJ together, with one a designated lead. Interviews occurred between 17 August and 26 November 2021 via Zoom video conferencing except for two by phone and one in-person. Recruitment ceased once the research team considered there was sufficient "information power" to meet the study aims [30]. Interviews were digitally audio-recorded and transcribed verbatim. Participants had an opportunity to amend or add to their transcript (member checking) [31] and some provided additional supplementary information (e.g. chronology or narrative of patient experience).

Analysis

Analysis occurred in two main stages. The first involved thematic analysis of transcripts and participants' supplementary information line by line with codes developed both deductively (from literature and iterative discussion of emerging themes) and inductively [22]. Seventeen interviews were double coded by BPW and RJ (codes discussed and refined periodically), with BPW coding the remainder. Iterative analysis occurred while collecting data with BPW and RJ debriefing after each interview, and regularly throughout data collection and analysis. This first stage of analysis included identifying those interviews that reported institutional objection, namely when a participant perceived an institution objected to some or all aspects of AD, including when this objection may not have been expressly stated. This included where participants reported perceiving access to AD would be affected because of an institution's stated religious affiliation, or because of interactions with an institution's staff, even if it was not expressly stated that AD would not be permitted.

The second stage involved a focused analysis of this subset of interviews reporting institutional objection. Using reflexive thematic analysis, BPW recoded this data inductively line by line to develop further sub-themes about how patients experienced institutional objection [22]. These preliminary findings were iteratively discussed by all authors, who also studied all institutional objection data, to enhance the richness of analysis. This second stage included reviewing transcripts as a whole to understand institutional objection in context (e.g. impact of geographic location, nature of illness, timing of AD experience). Both stages of analysis were aided by NVivo (release 1.6.1 QSR International) which was used to store, code, and search transcripts.

Results

Twenty-eight interviews were conducted with 32 family caregivers and one patient (Table 1) in relation to the experiences of 28 patients (Table 2). The sole patient interview involved a participant who spoke about their own experience of seeking AD. In the remaining family caregiver interviews, participants reported on the experience of their family member as a patient seeking AD, all of whom were deceased at the time of interview. The median length of interviews was 90 min, with a range of 56 min to 130 min.

Seventeen of the 28 interviews (Table 1) discussed an institutional objection (distinct from conscientious objection by an individual) impacting on patient access to, or experiences of, AD. These 17 interviews were all with family caregivers (n = 20), and related to the experience of 17 patients (Table 2). The median length of these interviews was 95 min, with a range of 56 min to 130 min. The remaining eleven interviews that did not consider institutional objection are not included in this further analysis.

A broad range of themes were identified: the basis and expression of the objection; nature of the AD-related activity objected to; impact of institutional objection; spectrum of staff views within objecting institutions; and factors mediating the impact of institutional objection.

Basis and expression of institutional objection

Participants principally cited Catholic institutions as manifesting objections to AD (Box 1). Some also saw palliative care philosophy as founding objections. Sometimes these grounds overlapped. Objections occurred across public and private healthcare settings and by hospitals, palliative care units, residential aged care facilities and community care organisations.

How and when an institutional objection was expressed varied. Some institutions made "explicit statements from the start" to patients and/or caregivers. But one participant reported being surprised because a clear direction that the AD medication could not be taken onsite was communicated to them and the patient very late in the process. Some stated they already knew an institution's objection through media statements or published policy positions.

Other times, an institution's objection was gleaned only through context and interactions and not explicitly stated. One participant spoke of just getting "a sense" a transfer of the patient would be needed. Sometimes participants inferred AD was off-limits because of religious affiliation: "it's a Catholic place".

Table 1 Characteristics of interview participants (total sample and institutional objection study sample)

Characteristics	Total sample (n = 33): number (n %)	Institutional objection study sample (n = 20): number (n %)
Age (years)	Mean: 56.6	Mean: 56.9
20–29	1 (3%)	0 (0%)
30–39	4 (12%)	2 (10%)
40–49	7 (21%)	5 (25%)
50–59	3 (9%)	3 (15%)
60–69	13 (39%)	7 (35%)
70–79	4 (12%)	3 (15%)
80–89	1 (3%)	0 (0%)
Sex		
Female	26 (79%)	18 (90%)
Male	7 (21%)	2 (10%)
Relationship to patient*		
Child (including stepchild, child in-law)	17 (50%)	12 (60%)
Spouse (including de facto partner)	10 (29%)	6 (30%)
Parent	3 (9%)	2 (10%)
Sibling	2 (6%)	0 (0%)
Close friend	1 (3%)	0 (0%)
Self	1 (3%)	0 (0%)

*One participant in the overall sample spoke about two patients so is included in two categories. Percentages in that section of the table are calculated using number of relationships (34)

Box 1: Participant quotes—Basis and expression of institutional objection

Many of the palliative care organisations are run by Catholic institutions who are not in favour of voluntary assisted dying. So that was always going to be a bit of an issue for us in talking about it with [patient name]… (Family caregiver of patient with cancer)

It was in the media. Catholic-based health facilities put out a joint statement, and their joint statement was that they were conscientious objectors to the voluntary assisted dying. (Family caregiver of patient with cancer)

I knew for a start that she couldn't die there… because I'd looked it up on their website. So we didn't even pursue it. So I always knew that it wasn't going to happen. (Family caregiver of patient with neurological condition)

Practices institutions objected to

Many objecting institutions prohibited most or all of the AD process. Participants' reports centred on three key aspects (Box 2). The first was not permitting AD eligibility assessments within the institution. Particular hospitals were described as barring entry to outside doctors attending to assess a patient's eligibility. The second was precluding receipt of the medication. Some institutions denied access to the Statewide Pharmacy Service, which delivers the medication to eligible patients. The third was not allowing AD medication to be taken or administered onsite. For inpatients or those in residential care, this meant having to be discharged or transferred to access AD. In one case, the institution would allow self-administration, but not practitioner administration, onsite. In another case, for a patient at home, a community care nurse was prohibited by her employer from being present when AD occurred.

In addition to these three key aspects of the AD process, participants also gave examples of staff not being allowed to discuss AD with them or patients, refusing admission to a residential facility for a patient intending to seek AD, and concerns about death certification.

Box 2: Participant quotes—Practices institutions objected to

[T]he oncologist said he would come to the hospital to do the second appointment, and when he heard I was at [Catholic hospital], he said, "Oh, sorry, I can't come there, you'll have to wait for [patient name] to come out of hospital." (Family caregiver of patient with cancer)

That was at the time when it was likely that Mum was going to be transferred to [Catholic hospital]

Table 2 Characteristics of patients whose voluntary assisted dying experience was the subject of interviews (total sample and institutional objection study sample)

Characteristic	Total sample (n = 28): number (%)	Institutional objection study sample (n = 17): number (%)
Age (years)	Mean 70.8	Mean 73.2
20–29	1 (4%)	0 (0%)
30–39	1 (4%)	1 (6%)
40–49	0 (0%)	0 (0%)
50–59	3 (11%)	1 (6%)
60–69	7 (25%)	4 (24%)
70–79	8 (29%)	5 (29%)
80–89	6 (21%)	5 (29%)
90–99	2 (7%)	1 (6%)
Sex		
Female	13 (46%)	7 (41%)
Male	15 (54%)	10 (59%)
Location		
Metropolitan	16 (57%)	13 (76%)
Regional	12* (43%)	4 (24%)
Highest level of education		
Some high school	7 (25%)	6 (35%)
High school	9 (32%)	4 (24%)
University–diploma	1 (4%)	0 (0%)
University–undergraduate	7 (25%)	4 (24%)
University–postgraduate (including graduate diploma)	4 (14%)	3 (18%)
Primary disease, illness, or medical condition		
Cancer	18 (64%)	10 (59%)
Neurological	9 (32%)	6 (35%)
Other	1 (4%)	1 (6%)
Eligibility for voluntary assisted dying and death		
Assessed as eligible	24 (86%)	16 (94%)
Patient died via self-administered medication	19 (68%)	12 (71%)
Patient died via practitioner administered medication	3 (11%)	3 (18%)
Patient died but did not take medication (natural death)	1 (4%)	1 (6%)
Patient waiting to take medication	1 (4%)	0 (0%)
Patient died prior to eligibility assessment completed	3 (11%)	1 (6%)
Patient assessed as ineligible and died	1 (4%)	0 (0%)
Timing of voluntary assisted death (or engagement with process)		
July–December 2019	4 (14%)	2 (12%)
January–June 2020	6 (21%)	4 (24%)
July–December 2020	3 (11%)	1 (6%)
January–June 2021	10 (36%)	6 (35%)
July–November 2021	5 (18%)	4 (24%)

*One patient in the overall sample who was classified as regional moved to a metropolitan area during the voluntary assisted dying process.

> because her pain was so severe… [Catholic hospital] actually told us that if she came … that they would not allow the state pharmacist representatives to come into the hospital at all. (Family caregiver of patient with neurological condition)

> They said, "… so do you think you'd like to go [home–town name] or is there somewhere else?" Dad said, "No, I will just do it here." At that point they said "Well, actually we can't do it on hospital grounds." So Dad [said], "Well, okay, push me out to the carpark

and I'll do it there." (Family caregiver of patient with cancer)

I was saying that "I'm actually really hoping that she goes down this avenue," and … she said, "I have to stop you there … I'm so sorry, but because of where I work I'm actually not allowed to actually have a conversation with you about assisted dying at all." (Family caregiver of patient with neurological condition)

Impact of institutional objection

Participants described three key ways that institutional objection hampered patient access to or experience of AD: patient delay in accessing AD; reduced choice for patients about AD; and emotional and relationship costs for patients and family caregivers (Box 3).

Delay for patients was the principal impact, either due to prohibiting access to doctors and pharmacists, or making patients wait until they left the institution to receive or take the medication.

Patient choice was also affected. Participants described patients needing to choose between progressing the AD process or being admitted to an objecting hospital to manage pain and symptoms. In terms of missing out, one of the three patients in this study who died while seeking AD experienced an institutional objection. Their participating family caregiver considered the objection contributed to this and delays occurred because eligibility could not be assessed in that faith-based hospital. However, access to AD for this patient was challenging because of rapid illness progression and other factors.

Institutional objection also affected patient choice about place or time of taking AD medication. Participants described transfers or patients getting "shipped to a completely different hospital" or facility, including away from staff who had been caring for the patient. This often meant waiting until a bed was available in the transferring facility, resulting in delays accessing AD. Sometimes a transfer was needed back to a patient's or family's home to take the medication, which was not the patient's preferred place to die.

Participants described emotional and relationship costs to patients (and families) of access being hampered by institutional objection. Both patients and families experienced anger and frustration at being in a holding pattern of not being able to seek AD. Some patients were fearful of missing out on their choice. One participant described her mother being "absolutely terrified that they would find out and … try and stop her." Others described the stress for patients and family of uncertainty and the extra steps associated with arranging transfers to take the AD medication, impacting on what should have otherwise been a special day. Some expressed "great sadness" about patients not being able to die in a residential facility which was their home, or at the time they wanted to, or say goodbye to favourite staff. One participant described her feeling of stigma and that the family were doing something "illegal", because of the institutional position.

There were also costs to the relationship between patient-caregiver and the treating institution with some participants reporting distrust from both caregivers and patients, with "question marks over motivations". Against this "background of AD", there was a loss of confidence or trust in medical advice with one participant asking, "What's their agenda?". Another described removing all traces of AD to ensure the death could be verified by the palliative care team.

Box 3: Participant quotes—Impact of institutional objection

If we had been able to begin the access in the hospital, maybe she would have then come home and been able to complete that at home. You know, actually take part in AD at home within a day of coming home, rather than having to prolong it. [long pause] So I think institutional policies have a part to play. So allowing free access to AD doctors to access patients, if that's what the patient wants, while they're in hospital. Because some people spend an awful long time in hospital… (Family caregiver of patient with neurological condition)

[T]hat was a significant challenge and just created a whole lot of stress on what was her last day. You know, it was this frantic rush and … then having to wheel her out and she couldn't say goodbye to people. … you get to the top of the mountain and then you've got that last big, huge boulder to climb over. It will always be a great sadness for me that the last few precious hours on Mum's last day were mostly filled with stress and distress, having to scurry around moving her out of her so-called "home". (Family caregiver of patient with neurological condition)

I spoke to the doctor who had helped us with the AD application … saying that [Catholic hospital] had really wanted the cognitive assessment. He said to me, "Do not let them do a cognitive assessment… you don't know what it's going to be used for." I actually went back to [relevant staff member] at [Catholic hospital], who was absolutely lovely, and I said, "Look, this is what the doctor has said … I'm sure that's not your motivation," but s/he actually said, "I can't guarantee that it may be somehow linked in with the AD process. So why don't we not do the cognitive assessment." … So s/he … didn't say like that was the agenda.

S/he just said, “Look, this whole thing is so grey and so new … I would not want to be doing anything that could potentially jeopardise your Mum’s choice in the AD thing.” So s/he was actually the one that said, “We’re just not going to do it.” [Mum] was still able to make her own decisions, but it definitely impacted what services we got from [Catholic hospital]. Because it was always in the background of AD. What’s their agenda? [C]ould it jeopardise it? And even [Catholic hospital] couldn’t say that it wouldn’t be used for something like that. (Family caregiver; no patient illness information provided to protect participant)

Position of staff within objecting institutions

Participants described staff within objecting institutions as having a spectrum of positions on AD (Box 4).

Some staff personally objected to AD, and this exacerbated the barrier for patients. Some participants also perceived, in addition to implementing institutional objection, some staff may have been “pushing … against the AD process” towards non-AD treatment options, or advocating for admission to care locations where AD was not possible to halt the AD process. Other staff were described as simply accepting their institution’s position that AD was “out of bounds” and passively implementing that view, including by declining to discuss it.

However, participants also identified staff who they perceived disagreed with their institution. Participants described this sometimes manifesting itself as an acknowledgement of the patient’s AD choice or private moral support, communicated to both patients and caregivers. Rarely, staff went further and provided support (generally surreptitiously) for the patient to navigate towards AD.

Box 4: Participant quotes—Position of staff within objecting institutions

[The staff member] said, “I can’t, because of my role, there’s nothing I can do to help you, I can’t do anything.” But she said, “I’m here for you.” (Family caregiver of patient with neurological condition)

There are people that work for [Catholic palliative care organisation] that don’t support it, but there are plenty of people that do. So I think they said, “We’ll make a note of it. But even the people that don’t support it will still care for you.” (Family caregiver of patient with cancer)

Quietly in the room. Not with other people listening. So it would be a one-on-one conversation and they said to me, “You can certainly take care of [patient name] at home. There’s no issue about that. It would be better for her if [patient] is at home.” So they were very sympathetic. They also helped direct us to a private company. Which [long pause] … that private company knew of that particular [staff member], because they said, “[Staff member] is very sympathetic and very helpful to a lot of people.” So [they] had a reputation, you would say, for looking after the patient’s needs versus the institution. Which if [they] got found out, [they] would lose [their] job. [long pause] … I’d be happy for that story to be included if I could be sure that [they were] protected. (Family caregiver; no patient illness information provided to protect participant and another person)

Mediating influences on the impact of institutional objection

Six factors mediated the impact of institutional objection (Box 5). The first was staff views about AD which, given its broader significance, is a standalone theme above. The impact of institutional objection was felt more acutely by patients when staff shared that position, but mitigated when staff disagreed with it.

A second mediating factor was the support of medical practitioners coordinating the AD process (external to the institution) and the Statewide Pharmacy Service. Participants described these individuals making particular efforts to facilitate access despite institutional objections. Examples were pharmacists fast-tracking appointments to deliver medication before a patient’s admission to an objecting hospital or busy medical specialists doing home visits.

A third factor was the nature of the patient’s illness. Institutional objection was more problematic if a key treating hospital for a patient’s illness opposed AD. This was mentioned particularly for neurological conditions.

A fourth factor was the progression or state of a patient’s illness. If their illness was so advanced or their need for pain and symptom management required either being admitted into an objecting institution, or staying at an objecting institution where they were already receiving care, this impeded access more than for those who were able to leave the institution or remain at home. A transfer for such patients to another facility was sometimes an option but often this was unsatisfactory, for example because their illness was best treated at their existing hospital or because a bed was not available elsewhere. Further, for patients whose illness was more progressed, any delay was experienced more acutely because of shorter time they had to navigate through the AD process.

Fifth, a patient's geographical location affected the impact of institutional objection. If there was only one health service in an area and it restricted AD, access was more complex. One participant described that a patient's inability to self-administer would require them to transfer away from the region to receive practitioner-administration as the local institution would not permit this.

A final mediating factor was a capable and assertive patient and/or family caregiver. Objecting institutions could be identified and navigated away from (particularly in the residential aged care setting): "the place was chosen because they would allow it [AD]". Assertive patients and caregivers also seemed more ready to challenge institutions or step past objections and seek AD privately. Some caregivers also described being able to bypass institutional objection through providing care at home, but this was not always possible. However, even participants who were highly competent and educated caregivers with health professional backgrounds found navigating institutional objection challenging.

Box 5: Participant quotes—Mediating influences on the impact of institutional objection

[T]here was … a huge conflict of interest. That the AD process is not supported by [Catholic hospital] and yet [Catholic hospital] is the hospital that you go to with motor neurone disease. (Family caregiver of patient with neurological condition)

So then we had to call the State Pharmacist and say, "You need to come really, really quickly because Mum's about to be transferred to [Catholic hospital] and you're not allowed in [Catholic hospital]." So they very kindly came a day earlier. I think it was on the day that Mum was actually transferred to [Catholic hospital]… So we did that, but that was stressful in itself. (Family caregiver of patient with neurological condition)

It wasn't an option in [rural town]. So it was only ever available as self-administered. If Dad had to have practitioner assisted, he had to be transported to [major city]. (Family caregiver of patient with cancer)

Discussion

Main findings

Most patient experiences of seeking AD were reported by participants to involve institutional objection (17/28 patient cases). These objections were primarily rooted in Catholic religion and/or moral opposition based on a palliative care philosophy. Participants identified three key processes affected: eligibility assessments, medication access, and taking/administration of the medication. Institutional objection occurred across health settings resulting in delays, transfers, choices between progressing an AD application and receiving palliative or other care, and adverse emotional and relationship experiences.

Six mediating influences on institutional objections were identified. Some compound the effect on patients, such as having a particular illness primarily cared for in an objecting institution. Others soften the impact, such as supportive staff in the institution. The schematic relationship between these themes is shown below (Fig. 1).

Implications of institutional objection as a barrier

The barriers to accessing AD caused by institutional objection can compromise the quality of a patient's end-of-life experience [9, 32]. Key factors in a "good death" include choice and control in the dying process, and receiving integrated end-of-life care including pain-free status, dignity, and emotional well-being [33]. Yet these findings suggest institutional objection can diminish patient options, require choice between progressing AD and receiving palliative care, and cause emotional discord and stress in a patient's final days.

Further, the impact of institutional objection on patient access to AD can compound existing access challenges. For example, time delays in the AD approval process can be problematic with patients "racing" to access AD before dying [34]. This is especially so in systems where eligibility criteria require a time period until death, as in Victoria (6 months or 12 months for neurodegenerative conditions) [16]. Delays from institutional objection, even if relatively brief, can threaten access altogether.

Institutional objection also exacerbated challenges for patients with neurological conditions. There were already fewer trained AD doctors in this specialty in Victoria at the time of this research [35], but patient access was reported as being further impeded due to a statewide neurological facility being an objecting institution. Given patients with neurological conditions are a recognised cohort who seek AD [35, 36], this institutional objection is problematic for access.

A linked observation, echoing Wiebe et al.'s [13] findings from Canada, is that these findings reveal a "lottery" of sorts, with some patients better able to navigate institutional objections if the right constellation of mediating factors is present. This creates inequities in care based on inappropriate considerations such as geographical location, illness, practitioners encountered, and available family and other supports.

Contested permissibility and scope of institutional objection

These findings inform debates about permissibility of institutional objections and, if allowed, their justifiable

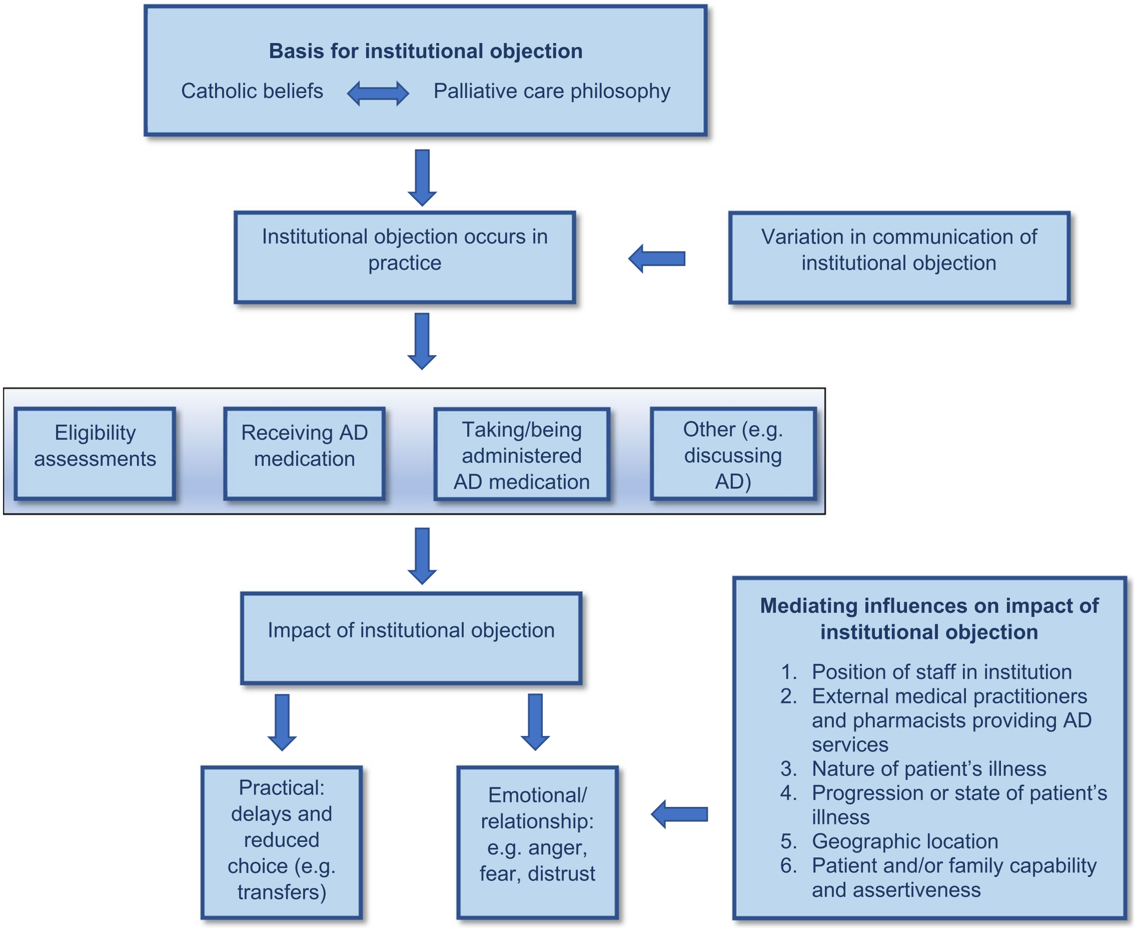

Fig. 1 Thematic schema of participants' perspectives on institutional objection in Victorian assisted dying system

boundaries. Given the dearth of empirical research on institutional objection, the adverse impacts on patients (and caregivers) in Victoria's AD system found in this study support at least some limits to institutional power. Further, findings of variability of staff views about AD within objecting institutions may undermine arguments to permit such objections. If safeguarding institutional "conscience" is based on protecting a broad staff consensus, such arguments are undermined by this finding, reflecting studies in other settings [37, 38].

These findings also raise questions about how best to respond to identified harms to patients from institutional objection. Should this be regulated by the state or left to practice, and if formally regulated, what model should be chosen (e.g. conscience absolutism, non-toleration or some form of reasonable accommodation) [3, 10]? There are also questions about how such regulation (if that path is chosen) should be implemented, e.g. through law, policy and/or funding mechanisms. Any regulatory response would also need to consider questions such as whether the intended duration of the care being provided by an institution impacts on its duties, and whether all stages of the AD process should be treated the same. To illustrate, legislation in the Australian state of Queensland imposes higher duties on long-term care institutions such as residential aged care facilities (which are regarded as a person's home) than on short-term places of care such as hospitals, and treats access to information about AD differently from taking or administering the medication [39].

Our observations are that the current Victorian approach, based on state-issued (optional) policy guidance, is not effective in achieving the objectives of respecting institutional positions while promoting patient access. This "soft regulation" approach appears to have allowed existing power, resource, and information asymmetry to prioritise institutions' positions over patient choice. Such an outcome is inconsistent with the wider policy goals of the *Voluntary Assisted Dying Act 2017*.[16]

A further concern was significant variation in how institutional objections were expressed. Some institutions objected explicitly, but other participants learned of objections obliquely, through progressive interactions with staff, and sometimes only after a period of time in care. Uncertainty about institutional positions reflects existing literature [40] and is problematic because it makes informed choices about care more difficult for patients and caregivers. Regardless of views about the permissibility of institutional objections to AD, transparency and clear communication of positions are desirable.

Limitations of the study

This is one of very few empirical studies internationally to examine institutional objection to AD. Importantly, it provides evidence about the adverse impact that institutional objection can have on patients (albeit as reported by family caregivers). However, a limitation of this research is that the perception of caregivers may differ from those of patients as caregivers may be affected by grief, bereavement, and their relationship with the patient they were supporting [25, 26]. However, proxies have been found to be a reliable source of information regarding quality of end-of-life services, demonstrating high concordance with patient views [41].

Another limitation is that the perceptions of our participants reported in this study are based on their experience of interactions with particular health professionals and institutions. Other perspectives are needed and further research with a broad range of key stakeholders is warranted, including to examine wider system issues such as the role played by institutional policies and protocols in managing objections.

Our sample may also be more favourably disposed towards AD, given our recruitment methods which included via patient interest groups. Further, only three patients in this study missed out on AD. More research with this cohort is needed, including whether objections by institutions contribute to a lack of access and the issues of equity to which that gives rise. Additionally, given many patients were still able to access AD *despite* objections by institutions, further investigation is needed as to the reasons for this, including the mediating factors identified in this research (e.g. a capable and assertive patient and/or family caregiver).

Finally, further research is also needed on the intersection between individual conscientious objection and institutional objection, including how one may shape the other. Findings here were that staff positions mediated institutional objections, but more research is needed.

Conclusion

Institutional objection is a much-debated aspect of AD practice yet is empirically understudied. This research found that in Victoria, it was regularly reported by participants and adversely affected patient and caregiver experience when accessing AD. This occurs in an already procedurally challenging system, particularly given the limited window patients have to apply. Better regulation may be needed to address this issue as the existing policy approach appears to preference institutional positions over patient's choice given existing power dynamics.

Abbreviation

AD	Assisted dying

Supplementary Information

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Additional file 1. Interview guide.

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Author contributions

Data was collected by BPW and RJ. BPW wrote most of the first draft of the manuscript, with other sections completed by RJ, EC and LW. BPW, RJ, EC and LW all made substantive revisions to iterative drafts of the manuscript. BPW finalised the text, which was approved by all authors. All authors read and approved the final manuscript.

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Availability of data and materials

The interview guide is available in Additional File 1. The data generated and analysed in this study are not publicly available due to confidentiality undertakings given to research participants as required by the study's ethics approval. Requests to discuss this should be directed to the corresponding author.

Declarations

Ethics approval and consent to participate

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

Consent for publication

Not applicable.

Competing interests

BPW and LW were engaged by the Victorian, Western Australian and Queensland governments to provide the legislatively mandated training for doctors involved in voluntary assisted dying. RJ and EC were employed on the Victorian, Western Australian and Queensland training projects. BPW is a member of the Queensland Civil and Administrative Tribunal, the quasi-judicial review body which has jurisdiction over some voluntary assisted dying matters. LW is a member of the relevant oversight body in Queensland, the Voluntary Assisted Dying Review Board. All views expressed in this article are those of the authors and not the organisations they are affiliated with.

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Publisher's Note

LEGISLATIVE OPTIONS TO ADDRESS INSTITUTIONAL OBJECTIONS TO VOLUNTARY ASSISTED DYING IN AUSTRALIA

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Voluntary assisted dying is being considered by parliaments and law reform bodies across Australia. Although individual conscientious objection is routinely considered in these deliberations, an institution's desire to object to providing voluntary assisted dying has received very little attention. After briefly considering the concept of institutional objection in voluntary assisted dying, this article examines the available (albeit limited) Australian evidence on this practice. Institutional objection is happening in Victoria (where voluntary assisted dying is lawful) and is likely to occur in other Australian states. The article proposes that regulation is needed and presents three models for parliaments and law reformers to consider. The first is 'conscientious absolutism', which grants institutions unrestricted ability to object to voluntary assisted dying. The second

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We disclose that Ben White and Lindy Willmott were engaged by the Victorian and Western Australian Governments to design and provide the legislatively-mandated training for doctors involved in voluntary assisted dying in those States. Both have also developed a model Bill for voluntary assisted dying for parliaments to consider. Eliana Close was employed on both voluntary assisted dying training projects. Jocelyn Downie was a member of the Royal Society of Canada Expert Panel on End of Life Decision-Making, a member of the plaintiffs' legal team in *Carter v Canada (A-G)* [2015] 1 SCR 331, a member of the Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying and a member of the Council of Canadian Academies Expert Panel on Medical Assistance in Dying. Ben White is a recipient of an Australian Research Council Future Fellowship (project number FT190100410: Enhancing End-of-Life Decision-Making: Optimal Regulation of Voluntary Assisted Dying) funded by the Australian Government.

is a 'compromise or reasonable accommodation' model, which aims to accommodate both institutional objection and a person's wish to access voluntary assisted dying. Different balances can be struck; we propose a model that prioritises a patient's interests. The third model is 'non-toleration', which would refuse to allow an institution to object at all. While there can be debate about the optimal model, the issue of institutional objection to voluntary assisted dying must be addressed.

I INTRODUCTION

After decades of unsuccessful attempts to legalise voluntary assisted dying ('VAD'),[1] the past few years have witnessed a flurry of reform activity in Australia. In Victoria, the *Voluntary Assisted Dying Act 2017* (Vic) ('*Victorian VAD Act*') commenced operation in June 2019. Western Australia largely followed the Victorian model and its *Voluntary Assisted Dying Act 2019* (WA) is due to commence operation on 1 July 2021. As this article was being published, Tasmania also passed its *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas) which is anticipated to commence in 2022. A VAD Bill has been introduced in South Australia,[2] one will be considered in Queensland in May 2021,[3] and New South Wales is likely to see such a Bill tabled in 2021 as well.[4]

Reflecting the contested nature of VAD legislation, such laws almost universally contain provisions to respect conscientious objections by individual health professionals. Both the Victorian and Western Australian laws state that a health professional has a right to refuse involvement with any aspect of the VAD process.[5] A more controversial issue, which has received limited consideration in Australia, is whether an *institution* should be able to prohibit access to VAD or any VAD-related activities (which include eligibility assessments and providing

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[1] A detailed discussion of attempts at law reform in Australia is available in: Lindy Willmott et al, '(Failed) Voluntary Euthanasia Law Reform in Australia: Two Decades of Trends, Models and Politics' (2016) 39(1) *University of New South Wales Law Journal* 1. See also further Bills in Ben White and Lindy Willmott, 'Future of Assisted Dying Reform in Australia' (2018) 42(6) *Australian Health Review* 616.

[2] Voluntary Assisted Dying Bill 2020 (SA).

[3] The Queensland Premier referred the issue to the Queensland Law Reform Commission to draft a Bill for the Government's consideration: Queensland Law Reform Commission, *Queensland's Laws Relating to Voluntary Assisted Dying* (Terms of Reference, 2020) <https://www.qlrc.qld.gov.au/__data/assets/pdf_file/0004/651379/vad-tor.pdf>. See also Queensland Law Reform Commission, *A Legal Framework for Voluntary Assisted Dying* (Consultation Paper No 79, October 2020) <https://www.qlrc.qld.gov.au/__data/assets/pdf_file/0003/658506/qlrc-wp-79-2020.pdf>.

[4] Michael Koziol, 'Fresh Bid to Legalise Assisted Dying Set to Test NSW Government', *The Sydney Morning Herald* (online, 13 December 2020) <https://www.smh.com.au/politics/nsw/fresh-bid-to-legalise-assisted-dying-set-to-test-nsw-government-20201209-p56m2t.html>.

[5] *Voluntary Assisted Dying Act 2017* (Vic) s 7 ('*Victorian VAD Act*'); *Voluntary Assisted Dying Act 2019* (WA) s 9.

information about VAD) within its facility.[6] The Victorian and Western Australian Acts are silent on this issue. However, this is important because institutions that object have the power to significantly curtail individuals' ability to access what is a lawful medical service.[7] When this occurs for reasons of conscience, this is problematic, particularly when these institutions are the sole providers of specialist end-of-life care in a particular geographic area.[8] This effectively creates barriers to access and the impact on patients can be extreme; those who are eligible for VAD are already experiencing intolerable suffering and such institutional objections can compound this.

Although the Victorian and Western Australian Acts do not address institutional objection, it is possible for legislation to regulate it. The Voluntary Assisted Dying Bill 2019, a model Bill that was recommended by the Queensland parliamentary inquiry considering VAD as the proposed basis for reform,[9] contains such a provision.[10] A proposed amendment to regulate institutional objections was also debated, though ultimately not passed, in the Legislative Council of Tasmania during debate on the *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas).[11]

During the debates in Tasmania, many parliamentarians expressed grave concern that institutions (particularly residential aged care facilities) would create unjustified barriers for individuals who were approaching the end of their lives, suffering intolerably, and seeking VAD. For example, Ms Forrest stated: 'I am really struggling with why we would require someone to be moved from their home because an organisation's policy was that they did not want to be involved in the matter'.[12] Indeed, several politicians expressed surprise that institutions

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[6] See, eg, Philip Shadd and Joshua Shadd, 'Institutional Non-Participation in Assisted Dying: Changing the Conversation' (2019) 33(1) *Bioethics* 207; LW Sumner, 'Institutional Refusal to Offer Assisted Dying: A Response to Shadd and Shadd' (2019) 33(8) *Bioethics* 970.

[7] See, eg, Sumner (n 6) 971.

[8] See, eg, Udo Schuklenk, 'Conscience-Based Refusal of Patient Care in Medicine: A Consequentialist Analysis' (2019) 40(6) *Theoretical Medicine and Bioethics* 523; Sumner (n 6) 971.

[9] Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee, Parliament of Queensland, *Inquiry into Aged Care, End-of-Life and Palliative Care and Voluntary Assisted Dying* (Report No 34, 31 March 2020) <https://www.parliament.qld.gov.au/Documents/TableOffice/TabledPapers/2020/5620T490.pdf> ('Queensland Parliamentary Report'). In Recommendation 1, the Committee recommended the Queensland Government use a draft voluntary assisted dying ('VAD') Bill written by two of the authors as the basis for legalising VAD in Queensland. For the model Bill, see: Ben White and Lindy Willmott, 'A Model Voluntary Assisted Dying Bill' (2019) 7(2) *Griffith Journal of Law and Human Dignity* 1, 15–43.

[10] White and Willmott (n 9) 36.

[11] The amendment proposed by Dr Bastian Seidel would require institutions that object to VAD to transfer a patient to a healthcare facility that does not object: Tasmania, *Parliamentary Debates*, Legislative Council, 30 October 2020, 2 (Bastian Seidel). Note also that clause 19(3) in the (defeated) Death with Dignity Bill 2016 (SA) addressed institutional objection to VAD. This clause indicated that an institution could refuse to provide VAD, but if it did so it must ensure the refusal is brought to the attention of individuals before being admitted, and if the person had already entered the institution without being aware of the objection, arrange a transfer.

[12] Tasmania, *Parliamentary Debates*, Legislative Council, 30 October 2020, 5 (Ruth Forrest).

could legally prevent health professionals from entering facilities for this purpose.[13]

This article explores how institutional objections to VAD in Australia are currently regulated, the potential consequences of such objections, and possible legislative responses. We commence by examining the concept of institutional objection, including a comparison with conscientious objection by individuals. We then outline how institutional objection is regulated in Victoria (by policy), evidence of the impact of such objection on individuals in Victoria, and likely outcomes in other parts of Australia if VAD is enacted. We also consider the recent Canadian experience to identify potential outcomes of institutional objections. We conclude by offering some regulatory options to govern institutional objection for parliaments and other bodies deliberating on VAD reform.

II THE CONCEPT OF INSTITUTIONAL CONSCIENTIOUS OBJECTION[14]

Conscientious objection in medicine can refer to a desire not to participate in providing a healthcare service based on concerns to 'preserve or maintain moral integrity'.[15] It is conceptually distinct from non-participation based on clinical judgment – that to provide a particular treatment would not be in accordance with good medical practice.[16] It is also to be distinguished from pragmatic reasons for non-participation, based on lack of expertise, financial or technological resources.[17]

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[13] See, eg, Tasmania, *Parliamentary Debates*, Legislative Council, 30 October 2020, 5–6 (Ruth Forrest), 10 (Meg Webb), 15–16 (Bastian Seidel).

[14] This article does not consider institutional objections made on the basis of institutional capacity (eg, not having the required human resources or equipment). We do briefly note here, though, that such objections may be difficult to sustain as VAD does not require specialised equipment or human resources that cannot be brought into a facility.

[15] Mark R Wicclair, 'Conscientious Objection in Medicine' (2000) 14(3) *Bioethics* 205, 213. See generally Morten Magelssen, 'When Should Conscientious Objection Be Accepted?' (2012) 38(1) *Journal of Medical Ethics* 18; Sara Fovargue and Mary Neal, '"In Good Conscience": Conscience-Based Exemptions and Proper Medical Treatment' (2015) 23(2) *Medical Law Review* 221, 222. See also Stephen Smith, who defines conscience from an individual perspective as 'an internal mental process focused on an inward-looking choice to engage in particular behaviour on the basis of a moral value': Stephen W Smith, 'The Responsibilities of Conscience in Healthcare Decisions: Moving Towards a Collaborative Framework' (2020) 79(1) *Cambridge Law Journal* 120, 124. While these authors defend the right to conscientiously object on the basis of preserving moral integrity, others frame the issue in terms of harm to the doctor and the health service: see, eg, Julian Savulescu, 'Conscientious Objection in Medicine' (2006) 332(7536) *British Medical Journal* 294.

[16] See Fovargue and Neal (n 15) 224–5; Smith (n 15) 129; Nadia N Sawicki, 'Mandating Disclosure of Conscience-Based Limitations on Medical Practice' (2016) 42(1) *American Journal of Law and Medicine* 85, 91–2.

[17] Shadd and Shadd (n 6) 208, 211.

While an individual's right to conscientiously object is traditionally recognised in law and policies,[18] it is more contentious whether an institution itself can have a 'conscientious objection'. Individuals are self-evidently moral agents, and possess human rights, including the right to freedom of religion, thought and conscience.[19] The status of institutions is less clear. Some argue there is no basis for an institution to have such an objection, as 'bricks and mortar' cannot have moral beliefs as people do.[20] Others consider a healthcare institution to be more than just a building, and view it as 'a group of people organized according to a series of roles and relationships designed to deliver the social good of healthcare'.[21] According to this view, institutions may have a distinctive mission, ethos and moral values, and should be recognised as having a conscience.[22] A middle ground, advanced by Wicclair, is to argue that while hospitals do not possess a conscience like individuals do, they could still justify claims to refuse a service on the basis of their identity and integrity. Nevertheless, they have obligations to prevent harm to patients, promote health and respect autonomy, which can outweigh identity or integrity-based claims.[23]

Institutional objections to VAD may be made by a range of different institutions, including hospitals, residential aged care facilities and other long-term care facilities, and hospices or other short-term care facilities.[24] Institutions may object to participating in VAD on at least three levels: 1) VAD administration; 2) eligibility assessments; and 3) providing information or referring individuals to facilitate VAD.[25] Firstly, an institution may not wish to have administration of

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[18] Wicclair, 'Conscientious Objection in Medicine' (n 15). For the contrary view, that an individual health practitioner should not be able to object on conscientious grounds, see Savulescu (n 15) 294; Julian Savulescu and Udo Schuklenk, 'Doctors Have No Right to Refuse Medical Assistance in Dying, Abortion or Contraception' (2017) 31(3) *Bioethics* 162, 165.

[19] *International Covenant on Civil and Political Rights*, opened for signature 16 December 1966, 999 UNTS 171 (entered into force 23 March 1976) art 18. See also Sumner (n 6) 972.

[20] Daphne Gilbert, 'Faith and/in Medicine: Religious and Conscientious Objections to MAiD' (2020) 43(2) *Dalhousie Law Journal* 1, 38. Gilbert argues that under Canadian law, religious institutions do not have the right to refuse to offer medical assistance in dying ('MAiD': the Canadian term for VAD), a publicly-funded and legal health service. See also George J Annas, 'At Law: Transferring the Ethical Hot Potato' (1987) 17(1) *The Hastings Center Report* 20, 21: 'Hospitals are corporations that have no natural personhood, and hence are incapable of having either "moral" or "ethical objections" to actions. … [H]ospitals don't practice medicine, physicians do'. Sumner (n 6) says it is 'debatable' whether institutions can have conscience rights: at 972 n 14.

[21] Shadd and Shadd (n 6) 208.

[22] See Cameron Flynn and Robin Fretwell Wilson, 'Institutional Conscience and Access to Services: Can We Have Both?' (2013) 15(3) *American Medical Association Journal of Ethics* 226, 227; Daniel P Sulmasy, 'What Is Conscience and Why Is Respect for It So Important?' (2008) 29(3) *Theoretical Medicine and Bioethics* 135; Kevin W Wildes, 'Institutional Identity, Integrity, and Conscience' (1997) 7(4) *Kennedy Institute of Ethics Journal* 413, 416. In New Zealand, a court has held that institutions may have 'an entrenched moral ethos through which it operates' and have a right to freedom of conscience: *Hospice New Zealand v A-G* [2020] NZHC 1356, [103] (Mallon J). Mallon J held that there is nothing in the *End of Life Choice Act 2019* (NZ) that requires institutions to offer VAD: at [103]–[117], [214].

[23] Mark R Wicclair, 'Conscientious Refusals by Hospitals and Emergency Contraception' (2011) 20(1) *Cambridge Quarterly of Healthcare Ethics* 130.

[24] See Shadd and Shadd (n 6) 208.

[25] Carpenter and Vivas note three types of individual objection to VAD: objection to administration, objection to participation in consultation and assessment, and, less commonly, objection to providing a direct referral: Travis Carpenter and Lucas Vivas, 'Ethical Arguments Against Coercing Provider

VAD occur in its facility.[26] It may achieve this by forbidding its staff or outside health professionals from administering or prescribing VAD medication to patients, and/or it may prohibit individuals themselves from taking it in the facility. Secondly, an institution may prohibit consultations or eligibility assessments for VAD occurring within the facility, whether conducted by staff or outside health professionals.[27] Thirdly, an institution may refuse to refer a patient to other institutions or health professionals who provide VAD services or object to providing information about VAD.

A common basis for institutional objection is religious belief. The Catholic Church has made prominent statements on VAD, with its most recent pronouncement concluding that 'euthanasia … is an intrinsically evil act',[28] and that complicity by '[a]ny formal or immediate material cooperation in such an act is a grave sin against human life'.[29] This is significant as Catholic hospitals and institutions (eg, hospices and long-term care facilities) provide a significant proportion of end-of-life care in Australia.[30] Other religions, including Judaism and Islam, have expressed the same viewpoint.[31] This has led some religious organisations to refuse to permit VAD assessments or administration in their

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Participation in MAiD (Medical Assistance in Dying) in Ontario, Canada' (2020) 21 *BMC Medical Ethics* 46:1–5, 1–2. Institutional objections may also extend to a refusal to allow individuals to complete paperwork relating to VAD onsite: see, eg, Jennie Russell, 'Paralyzed, Terminally Ill Man Had to Sign Assisted-Dying Papers in Bus Shelter', *CBC News* (online, 2 November 2018) <https://www.cbc.ca/news/canada/edmonton/convenant-health-assisted-dying-edmonton-1.4888114> ('CBC Coverage of Bob Hergott'); Jennie Russell, 'Unassisted Death', *CBC News* (online) <https://newsinteractives.cbc.ca/longform/unassisted-death> ('CBC Coverage of Doreen Nowicki').

[26] See, eg, the case of a Victorian patient discussed below: Eswaran Waran and Leeroy William, 'Navigating the Complexities of Voluntary Assisted Dying in Palliative Care' (2020) 213(5) *Medical Journal of Australia* 204.

[27] In Victoria, some institutions (such as facilities run by Catholic Health Australia, discussed below) have indicated that they will refuse to participate in assessment or administration of VAD.

[28] Congregation for the Doctrine of the Faith, '*Samaritanus Bonus*: On the Care of Persons in the Critical and Terminal Phases of Life' (Letter, 22 September 2020) 8 <http://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_20200714_samaritanus-bonus_en.html>. This position is also reflected in Catholic Health Australia, *Code of Ethical Standards for Catholic Health and Aged Care Services in Australia* (2001). The Code states in its section on euthanasia: 'It is never permissible to end a person's life (whether that decision is made to relieve a patient's suffering by euthanasia, to comply with the wishes of the family, to assist suicide, or to vacate a bed)': at 46 [5.20].

[29] Congregation for the Doctrine of the Faith (n 28) 9 (emphasis omitted).

[30] The South Australia End of Life Choices Report notes that approximately 13% of palliative care in Australia is provided in Catholic hospitals, and in South Australia the Catholic Church is the largest provider of private palliative care beds: Joint Committee on End of Life Choices, Parliament of South Australia, *Report of the Joint Committee on End of Life Choices* (Report, 13 October 2020) 12.

[31] Rhiannon Shine, 'Voluntary Euthanasia Legislation Leaves WA's Religious Communities Debating Doctrine and Death', *ABC News* (online, 10 August 2019) <https://www.abc.net.au/news/2019-08-10/where-do-different-religions-stand-on-voluntary-euthanasia/11399138>; Jewish Care, 'Voluntary Assisted Dying' (Position Statement, April 2019).

facilities.[32] They may, however, be willing to provide information about VAD, refer to an external source of information,[33] or facilitate a transfer of care.[34]

Institutional objections need not be grounded in religion.[35] An example of this is an objection based on an institution's philosophy of palliative care, which for some[36] (but not others)[37] warrants a strict separation from VAD. For other institutions, objections to VAD may be grounded in their view about the purpose of medicine; namely, to promote health and preserve life, rather than to take life.

III EXISTING EVIDENCE ABOUT LAW AND POLICY RESPONSES

A Victoria

The *Victorian VAD Act* is silent on institutional objection.[38] Instead, the Department of Health and Human Services ('DHHS') has addressed this issue using a series of policy documents aimed directly at institutions.[39] The DHHS

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[32] Catholic Health Australia, 'Our Enduring Commitment to End of Life Care: Catholic Health and Aged Care Services in Australia' (Report, February 2019) ('CHA Taskforce Document'); Catholic Health Australia, 'CHA VAD Response Taskforce: Clinical Governance Recommendations' (Report, February 2019) ('CHA Clinical Governance Recommendations'); Catholic Health Australia, 'Catholic Health and Aged Care Services Response to the "Voluntary Assisted Dying Act"' (Media Statement, 19 June 2019) ('CHA Media Statement'); Jewish Care (n 31).

[33] Jewish Care (n 31).

[34] CHA Media Statement (n 32) 1.

[35] Andrew McGee, 'Voluntary Assisted Dying: Should Conscientious Objection Be Unconditional?' (2020) 50(2) *Journal of Pharmacy Practice and Research* 117, 118.

[36] Australian and New Zealand Society of Palliative Medicine, 'The Practice of Euthanasia and Physician-Assisted Suicide' (Position Statement, September 2020); Waran and William (n 26) 205. This position was also advanced by Hospice New Zealand in *Hospice New Zealand v A-G* [2020] NZHC 1356, [18] (Mallon J).

[37] Palliative Care Australia, 'Palliative Care and Voluntary Assisted Dying' (Position Statement, September 2019) ('PCA Position Statement'). The PCA Position Statement also draws a distinction between VAD and palliative care, but suggests palliative care practitioners may decide whether to be involved in VAD.

[38] Conscientious objection is addressed in section 7 of the *Victorian VAD Act 2017* (Vic), but this is limited to registered health practitioners. Section 7 indicates registered health practitioners may refuse to: provide information; participate in the request and assessment process; apply for a VAD permit; supply, prescribe, or administer the medication; be present at the time of administration; or dispense a VAD prescription. The *Victorian VAD Act 2017* (Vic) does not specify whether the health practitioner must refer the patient or disclose their conscientious objection.

[39] Department of Health and Human Services, State Government of Victoria, 'Voluntary Assisted Dying Model of Care Pathways for Health Services' (Guidance, January 2019) <https://www2.health.vic.gov.au/~/media/Health/Files/Collections/Policies%20and%20guidelines/V/VAD%20Model%20of%20care%20pathways%20for%20health%20services> ('DHHS Model of Care Pathways'); Department of Health and Human Services, State Government of Victoria, 'Preparing for Voluntary Assisted Dying: *Voluntary Assisted Dying Act 2017*' (Guidance, 24 April 2019) <https://www2.health.vic.gov.au/about/publications/policiesandguidelines/preparing-for-voluntary-assisted-dying>; Department of Health and Human Services, State Government of Victoria, 'Voluntary Assisted Dying Guidance for Aged Care Providers' (Guidance, 17 April 2019) <https://www2.health.vic.gov.au/about/publications/policiesandguidelines/vad-guidance-aged-care-providers>; Department of Health and Human Services, State Government of Victoria, 'Voluntary Assisted Dying Safety and Quality Guidance for Health Services' (Guidance, January 2019); Department of Health and Human Services, State Government of Victoria, 'Health Service Participation in Voluntary

instructs health services to assess their capacity to provide VAD, and determine whether it is congruent with their 'staff or service mix' and the health service's values.[40] The guidance indicates that 'most health services will fall into one of three high-level pathways':[41]

- Pathway A: Single service – Health services that are willing and able to provide VAD within their facilities;
- Pathway B: Partnership service – Institutions that can provide access to some elements of VAD but require assistance from existing external partnerships and referral pathways;[42] and
- Pathway C: Information and support service – Health services that either choose or are not able to provide VAD, including those that do not provide end-of-life care. The DHHS guidance indicates that organisations who adopt Pathway C 'will be able to provide' support and information about VAD and '[a]ll health services should be prepared to respond to requests for information about, or access to, voluntary assisted dying'.[43]

The DHHS guidance characterises institutional objection both as a matter of conscience and as a matter of self-governance.[44] It suggests an institution that objects to VAD will typically fall under Pathway C.[45] A health service is not obliged to refer the patient to a VAD provider, but must not 'inhibit a person's

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Assisted Dying' (Guidance, August 2018) <https://www2.health.vic.gov.au/~/media/Health/Files/Collections/Factsheets/V/VAD-health-service-participation> ('DHHS Health Service Participation'); Department of Health and Human Services, State Government of Victoria, 'Health Service Policy Guidance for Voluntary Assisted Dying' (Guidance, 12 June 2019) <https://www2.health.vic.gov.au/about/publications/policiesandguidelines/Health-service-policy-guidance-for-voluntary-assisted-dying>. All Department of Health and Human Services policy documents aimed at institutions can be found here: 'Health Services Information', *Department of Health and Human Services, State Government of Victoria*, (Web Page) <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying/health-services-information>.

[40] DHHS Model of Care Pathways (n 39) 3. See also DHHS Health Service Participation (n 39) 1.

[41] DHHS Model of Care Pathways (n 39) 9.

[42] For example, partnering with general practitioners to conduct VAD assessments.

[43] DHHS Model of Care Pathways (n 39) 3, 9.

[44] The DHHS Model of Care Pathways (n 39) document invites institutions to assess their staff or service mix and their organisational values. It states: 'After assessing the capacity of their service to provide voluntary assisted dying, a health service may determine they do not have the appropriate staff or service mix to provide access to voluntary assisted dying, or that providing access to voluntary assisted dying would not be consistent with the values of the health service': at 3. See also Shadd and Shadd (n 6). Cf Sumner (n 6).

[45] The DHHS Model of Care Pathways (n 39) document states that Pathway C 'is likely to include health services that do not provide care to people who are at the end of their life as well as health services that have chosen not to provide voluntary assisted dying': at 9. Note, however, that Pathway B may apply depending on the nature of the objection (eg, if the objection extends only to providing access to VAD and does not include the provision of information or eligibility assessment). For example, an aged care facility might choose to partner with general practitioners to provide VAD assessments but object to their residents consuming the VAD medication onsite.

access to treatment'.[46] Additionally, health services should inform the patient 'as soon as practicable that they will not assist them'[47] and health professionals (in accordance with professional codes of conduct) must not use their objection to 'impede access to treatments that are legal'.[48] The policies strongly suggest (but do not require) that organisations nominate a VAD contact, but if no one is designated, organisations may direct patients to the Statewide Care Navigator Service ('VAD Navigators'), which can provide information, support and referrals.[49]

On its face, the DHHS policy position suggests, at a minimum, that objecting institutions should provide information and support to those seeking VAD, and should consider how to provide 'compassionate person-centred care' to those who request information or access to VAD.[50] However, the policies allow latitude for institutions to depart from this, with the DHHS indicating that '[h]ealth services may adapt the care pathways'.[51]

Some organisations have created specific policies stating that they will not permit access to VAD. For example, Catholic Health Australia ('CHA'), the largest non-governmental grouping of hospitals and aged care providers in Australia, will not provide VAD in its facilities.[52] Their taskforce document in response to the *Victorian VAD Act* does not explicitly mention referral, but indicates that organisations under the CHA umbrella 'will not facilitate or participate in assessments' for the purpose of VAD.[53]

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[46] DHHS Health Service Participation (n 39) 1.

[47] Ibid.

[48] DHHS Model of Care Pathways (n 39) 6. The DHHS Model of Care Pathways document puts forward this language from the Medical Board of Australian Code of Conduct. It also addresses nursing and pharmacy professional codes of conduct.

[49] Department of Health and Human Services, State Government of Victoria, 'The Statewide Voluntary Assisted Dying Care Navigator Service' (Fact Sheet, September 2019) <https://www2.health.vic.gov.au/Api/downloadmedia/%7B443D45A2-9F81-4BCB-9D3A-EE3B36FD3306%7D> ('DHHS VAD Care Navigators').

[50] DHHS Model of Care Pathways (n 39) 3.

[51] Ibid 7.

[52] CHA Taskforce Document (n 32). This statement was contributed to by CHA member organisations: Calvary Health Care; Cabrini; Mercy Health; St John of God; St Vincent's Health; and Vita Maria Catholic Homes ('VMCH'). See also CHA Media Statement (n 32).

[53] CHA Taskforce Document (n 32) 2. It appears that at least some organisations under the Catholic Health umbrella will facilitate referrals or transfers of care. The CHA Media Statement (n 32) that accompanied the commencement of the *Victorian VAD Act 2017* (Vic) indicates that '[e]ach of our services has a system in place that will respond respectfully and compassionately to any questions about "VAD". This includes coordinating transfer of care to other providers if a patient/resident wishes to seek "VAD". We will not impede access to the provision of "VAD" elsewhere': at 1. Note, also, that guidance has been issued by the Australian Medical Association in its broad statement on conscientious objection in medicine. The statement also addresses institutional objection and may inform Victorian health providers' responses. It states that institutions may object to providing certain services, and if this occurs the institution should visibly inform the public so potential patients can seek care elsewhere. It indicates that where a patient admitted to an institution requests VAD, doctors should still be allowed to refer the patient to a VAD provider outside the facility. In other words, the organisation should not limit its staff from making appropriate referrals. This guidance is likely to pose difficulties for religious organisations that would seek to limit VAD referrals: see 'Conscientious Objection: 2019', *Australian Medical Association* (Web Page, 27 March 2019) [3.1]–[3.2] <https://ama.com.au/position-statement/conscientious-objection-2019>.

To date, evidence of how VAD is operating in practice is limited. Waran and William describe a transfer of care due to an institutional objection to VAD.[54] A 53-year-old woman sought VAD for metastatic breast cancer, but after she was assessed as eligible, she required admission to a palliative care unit to manage her worsening symptoms. Since the woman could not return home, she sought to take the VAD substance in the unit but was refused because of the organisation's policy against providing VAD.[55] She was then referred to another site within the same health service, which also objected. She was eventually transferred to a third venue in the service and was able to take the VAD substance on her preferred date. In describing the case, the authors emphasise the position taken by the DHHS: there is no duty for a health service to refer a patient, but health services must not actively inhibit a patient's access. It is not clear from the article whether the original palliative care unit facilitated the referral or used the VAD Navigators.

There has also been a media report of institutional objection where a patient in a Catholic hospice was not permitted to take delivery of their VAD substance after pharmacists were refused entry to the premises.[56] As a result, the patient needed to be transported out of the hospice and to a hospital where they were then able to receive their VAD substance. In addition, although not an institutional objection of the type discussed in this article, that media report also described a decision by a large palliative care service to decline to certify deaths of patients who had died at home from VAD. Although at this early stage there is only anecdotal evidence that institutional objection is occurring in Victoria, given that there is no legislative requirement for institutions to permit access or make a referral, and that the government policy confirms this, we anticipate that institutions will continue to object to VAD.

B Other Australian Jurisdictions

There is no reason to believe the situation in relation to institutional objections will be different in other Australian states if and when VAD legislation is enacted. Some religious institutions have adopted a position at a national level, so institutions affiliated with these entities can reasonably be expected to have similar objections.[57]

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[54] Waran and William (n 26).

[55] Waran and William (n 26) describe that the policy was also grounded in 'the need to minimise misperceptions' about the role of the palliative care unit: at 204. The Royal Australasian College of Physicians ('RACP') statement on VAD was cited to justify this stance, which recommends 'voluntary assisted dying must not be seen as part of palliative care': Royal Australasian College of Physicians, 'Statement on Voluntary Assisted Dying' (Position Statement, November 2018) 2 (emphasis omitted).

[56] Melissa Cunningham, '"Discriminatory and Unethical": Palliative Care Service Criticised Over Failure to Verify Euthanasia Deaths', *The Age* (online, 17 April 2021) <https://www.theage.com.au/national/discriminatory-and-unethical-palliative-care-service-criticised-over-failure-to-verify-euthanasia-deaths-20210415-p57jif.html>.

[57] See, eg, CHA Clinical Governance Recommendations (n 32); CHA Taskforce Document (n 32).

As mentioned, the VAD legislation in Western Australia is silent on whether a non-participating institution must refer or facilitate transfer of a patient who wishes to access VAD. The Catholic Church is committed to ensuring Catholic hospitals, aged care facilities and palliative care facilities in Western Australia remain 'VAD free spaces',[58] suggesting they will permit neither VAD assessment nor administration. Anglican, Jewish and Muslim leaders in Western Australia have also expressed opposition to VAD.[59] It is anticipated that healthcare and aged care facilities run by these religious institutions may well prohibit the assessment or administration of VAD, or provision of information about VAD, or referrals out occurring within their facilities.

In Queensland, members of the Presbyterian Church, the Anglican Church, the Baptist Church and the Catholic Church all expressed their opposition to VAD before the parliamentary inquiry.[60] Similarly, in Tasmania, CHA has stated that Catholic hospitals and aged care facilities will not provide VAD prescriptions nor administer a lethal injection.[61] They will also not allow external providers to enter the facility to conduct VAD consultations, and will not be making specific referrals to non-objecting institutions.[62]

It seems, however, that some institutions which object to VAD on the ground of conscience will refer individuals to a central government coordination and referral agency, rather than provide a direct referral to a known VAD provider.[63]

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[58] Don Sproxton, 'Euthanasia in Western Australia' (Speech, 2019 Australian Catholic Youth Festival, 8 December 2019) <http://perthcatholic.org.au/Our_Archdiocese-Bishop-Speeches_Statements_and_Letters-2019-Speech__Euthanasia_in_Western_Australia.htm>.

[59] Shine (n 31). However, not all religious institutions in Western Australia are opposed to VAD. The Buddhist Council expressed support for the legislation, and the Uniting Church has put forward a resolution to allow VAD assessment and administration to occur within its facilities: see, eg, Synod of the Uniting Church in Western Australia, 'Proposal 9: Voluntary Assisted Dying Task Group' (Policy Proposal, September 2020) <https://unitingchurchwa-startdigital.netdna-ssl.com/wp-content/uploads/2020/09/VAD-Task-Group-3.pdf>.

[60] Queensland Parliamentary Report (n 9) 50. Similar views were expressed by religious groups to other parliamentary inquiries: see, eg, Legal and Social Issues Committee, Parliament of Victoria, *Inquiry into End of Life Choices* (Final Report No 174, June 2016) 213 <https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf>; Select Committee on End of Life Choices in the ACT, Parliament of the Australian Capital Territory, *End of Life Choices in the ACT* (Report, March 2019) 89–90 <https://www.parliament.act.gov.au/__data/assets/pdf_file/0004/1334992/9th-EOLC-Report.pdf>.

[61] This includes the four hospitals run by Calvary Healthcare and around nine aged care facilities operated by Southern Cross Care in Tasmania: Marilyn Rodrigues, 'Peak Health Group Rejects Dying Bill', *Catholic Weekly* (online, 17 September 2020) <https://www.catholicweekly.com.au/peak-health-group-rejects-dying-bill/>.

[62] Tasmania, *Parliamentary Debates*, Legislative Council, 30 October 2020, 15 (Bastian Seidel). The Anglican Church has also publicly voiced its opposition to VAD: Sue Bailey, 'Two Churches Have Strongly Opposed an Assisted Dying Bill Being Prepared for Parliament', *The Advocate* (online, 22 September 2019) <https://www.theadvocate.com.au/story/6399252/assisted-dying-proposal-rebuffed-by-churches/>.

[63] In Victoria, the Department of Health and Human Services established a Statewide Voluntary Assisted Dying Care Navigator Service to provide this referral function: DHHS VAD Care Navigators (n 49). In the first year of the *Victorian VAD Act 2017* (Vic), this service provided support to 613 people (the data does not state whether these supports were a result of institutional objections): Voluntary Assisted Dying Review Board, 'Report of Operations: January–June 2020' (Report, 31 August 2020) 5

C Some Illustrative Canadian Examples

Allowing institutional objections to VAD can sometimes result in patients being transferred seamlessly and painlessly to another institution, community space, or home for assessments and provision of VAD. However, as the longer Canadian experience with VAD has shown,[64] it can also result in indignity, extreme pain, and loss of access. There is insufficient scope here to report all such reported cases, but those described below are illustrative.[65]

Two cases that resulted in indignity were Doreen Nowicki and Bob Hergott. Doreen Nowicki was a woman in her late 60s with advanced motor neurone disease.[66] She was living in a continuing care facility run by a Catholic provider. She was taken from her bed with a mechanical lift, put in a wheelchair, and brought out of the facility to benches situated across the street (off the property) for her VAD eligibility assessment. This was intensely distressing for her. Bob Hergott, a 72-year-old man also with motor neurone disease, had to leave the hospital where he had been an in-patient for five years, cross the street in the rain to a bus shelter, and meet the two witnesses required as he signed his form requesting VAD.[67]

An institutional objection can also result in extreme pain to the patient. Ian Shearer was an 87-year-old man with spinal stenosis.[68] His pain medications were reduced to ensure he would have decision-making capacity following the transfer. The ambulance was more than three hours late. The time waiting for the ambulance was increasingly painful and the trip across the streets of Vancouver was agonising.

Institutional objections have also resulted in limitations or removal of access. Gerald Wallace was an 80-year-old man with pancreatic cancer in a rural hospital run by a Catholic organisation.[69] He was prevented from accessing VAD and died

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<https://www.bettersafercare.vic.gov.au/sites/default/files/2020-08/VADRB_Report%20of%20operations%20August%202020%20FINAL_0.pdf>. The *End of Life Choice Act 2019* (NZ) has mandated the creation of a support and referral group in its legislation: at s 25.

[64] As noted above, in Canada, VAD is referred to as ‘medical assistance in dying’ (‘MAiD’), but we use the term VAD in this section for consistency with the rest of the article.

[65] We do not have full information on the scope of the problem as the data is not collected in all jurisdictions. However, in Alberta, a province that collects and publishes data on this issue, between 17 June 2016 and 30 April 2020 (noting, though, that the website states it is current as of April 2020 but actually only includes data up to end of 2019), 125 patients were transferred from faith-based (109) or non-participating (16) sites to a participating facility or the patient’s home. This data suggests that 10% of VAD deaths in Alberta follow a transfer from a faith-based site: ‘Data & Statistics: Medical Assistance in Dying’, *Alberta Health Services* (Web Page, 28 February 2021) <https://www.albertahealthservices.ca/info/Page14930.aspx>.

[66] CBC Coverage of Doreen Nowicki (n 25).

[67] CBC Coverage of Bob Hergott (n 25).

[68] Tom Blackwell, ‘BC Man Faced Excruciating Transfer after Catholic Hospital Refused Assisted-Death Request’, *National Post* (online, 27 September 2016) <https://perma.cc/DE36-V9TA>.

[69] Jennie Russell, ‘Camrose Man Died in Pain after Covenant Health Hindered Access to Assisted-Dying Services, Son Says’, *CBC News* (online, 1 December 2018)

in pain. Additionally, Horst Saffarek, an elderly man whose lungs were failing, was admitted to a Catholic hospital.[70] He was found eligible for VAD but the hospital refused to allow it to be provided on their premises. He had to be transferred to a city more than an hour away, but he died before he was able to access VAD.

IV THREE POSSIBLE MODELS OF LEGAL REGULATION

The limited evidence in Australia about institutional objection, as discussed in Part III(A) and (B), reveals that some institutions in Victoria are currently objecting to VAD in various ways and this is likely to occur in other states that legalise VAD. These objections, as also shown in the longer Canadian experience, can adversely affect individuals who are eligible for VAD but cannot access it in such institutions. Governments exploring VAD reform must consider this issue and the appropriate regulatory response, whether that is prohibiting institutions from conscientiously objecting, not restricting this ability in any way, or a compromise of these two extremes. Ultimately, a government's position will depend on how it balances institutional and individual interests. At the heart of this decision is how best to weigh an individual's ability to access VAD against an institution's desire not to permit access to VAD within its facility.[71]

This balancing exercise has been subject to extensive debate[72] and there is not scope in this article to engage further with those arguments. Instead, our goal is to describe possible regulatory models that chart three broad options, and briefly observe the implications of each model for institutional and individual interests.

The three regulatory responses proffered draw on Wicclair's terminology in relation to conscientious objection by individuals,[73] and are framed as:

- 'conscience absolutism' – permitting institutional objections without limit;
- 'compromise or reasonable accommodation' – permitting institutional objections but imposing limits on them; and
- 'non-toleration' – institutional objections are not permitted.

But before considering these three options, we raise two threshold issues. The first is whether a regulatory response should comprise of legislation or policy. We propose that legislation is optimal (which would allow for accompanying policy), and regulatory responses in Part IV(B) and (C) below are framed accordingly. Policy alone is a weaker form of regulation with less coercive force.

<https://www.cbc.ca/news/canada/edmonton/camrose-man-died-in-pain-after-covenant-health-hindered-access-to-assisted-dying-services-son-says-1.4927739>.

[70] 'Should Catholic Hospitals Have to Provide Access to Medically Assisted Dying?', *CBC Radio* (online, 11 January 2018) <https://www.cbc.ca/radio/thecurrent/the-current-for-january-11-2018-1.4481312/should-catholic-hospitals-have-to-provide-access-to-medically-assisted-dying-1.4482372>.

[71] Flynn and Wilson (n 22) 228–9.

[72] See Carpenter and Vivas (n 25); Flynn and Wilson (n 22); Gilbert (n 20); Shadd and Shadd (n 6); Sumner (n 6).

[73] Mark R Wicclair, 'Preventing Conscientious Objection in Medicine from Running Amok: A Defense of Reasonable Accommodation' (2019) 40(6) *Theoretical Medicine and Bioethics* 539.

While a policy approach is often appropriate to regulate aspects of healthcare, we consider this is not the case where the proposed policy response conflicts with deeply-held views of the target of regulation (here, institutions). The stronger normative and coercive force of law is more likely to be needed here, particularly if an individual citizen is seeking to rely on it to compel an institution (often large and well-resourced) to comply with regulation.[74] Further, a legislative approach ensures any changes occur only with the transparency and public accountability of parliamentary consideration.

The second threshold point we make is that, regardless of which regulatory response is adopted, it should require organisations to disclose their objections publicly.[75]

A 'Conscience Absolutism'

The first regulatory option is for legislation to enshrine the ability of an institution to object. The model gives all weight to an institution's position on VAD and no weight at all to the patient's interests, and enables institutions that effectively have a monopoly on the provision of specialist services to bar individuals from accessing legally-available health services.[76]

Such an approach would bestow greater powers on institutions to object than individuals, upon whom law and ethics in medicine traditionally impose at least some compromise or accommodation duties – eg, providing information or effective referral.[77] Allowing absolutism for institutions could effectively deprive eligible people of access to VAD, even more so than objections by individual health professionals. While changing doctors is not straightforward, it generally remains possible, whereas for a person unable to move from an institution, absolutism is a veto on that person's ability to access VAD.[78] Even if a person was able to move, they may require the cooperation or assistance of the institution to facilitate the transfer, which absolutism would allow them to withhold.

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[74] We note it would be possible, however, to design a policy response which may nevertheless be effective in ensuring compliance by institutions – eg, if linked to accreditation or funding requirements.

[75] A provision requiring such disclosure was included in the Voluntary Euthanasia Bill 2016 (SA) clause 21(3)(a). We do not propose this disclosure being a ground for refusing access to VAD. Rather, we consider the utility of such a provision is to help avoid situations, where possible, of a person finding out subsequent to their admission or residence that the facility objects to access to VAD.

[76] See, eg, Schuklenk (n 8).

[77] It is worth noting that while the *Voluntary Assisted Dying Act 2019* (WA) section 20(5) requires conscientiously objecting health professionals to provide certain information to their patients, the *Victorian VAD Act 2017* (Vic) s 7 imposes no accommodation duties on doctors who conscientiously object.

[78] Sumner (n 6) 972.

B ‘Compromise or Reasonable Accommodation’ of Institutional Objection

This section outlines how legislation could present a ‘compromise or reasonable accommodation’ model for institutional objection to VAD. Such an approach recognises that institutional objections to VAD will occur and allows them, but aims to regulate them to ensure as little impact on the person seeking VAD as possible, while still permitting some degree of institutional objection. This need not imply legislative endorsement of these objections; the focus is instead on creating processes to facilitate a person’s access to VAD where objections occur. Two of the authors included a clause in their model VAD Bill which aimed to address this by requiring the objecting institution to arrange a transfer if requested.[79] However, in light of the impacts of institutional objections on patients in practice, as described earlier in the article, more may be needed to better support access to VAD when institutions object.

While there are various compromise models that could be designed, in our view, all compromise models should, at a minimum, require institutions to provide information about VAD and facilitate effective referral to a VAD provider. This obligation does not require an objecting institution to endorse VAD, or to be involved with its assessment or administration. Although some organisations may consider that providing information or directly referring to a VAD provider makes them complicit in the activity to which they object,[80] a workable alternative is to connect individuals with a central coordination service (such as the VAD Navigators in Victoria).[81] Therefore, our discussion below focuses on the two other aspects of VAD provision that institutions may object to: conducting VAD assessments and administration.

A final general point is that this compromise or reasonable accommodation category is very broad: legislation could be drawn to require either very little compromise or a great deal of compromise from objecting institutions. The below approach is one put forward for consideration which weighs the balance between individual and institution in favour of the person seeking access to VAD. As explained below, we have struck the balance in favour of the patient when the institutional objection will unduly compromise the patient’s interests. This is because the patient, who is close to death and intolerably suffering, is in a vulnerable position.

1 Nature of Provision: No New Rights for Institutions; Creates Process Only

Under this model, legislation should provide that ‘nothing in this section creates a right for an institution to refuse to provide access to VAD’. This addresses concerns raised in the Tasmanian debates[82] that legislatively regulating this issue

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[79] White and Willmott (n 9) 36. See also Voluntary Euthanasia Bill 2016 (SA) cl 21(3)(b). Such a clause was also reflected in amendments proposed in Tasmania to its *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas): see Tasmania, *Parliamentary Debates*, Legislative Council, 30 October 2020, 2 (Bastian Seidel).

[80] Congregation for the Doctrine of the Faith (n 28) 8, 14.

[81] This is also the position that has been adopted in Alberta and Quebec, Canada: Gilbert (n 20) 9.

[82] See, eg, Tasmania, *Parliamentary Debates*, Legislative Council, 30 October 2020, 10 (Meg Webb).

might be seen as implicit recognition of institutional objections and conscience rights.[83] Further, the provision should be framed as establishing a process to ensure a person's access to VAD is not unreasonably denied. For example, it could state: 'An institution wishing to refuse a person's request to access VAD within a facility must follow the process outlined in this section'.

2 Would the Patient's Interests Be Unduly Compromised by Requiring Access to VAD Outside the Facility?

One way to accommodate both an institution's objection and a person's desire to access VAD is for VAD assessments and administration to occur outside the facility. This could occur by transferring a person's care or residence to another, non-objecting, institution. However, it is also possible for VAD to occur without a formal transfer. For instance, a person in a residential aged care facility may remain living there but, if well enough to do so, may leave the facility for VAD assessments and then again attend elsewhere to take the VAD medication at a time of their choosing. Determining when this should be required would depend both on establishing criteria to assess the impact on the patient's interests, and identifying who would decide whether these criteria were met.

To address the undesirable consequences for persons seeking VAD outlined above, this criteria could include that it is not appropriate for an institution to refuse access to VAD where:

- that would cause harm to the person (eg, this could be pain or a deterioration of their condition from the required transfer);
- that would prejudice a person's access to VAD (eg, the transfer logistics to another institution mean a person is likely to lose capacity or die first; or pain medication required to manage the transfer means they are likely to lose capacity);
- that would cause undue delay (and thereby extended intolerable suffering) in accessing VAD; or
- access to VAD is not reasonably possible at another institution (eg, another institution will not accept a transfer or the institution is the only facility in the district that could manage the patient in their condition).

Given the criteria (which are medical in nature or at least involve navigating the health system), we consider it appropriate that whether they are met is decided by a doctor. We would propose a doctor who is chosen by or acceptable to the patient. A doctor employed by an objecting institution may not be free to adopt a position contrary to the institution, although we note that a patient might choose to nominate a doctor working in an objecting institution if they considered that doctor was independent.

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[83] This provision would not, of course, create a right or duty to provide VAD.

This may raise issues if the objecting institution considers that granting permission for this doctor to meet with the person is facilitating access to VAD and so is inconsistent with the institutional objection. However, failing to allow this access to the facility by the doctor could preclude a person's access to VAD altogether, so this is required to appropriately balance institutional and individual interests.

3 Obligations Where Access to VAD Will Occur Outside the Objecting Institution

Where the criteria above mean that access to VAD will occur outside the objecting institution, the institution must offer and take reasonable steps to facilitate this access. For instance, this may require supporting a transfer of the care or residence of the person to a place at which VAD can be assessed or provided by a doctor who does not have a conscientious objection to VAD.

Further, a person must not experience financial detriment because of such a transfer, which could in some instances have financial implications for a person so serious as to create an unconscionable or insurmountable barrier. This detriment could range from the cost of transport between institutions through to costs due to complex financial arrangements associated with entry into and exit from a residential aged care facility. Because the need for a transfer arises from the institution's objection, the legislation should provide that no financial detriment will occur as a result.

4 Obligations Where Access to VAD Will Occur Inside the Objecting Institution

Where the criteria above mean that access to VAD will occur inside the objecting institution, the legislation should provide that access must be permitted by the institution. This is based on a person's claim to access VAD outweighing an institution's objection, when both outcomes cannot be achieved. Not taking this approach would effectively mean that a person who is unable to be reasonably transferred or leave the institution for periods to access VAD would be prevented from accessing VAD by an institution that is objecting.

The legislation should state that an objecting institution will be required to permit a person to access VAD within the institution and will take reasonable steps to allow this where transfer is not possible or unduly harms the person's interests. This may include permitting existing staff (who are willing) to be involved in conducting VAD assessments or administering the VAD medication to this person, or allowing other doctors to visit the person onsite and provide the assistance required. The institution would also not be allowed to impede a person self-administering VAD medication onsite.

C 'Non-Toleration' of Institutional Objection

Under this model, legislation would prohibit an institution from preventing access to VAD on the basis of an objection. The provision could be framed broadly and prohibit an institution from impeding access of a person seeking VAD.[84] For clarity, it may be desirable for the legislation to specify that the institution could not prohibit entry to its facility of any health professional for the purpose of discussing VAD with a patient, assessing eligibility for VAD, or providing VAD. The institution also could not prohibit a patient from self-administering a VAD substance.

Under this approach, VAD would be available to all eligible individuals who wish to access it, not just for those for whom transfer would be problematic (as canvassed above). This model gives the strongest recognition of the three approaches to the right of an individual to access VAD despite an institution's objection.

V CONCLUSION

This article aims to highlight an important, but largely neglected, aspect of the VAD debate in Australia: objections by institutions when a person seeks lawful access to VAD. Patients and residents being cared for or residing in such institutions may effectively be denied access to VAD or have to overcome significant barriers to access it. There is evidence of institutional objection in Australia, and experience in Canada demonstrates the impact these objections can have on individuals who wish to access VAD and are experiencing intolerable suffering.

This article proposes three possible legislative models to regulate institutional objection. One is conscientious absolutism: legislation that enshrines the ability of an institution to object and imposes no limitation on that right. This model will have adverse outcomes for some individuals, particularly those who are unable to transfer from that facility, as they are effectively deprived of choice, unable to move, and without access to VAD. This prioritises the institutional position at the expense of the individual. At the other end of the spectrum, non-toleration, where an institution is prohibited from exercising an objection in any circumstances, the individual is prioritised even if the institution may be in a position and willing to transfer their care.

The middle ground, the 'compromise or reasonable accommodation' model, is a legislative option worthy of consideration. It does not grant absolute priority to either the institution or the individual seeking VAD, but seeks to accommodate both. The specific compromise model proposed in this article, however, does prioritise the individual if both positions cannot be reasonably accommodated.

Parliaments and law reform bodies considering VAD reform must consider the issue of institutional objection, and select a policy position on how to balance the

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[84] A stricter version would be to require institutions to employ staff capable of and willing to be involved in the provision of VAD.

desire of an institution to determine what practices are permitted within their facilities and the interests of an individual seeking access to VAD, a lawful medical service. As argued above, this should not be left to policy alone and is an issue that should be explicitly addressed in VAD legislation.

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RESEARCH **Open Access**

A qualitative study of experiences of institutional objection to medical assistance in dying in Canada: ongoing challenges and catalysts for change

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Abstract

Background In June 2016, Canada legalized medical assistance in dying (MAiD). From the outset, some healthcare institutions (including faith-based and non-faith-based hospitals, hospices, and residential aged care facilities) have refused to allow aspects of MAiD onsite, resulting in patient transfers for MAiD assessments and provision. There have been media reports highlighting the negative consequences of these "institutional objections", however, very little research has examined their nature and impact.

Methods This study reports on findings from 48 semi-structured qualitative interviews conducted with MAiD assessors and providers, MAiD team members (working to coordinate care and lead MAiD programs in institutions and health authorities), and family caregivers on their experiences with institutional objection. Participants were recruited from the Canadian provinces of British Columbia, Ontario, and Nova Scotia. Data were analyzed using inductive thematic analysis.

Results Themes identified were: (1) basis for institutional objection (with objections commonly rooted in religious values and a particular philosophy of palliative care); (2) scope of objection (demonstrating a wide range of practices objected to); (3) lack of transparency regarding institutional position; (4) impacts on patients; (5) impacts on health practitioners; and (6) catalysts for change. Participants reported that many institutions' objections had softened over time, lessening barriers to MAiD access and adverse impacts on patients and health practitioners. Participants attributed this positive change to a range of catalysts including advocacy by health practitioners and family members, policymaking by local health authorities, education, and relationship building. Nevertheless, some institutions, particularly faith-based ones, retained strong objections to MAiD, resulting in forced transfers and negative emotional and psychological impacts on patients, family members, and health practitioners.

Conclusions This paper adds to the limited evidence base about the impacts of institutional objection and can inform practical and regulatory solutions in Canada and abroad. Reform is needed to minimize the negative impacts on patients, their caregivers, and health practitioners involved in MAiD practice.

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Keywords Assisted dying, Medical assistance in dying, Euthanasia, Assisted suicide, Institutional objection, Conscientious objection, Patient experience, Health professional experience

Background

A growing number of jurisdictions have legalized medical assistance in dying (MAiD) (elsewhere known as euthanasia and physician-assisted suicide, or voluntary assisted dying) [1, 2]. MAiD is now potentially available to many millions of people worldwide [1]. Despite this trend, barriers exist which restrict the ability of individuals to access MAiD. One such barrier is "institutional conscientious objection" or "institutional objection" [3, 4] by hospitals, hospices, and residential aged care facilities, which seek to exclude aspects of MAiD on conscientious or religious grounds.

In Canada, where MAiD has been legal since 2016, [5][1] approximately 3% of all deaths annually are through MAiD (3.3% in 2021) [6]. To be eligible for MAiD, two independent medical or nurse practitioners must assess the patient and determine that they meet the relevant legislative criteria. Both physician-administered and oral MAiD are permitted by law, but to date, the vast majority of MAiD deaths have been administered by a physician or nurse practitioner, rather than administered by patients themselves [6].[2] More than half of all MAiD provisions have occurred in a healthcare institution such as a hospital (28.6% of MAiD deaths in 2021), palliative care facility (19.6%), or residential aged care facility (6.1%) [6]. Some institutions facilitate or passively permit MAiD, while others refuse to be involved or prohibit it happening onsite [7–9].

Due to the constitutional division of powers in Canada, institutional objection is dealt with on a provincial/territorial level [10].[3] As a result, the legal position of objecting institutions varies across Canadian provinces and territories [7]. In Quebec, all "institutions" (defined to include hospitals and residential and long-term care facilities, but not palliative care hospices) must offer end-of-life care, including MAiD [11]. In Nova Scotia, all facilities operated by the Nova Scotia Health Authority (which owns and operates all hospitals) must provide or allow access to MAiD [12]. Likewise, in Prince Edward Island, the provincial health department indicates eligible individuals can receive MAiD education, assessments, and procedures at the location of their choice, including "any publicly funded health care institution in the community, health care centre or hospital." [13] In the remaining provinces, some degree of institutional objection is protected either by legislation or through agreements between the provincial government and faith-based healthcare institutions [7]. For example, in British Columbia, institutions which have over 50% of their beds publicly funded are required by government policy to allow MAiD assessment and provision with an important exception [14] – faith-based institutions can prohibit MAiD in their facilities under a broad "Master Agreement" between the province and the Denominational Health Care Facilities Association [15].

Like the Canadian regulatory position, the ethical literature on institutional objection lacks consensus. While the ability of individual health practitioners to refuse to participate in MAiD is a well-recognised albeit not universally accepted ethical principle (which is also reflected in laws and policies), [16] institutional objection is more contested. Some argue that institutions cannot claim to have a conscience since they are "bricks and mortar" and cannot suffer moral injury like individual health practitioners can [4, 17]. Others argue that institutions with a distinct ethos, such as a religious organization, can claim a shared set of values akin to an individual's conscience, which should be protected [4, 18]. Still others argue that institutional objection is justifiable not on the basis of conscience, but rather as a matter of self-governance [19]. Yet, given the considerable harms to patients that can result from institutional objection, detractors suggest it should be prohibited, or at least curtailed [3, 4, 20, 21]. Institutional objections, they say, can restrict the availability of certain health services for many people and "will almost always wipe out access for huge numbers of

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[1] MAiD was legalized federally in 2016 when the Canadian government introduced Bill C-14, An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying), 1st Sess, 42nd Parl, 2016 to respond to the Supreme Court of Canada's decision in *Carter v Canada (Attorney General)*, 2015 SCC 5. However, provincial legislation permitting MAiD was first enacted in Québec which commenced operation in 2015: *Act Respecting End-of-Life Care*, RSQ c S-32.0001.

[2] The most recent Health Canada annual report states that there were 10,064 MAID provisions in 2021 and "fewer than 7" (0.0007%) were due to self-administration (a trend consistent with previous years). See: Health Canada. Third annual report on medical assistance in dying in Canada 2021. 2022. https://www.canada.ca/en/health-canada/services/medical-assistance-dying/annual-report-2021.html. Accessed 17 Apr 2023.

[3] In Canada, criminal law is the responsibility of the federal government, while the administration and delivery of health care is the responsibility of the provinces and territories: *Constitution Act 1867*. The federal *Criminal Code of Canada*, RSC 1985 c. C-46 ("*Criminal Code*") contained prohibitions on MAiD, which were amended by Bill C-14, An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying), 1st Sess, 42nd Parl, 2016 and subsequently by Bill C-7, An Act to Amend the Criminal Code (Medical Assistance in Dying), SC 2021, c. 2. While the core legal parameters for MAiD are set out in the *Criminal Code*, how MAiD is administered and delivered is up to each provincial and territorial government. For more information see: Downie J, Scallion K. The path from Rodriguez to Bill C-14 and beyond: lessons about MAiD law reform from Canada. In: White BP, Willmott L, editors. International perspectives on end-of-life law reform: politics, persuasion and persistence. Cambridge: Cambridge University Press; 2021. p. 17–39.

people because institutions serve huge numbers of people" [22].

There is very limited data on the prevalence of institutional objection to MAiD in Canada. In a retrospective chart review of MAiD deaths in the Vancouver Coastal Health Authority in British Columbia from 17 June 2016–17 June 2019, Wiebe et al. found 9.5% (42 cases) involved a forced transfer [8]. Alberta Health Services reported that of 842 persons who accessed MAiD in a major hospital facility between 17 June 2016 and 30 September 2020, 15% (124) were transferred for the procedure. Of those transferred, 87% (109) were transferred from a faith-based facility (13% of persons who accessed MAiD in Alberta) (this data is no longer available on the Alberta Health Services website) [23]. Providence Health Care, a non-profit Catholic health care organization that operates hospitals and residential aged care facilities in British Columbia, has indicated that from June 2016 (when MAiD was legalized) to June 2023, 402 patients made formal MAiD requests and 131 patients were transferred elsewhere for MAiD provision [24].

A small but growing body of research in Canada and internationally has demonstrated a range of harms to patients caused by institutional objections [3, 8, 9, 25, 26]. Institutions have refused to provide patients with information about MAiD, and have refused to permit assessments and provisions onsite, resulting in some patients being transferred out of a facility [3, 8, 9, 25, 26]. These transfers have caused patients to experience additional pain, and psychological, emotional, and psychosocial suffering [3, 8, 24–26, 28]. In some circumstances, institutional objections have blocked patients' access altogether, such as when there was no other entity to receive a transfer of the patient or the transfer was physically unbearable for the patients or otherwise impossible [8, 28]. Some studies have also found more insidious effects of institutional objection, which can adversely affect a patient's end-of-life experience. In a study of the perceptions of health providers, patients and family members from a Saskatchewan regional health authority, Brown et al. found that participants perceived institutional policies prohibiting MAiD as creating barriers to access and challenges in navigating institutional procedures [25]. In particular, participants reported being unclear who in an institution was "safe to approach when accessing, receiving, and providing care." [25] Some family caregivers in the Australian state of Victoria also reported institutional objection to MAiD adversely affecting trust in clinical advice [26].

There is also some emerging evidence internationally that institutional objections also cause harms to health professionals, and reduce willingness to participate in MAiD [9, 27–29]. Physicians have described structural and emotional challenges from faith-based institutions refusing to allow entry to undertake MAiD assessments and provisions onsite, practising privileges not being honoured, significant travel needed as assessments cannot be carried out onsite, uncertainty caused by lack of protocols and policies, and onerous reporting requirements [9, 28, 29]. Nurses in Belgium have reported that a lack of professional support constrained their ability to represent the patient's interests [30]. Health professionals who do not share the institution's position experience moral distress when compelled to act against their values as a result of an institutional position [8, 25, 30]. Volunteer witnesses also described concerns about forced transfers and challenges when witnessing MAiD requests in faith-based institutions [31].

There are limited studies addressing institutional objections to MAiD in Canada to date [8, 9, 25, 31]. Existing evidence has largely arisen as a minor subset of findings from wider studies reporting on experiences with the MAiD system more broadly, with the exception of Wiebe et al's 2021 examination of forced and chosen transfers before and during the COVID-19 pandemic [8]. Additionally, existing evidence on institutional objection has mostly been from studies conducted in the first year or two of MAiD being legal in Canada, during a period when the MAiD system was still developing. This article examines experiences of institutional objection in Canada, six years after MAiD was legalized with the passage of Bill C-14 in June 2016. Its purpose is to report on perceptions of the impacts of institutional objection to MAiD on patients and health practitioners in contemporary practice now that the system in Canada has become more established. It aims to identify how institutional objections are experienced and the factors that have shaped practice over time.

Methods

Study design

This study is part of a broader comparative international project investigating factors that shape decision-making about MAiD in Canada, Australia and Belgium, to inform an optimal holistic model of regulation [32]. A discrete area of investigation was perceptions of the impact of institutional objection to MAiD in practice. This paper reports on the Canadian experience from data collected through semi-structured interviews with family caregivers of persons who sought MAiD, and physicians, nurse practitioners, and other health professionals who are involved in MAiD as assessors and providers or as members of institutional or health authority MAiD teams. The method is reported in accordance with the consolidated criteria for reporting qualitative studies (COREQ) [33].

Sampling and recruitment

For feasibility, since the study aimed to capture the specific regulatory context relevant to MAiD, which varies by province/territory, [34] the research team selected three target provinces to recruit from: British Columbia, Ontario, and Nova Scotia. These provinces were selected to provide diversity in geography, size, and population distribution. Individuals were eligible to participate in the study if they were over 18 and involved in decision-making about MAiD in the target provinces in one (or more) of three roles:

1. *Individuals and family caregivers*. Persons seeking MAiD who had initiated the process were eligible to participate, whether or not they had been assessed for MAiD or found eligible. Since patients suffering from grievous and irremediable conditions can be a difficult cohort to recruit, [35] particularly because they are by definition experiencing enduring and intolerable suffering, we also sought perspectives of family caregivers of patients who had experienced the MAiD process. Family caregivers were eligible to participate if they had supported a family member through the MAiD process (whether or not they had been found eligible) and could therefore speak to the patient's experiences. These participants were initially recruited using social media (Twitter and the project website) and through emails from Dying with Dignity Canada (the leading national patient advocacy, education, and support group for MAiD).
2. *MAiD assessors/providers*. Physicians and nurse practitioners were eligible to participate if they had acted as a MAiD assessor (assessing patient eligibility) or as a provider of MAiD (assessing the patient's eligibility and administering or prescribing the medication). These participants were initially recruited using social media (Twitter and the project website), and through the Canadian Association of MAiD Assessors and Providers (CAMAP) (the national professional organization for health professionals involved in MAiD).
3. *MAiD team members.* The third group was comprised of individuals who had a professional role as a member of a MAiD program (typically involved in activities including program management, care coordination, education, and research) either with a health authority or within an institution. These participants were initially recruited using social media (Twitter and the project website), and through CAMAP.

Since this investigation is part of a broader study on optimal regulation of MAiD, as noted in the study design, advertisements were framed broadly, seeking participants with experience of decision-making about MAiD and views on the impact of regulation (including law, policy, and procedures). Initially, all participants were recruited using convenience sampling, based on who had responded to preliminary recruitment efforts, as detailed above. We subsequently used purposive sampling to enhance diversity in terms of sex, location (metropolitan/regional), and patient, provider, and MAiD team experiences. Snowball sampling was also used to identify additional participants, also targeting diversity in experiences and location. Recruitment ceased when the research team determined there was sufficient "information power" to meet the study aims [36].

Data collection

The research team developed semi-structured interview guides for each interview cohort (Additional files 1, 2, 3, 4). Interviews covered a range of issues as part of the broader study on decision-making about MAiD mentioned above, and institutional objection was raised using prompts if participants did not raise it themselves. The key open-ended prompts for each interview cohort were:

- *Interviews with patients or family caregivers (regarding patients in an institution)*: "Did the facility facilitate access to MAiD or was it a barrier to access?";
- *Interviews with MAiD assessors/providers*: "Have you experienced any issues with institutions which object to MAiD at any stage of the MAiD process?"; and.
- *Interviews with MAiD team members*: "Have you been involved with addressing institutional objections and/or transfers?"

When a participant discussed institutional objection (either explicitly using that term or others, e.g. "forced transfers"), follow up questions explored issues including: the nature of the objection (e.g. where and at what stage of the process it arose, and how it was communicated); what the impact of the objection was (e.g. how it affected the patient, family members, and staff); and any action taken to respond to the objection. The interviewers used techniques including paraphrasing and summarizing in interviews to check understanding of the participants' views and experiences.

Patient and family caregiver interviews were conducted by RJ (with JD present for 2 interviews and EC for 10 interviews to pilot the interview guide and provide feedback as part of RJ's PhD research training). Interviews with MAiD assessors/providers and MAiD team members were conducted by EC (with JD present for 3 initial interviews to refine the interview guide). One interview was conducted jointly by EC and RJ as the participant was both a family caregiver and MAiD assessor/provider.

Interviews were conducted between 6 October 2021 and 9 August 2022 using Zoom videoconferencing software. All participants provided informed consent prior to the interview. For all family caregiver interviews, the patient whose experience they were sharing had died, and so patient consent was not sought. EC and RJ (and where applicable, JD) debriefed after interviews, and maintained reflexive journals. Interview audio was recorded using Zoom and professionally transcribed verbatim. Participants were given the opportunity to add to, clarify or amend their transcript.

Analysis

All transcripts were uploaded to NVivo (release 1.6.1, QSR International) for analysis. EC and RJ identified the transcripts that described experiences with institutional objection. Institutional objection was defined as occurring when a participant perceived an institution (including a hospital, hospice, aged-care facility, or long-term care facility) objected to some or all aspects of MAiD on the basis of values (rather than purely logistical considerations), including when this objection was not explicitly stated. For example, this included participants that reported access to MAiD was affected because of an institution's religious affiliation or due to interactions with staff, even if the institution did not have an explicit position against MAiD.

Once these transcripts were identified, EC and RJ selected 10 transcripts (5 involving family caregivers, 4 with MAiD assessors/providers and 1 with a MAiD team member) and each independently inductively coded all extracts addressing institutional objection, using Braun and Clarke's reflexive thematic analysis [36]. After this initial coding, EC and RJ discussed coding approaches to achieve a richer understanding of the data, [37] and refined the codes. EC and RJ then each independently coded the remainder of the transcripts. To enrich analysis, EC and RJ identified areas of convergence and divergence, particularly between data collected from each of the three distinct participant groups and provinces. Using this coding and considering the reflexive journals, EC and RJ developed themes and sub-themes, which were discussed and iteratively refined by all authors after reviewing the data.

Results

Sample description

Seventy interviews were conducted for the broader project on MAiD decision-making: 31 with family caregivers; one with a patient; 32 with MAiD assessors/providers (25 physicians and 7 nurse practitioners); and 11 with members of MAiD teams at health authorities and institutions. Five participants had overlapping roles: four MAiD team members were also MAiD assessors/providers, and one MAiD assessor/provider was also a family caregiver. Two interviews with family caregivers involved two participants, at the interviewees' request (e.g. a child of a deceased parent and their spouse).

In 48 of the 70 interviews, participants discussed institutional objection: 40 interviews described direct experiences, while 8 interviews solely involved participants' perceptions of institutional objection more generally. The proportion of participants discussing institutional objection by participant role is set out in Table 1.

This subset of 48 interviews discussing institutional objection, which was analyzed for this study, ranged from 50 to 203 min (median of 94 min). Table 2 sets out participant demographics. Table 3 sets out characteristics of the 6 patients who family caregivers described experienced an institutional objection (characteristics of patients reported on by family caregivers from the broader study are also included to facilitate comparison).

Participants reported institutional objections from a range of faith-based and non-faith-based institutions including hospitals, palliative care units, hospices, and long-term care facilities. While institutional objection occurred in all provinces, MAiD assessors/providers and MAiD team members from Ontario commented on more ongoing challenges with institutional objection than those in British Columbia and Nova Scotia.

We identified six overarching themes: (1) basis of institutional objection; (2) scope of objection; (3) transparency of position; (4) impacts on patients; (5) impacts on health practitioners; and (6) catalysts for institutional change. Additional illustrative quotes for each theme are provided in Table 4.

Theme 1. basis for institutional objection

There were two primary bases for institutional objections. First, objections based on religious values, which commonly arose in faith-based institutions (including hospitals, hospices, long-term care facilities, and home care providers). A physician noted:

> *"Catholic hospitals and some of the Jewish hospitals will not allow it and some of the hospices that have religious affiliations won't allow it. So, you don't get to see patients in them." (MAiD assessor/provider 4)*

The second basis for institutional objection was a particular philosophy of palliative care which arose in both faith-based and non-faith based palliative care settings (including hospices, and palliative care units within hospitals). For example:

> *"In the beginning there were a lot of palliative care facilities that also just said, 'well we won't do that work.' Non-faith based, just philosophically, ideologically." (MAiD assessor/provider 8)*

Table 1 Interviews in which participants discussed institutional objection

Role	Number of interviews: Total sample	Number of interviews: Institutional objection sample (% of total sample)	Number of interviews with direct experiences of institutional objection (% of institutional objection sample)	Examples of direct experiences of institutional objection
Family caregivers	31	12 (39%)	9 (75%)	• Supporting a patient who experienced an institutional objection (6 interviews) • Experience in participant's capacity as a healthcare worker (2 interviews) • Experience as a volunteer witness for MAiD (1 interview)
Patient	1	1 (100%)	-	• N/A[4]
MAiD assessors/providers	32	31 (97%)	27 (87%)	• Negotiating access to MAiD with objecting institutions • Conducting MAiD assessments in objecting institutions • Caring for patients who experienced forced transfers
MAiD team members	11	9 (82%)	9 (100%)	• Managing care coordination with objecting institutions • Education • Policy development and implementation
Total[5]	70	48 (69%)	40 (83%)	-

> *"There's a large amount of overlap because many palliative care institutions are faith-based, especially hospices, because palliative care is sort of a 'churchy' speciality. I think palliative care has a role to play in that lack of access, in those difficulties of access as well." (MAiD assessor/provider 15)*

Participants also reported that how an institution's values shaped its position on MAiD was often determined by a key internal stakeholder, for example, the medical director of a palliative care unit, or chair of the board of directors. Staff in an institution were described as often being supportive of MAiD, despite the top-down decision. For example, a family caregiver commented:

> *"...even though the majority of the people who worked at [institution] were intensely religious, either intensely Catholic or intensely Jewish ... everybody supported [the patient's] choice ... It was specifically the board, and the chairman of the board, with them saying 'No, we are too Jewish for that. We will not allow it." (Family caregiver 28)*

Similarly, a nurse practitioner noted:

> *"...the people in the high positions, somebody has an opinion and becomes vocal and shuts it down for the entire facility." (MAiD assessor/provider 26)*

Some participants provided examples in which the board's position seemed driven by a desire to maintain the faith-based ethos of the facility, not because the board members necessarily agreed with this position, but rather to appease stakeholders, such as charitable donors, outside of the organization. For example:

> *"Hospices in Ontario are funded mostly by charitable donations. ... the board of [hospice name] would need to make a decision that we are ... forgoing that gift and willing to pay for another piece of property in order to have the option of doing this." (MAiD assessor/provider 26)*

Several participants highlighted that institutional objections in faith-based and palliative care hospitals, hospices, and aged care facilities were not universal. A physician noted:

> *"For me institutionally, I haven't had any issues. Our palliative care unit is very supportive of MAiD ... the downtown one the same thing. ... There's no beef between palliative care and MAiD. Which when I first discovered that was a thing, it kind of blew my mind." (MAiD assessor/provider 20)*

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[4] The sole patient in the total sample was living in the community and did not experience institutional objection but described engaging in advocacy to combat it.

[5] Note that all totals reflect that 5 participants had overlapping roles as described in the results.

Table 2 Characteristics of participants (total sample and institutional objection sample)

Characteristics	**Total sample: Number (%)**	**Institutional objection sample: Number (%)**	**Institutional objection sample (direct experiences): Number (%)**
Family caregivers (n = 33 in total sample, 14 in institutional objection sample, 11 with direct experiences)[6]			
Gender			
Female	25 (76%)	11 (79%)	2 (18%)
Male	8 (24%)	3 (21%)	9 (82%)
Age			
Median (interquartile range)	60 (51–72)	61.5 (55.5–70)	60 (50.5–62.5)
Province			
British Columbia	9 (27%)	3 (21%)	2 (18%)
Ontario	17 (52%)	9 (64%)	8 (73%)
Nova Scotia	6 (18%)	2 (14%)	1 (9%)
Other[7]	1 (3%)	-	-
Relationship to patient			
Child/child-in-law	16 (48%)	8 (57%)	8 (73%)
Spouse/partner	12 (36%)	5 (36%)	2 (18%)
Parent	2 (6%)	1 (7%)	1 (9%)
Close friend	2 (6%)	-	-
Niece	1 (3%)	-	-
Relationship to patient			
Child/child-in-law	16 (48%)	8 (57%)	8 (73%)
Spouse/partner	12 (36%)	5 (36%)	2 (18%)
Parent	2 (6%)	1 (7%)	1 (9%)
Close friend	2 (6%)	-	-
Niece	1 (3%)	-	-
Patient (n = 1 in total sample, 1 in institutional objection sample)[8]			
Gender			
Female	-	-	-
Male	1 (100%)	1 (100%)	-
Province			
British Columbia	1 (100%)	1 (100%)	-
Ontario	-	-	-
Nova Scotia	-	-	-
Illness, disease or disability for which MAiD is sought			
Cancer	-	-	-
Neurological condition	-	-	-
Cardiovascular condition	-	-	-
Respiratory condition	-	-	-
Other condition	1 (100%)	1 (100%)	-
MAiD assessors/providers (n = 32 in total sample, 31 in institutional objection sample, 27 with direct experiences)			
Gender			
Female	21 (66%)	20 (65%)	18 (67%)
Male	11 (34%)	11 (35%)	9 (33%)
Age			
Median (interquartile range)	50.5 (42–61)	50 (42–61)	52 (42–62)
Province			
British Columbia	10 (31%)	10 (32%)	8 (30%)
Ontario	15 (47%)	14 (45%)	13 (48%)
Nova Scotia	7 (22%)	7 (23%)	6 (22%)
Population Centre and Rural Area Classification [51]			
Large urban population centre (> 100,000)	17 (53%)	16 (52%)	14 (52%)
Medium population centre (30,000–99,999)	5 (16%)	5 (16%)	3 (11%)
Small population centre (1,000–29,999)	6 (19%)	6 (19%)	6 (22%)
Rural area	4 (13%)	4 (13%)	4 (15%)

Table 2 (continued)

Characteristics	Total sample: Number (%)	Institutional objection sample: Number (%)	Institutional objection sample (direct experiences): Number (%)
Type of assessor/provider			
Physician	25 (78%)	24 (77%)	21 (78%)
Nurse practitioner	7 (22%)	7 (23%)	6 (22%)
Main clinical specialty			
Family medicine	14 (44%)	14 (45%)	13 (48%)
Primary care	6 (19%)	5 (16%)	5 (19%)
Palliative care	4 (13%)	4 (13%)	2 (7%)
Psychiatry	3 (9%)	3 (10%)	2 (7%)
Anaesthesia	1 (3%)	1 (3%)	1 (4%)
Geriatric medicine	1 (3%)	1 (3%)	1 (4%)
Internal medicine	1 (3%)	1 (3%)	1 (4%)
Neurology	1 (3%)	1 (3%)	1 (4%)
Oncology	1 (3%)	1 (3%)	1 (4%)
Practice setting			
Community only	16 (50%)	16 (52%)	14 (52%)
Hospital only	5 (16%)	5 (16%)	5 (19%)
Multiple settings (including community, hospital, hospice)	11 (34%)	10 (32%)	8 (30%)
Years of experience in health care			
Median (interquartile range)	20.5 (11-33.8)	21 (11–35)	21 (11–37)
Number of MAiD cases as assessor and/or provider			
Median (interquartile range)	112.5 (51.3-337.5)	125 (50–350)	200 (38.75–387.5)
MAiD team members (n = 11 in total sample, 9 in institutional objection sample, 9 with direct experiences)			
Gender			
Female	7 (64%)	6 (67%)	6 (67%)
Male	4 (36%)	3 (33%)	3 (33%)
Age			
Median (interquartile range)	49 (41–54)	49 (42–58)	49 (42–58)
Province			
British Columbia	4 (36%)	4 (44%)	4 (44%)
Ontario	4 (36%)	2 (22%)	2 (22%)
Nova Scotia	3 (27%)	1 (33%)	1 (33%)
Population Centre and Rural Area Classification [51]			
Large urban population centre (> 100,000)	8 (73%)	6 (67%)	6 (67%)
Medium population centre (30,000–99,999)	2 (18%)	2 (22%)	2 (22%)
Small population centre (1,000–29,999)	-	-	-
Rural area	1 (9%)	1 (11%)	1 (11%)
Setting			
Health authority	8 (73%)	8 (89%)	8 (89%)
Institution	3 (27%)	1 (11%)	1 (11%)

[6] Note: 31 interviews were conducted with 33 family caregivers (2 interviews with family caregivers each involved 2 participants; these are included in both the total sample and institutional objection sample)

[7] One family caregiver was based internationally but spoke about patient experiences in British Columbia and another province

[8] Since only a single patient was recruited, patient age is not reported to protect patient privacy

Theme 2. scope of objection

Participants described a range of aspects of MAiD that institutions objected to. Some institutions would not provide any aspect of MAiD or allow it to occur onsite. For example:

> *"...there is a care home downtown that I know I can't go in and do an assessment there, I can't go in and do a provision there, those patients need to come off the grounds of that building if I'm going to do assessments. I've done one in a café, I've done one in the park, done one on a park bench." (MAiD assessor/provider 8)*

Other aspects that institutions objected to included: providing information; allowing request forms to be signed

Table 3 Characteristics of patients discussed by family caregivers (total sample and patients who experienced an institutional objection)

Characteristic	**Total sample (n = 32)**[9] **Number (%)**	**Patients who experienced an institutional objection (n = 6) Number (%)**
Gender		
Female	18 (56%)	4 (67%)
Male	14 (44%)	2 (33%)
Age		
Median (interquartile range)	74.5 (66-81.25)	69.5 (66.3–72.8)
Province		
British Columbia	10 (31%)	2 (33%)
Ontario	14 (44%)	2 (33%)
Nova Scotia	6 (19%)	1 (17%)
Other[10]	2 (6%)	1 (17%)
Population Centre and Rural Area Classification [51]		
Large urban population centre (> 100,000)	18 (56%)	3 (50%)
Medium population centre (30,000–99,999)	6 (19%)	1 (17%)
Small population centre (1,000–29,999)	4 (13%)	-
Rural area	4 (13%)	2 (33%)
Place of death		
Residence	17 (53%)	2 (33%)
Hospital	8 (25%)	-
Hospice	1 (3%)	1 (17%)
Long-term care facility	4 (13%)	2 (33%)
Assisted living facility	1 (3%)	-
Other	1 (3%)	1 (17%)
Patient status at time of interview		
MAiD death	29 (91%)	6 (100%)
Non-MAiD death		
Assessed as eligible for MAiD but lost capacity	2 (6%)	-
Assessed as ineligible for MAiD	1 (3%)	-
Illness, disease or disability for which MAiD was sought		
Cancer	20 (63%)	3 (50%)
Neurological condition	7 (22%)	2 (33%)
Cardiovascular condition	2 (6%)	-
Respiratory condition	2 (6%)	-
Other condition	1 (6%)	1 (17%)
Year of death		
2016	1 (3%)	-
2017	5 (16%)	3 (50%)
2018	10 (31%)	1 (17%)
2019	3 (9%)	1 (17%)
2020	5 (16%)	-
2021	8 (25%)	1 (17%)

[9] One interview from the total sample of 31 family caregiver interviews discussed 2 patient experiences

[10] A participant based in one of the three target provinces described a patient experience in another province

and/or witnessed onsite; transferring patient records to a MAiD assessor or provider; inserting the IV for MAiD provision; and enabling specialist consultations (e.g. a psychiatry consultation).

In contrast to institutions with blanket refusals, other institutions took less restrictive positions to MAiD. Some prohibited MAiD provision but allowed eligibility assessments. Participants also discussed hospices that would permit MAiD but would not allow patients to be admitted for this purpose. For example, a physician observed:

> *"…they don't admit people just for MAiD. So, if you were at home and wanted MAiD, they wouldn't bring you in to get that, but they do have people who are there who request MAiD and have procedures there…" (MAiD assessor/provider 11).*

Table 4 Additional illustrative quotes regarding institutional objection by theme

Theme	Illustrative quotes (additional examples to what is provided in the text)
1. Basis for institutional objection	*Religious values*
	"So all the facilities over the country who claim to not participate – mostly Catholic, some other private ones – do it on the basis of their faith…" (MAiD assessor/provider 24)
	"…they were looking at it from the perspective of we are a Jewish hospital and Jewish laws don't believe in medically assisted death." (Family caregiver 11)
	Philosophy of palliative care
	"… our hospice isn't even a religious organization … and they wanted none of it, and the palliative physicians didn't want any part of it." (MAiD assessor/provider 3)
	"…it's a huge barrier. We can't go into hospice. In fact, hospice tells patients when they're interviewing them that if they are considering MAID they will not be allowed to come into hospice." (MAiD assessor/provider 23)
	Influence of key stakeholder
	"I think it's completely at the board level. Like all things, governance decides everything institutionally. And I think what's keeping the governance from accepting it is probably … perceptions around reputation risk." (MAiD team member 9)
	"…[the director] is the one that puts a kibosh on [i.e. puts a stop to] anything remotely concerning MAID … The only inpatient palliative care unit we have … we still have forced transfers, we still have – people aren't even allowed to be assessed on site. They have to move for both assessments and provision." (MAiD assessor/provider 1)
	"…they're all funded with public money [faith-based institutions] and the patients and the staff don't reflect those same values." (MAiD assessor/provider 24)
2. Scope of refusal	*Blanket refusal*
	"So, the [hospital] today, I went to the parking lot to do the assessment. They won't let me in the building." (MAiD assessor/provider 26)
	Shift to allow assessments
	"I think that's what they came down to, it's the act of actually ending a life which is what their religion says you can't do. Talking about it, finding someone eligible, until you've actually ended life you haven't done something which is against God's law." MAiD assessor/provider 6)
	"They said they would allow the assessment but not the provision, and then they upheld that. …we did think, especially as a provincially-funded health facility, that they would be required to abide by provincial health laws. But, in fact, religion trumped the law." (Family caregiver 28)
	Other aspects of the MAiD process
	Information: "I still think there is an active access issue because providers in that institution are not telling people that it's an option." (MAiD assessor/provider 11)
	"…who feels empowered to even ask about MAID in a Catholic institution in which they know it's not allowed? And whose conversation about MAID gets passed the nurse who says "No, we don't do that here," or the resident who says "No, we don't do that here,"? Like the persistence required to even get an assessment or have a conversation with your MRP [Most Responsible Physician] about MAID in a Catholic institution must be enormous, and it is enormous." (MAiD assessor/provider 15)
	IV access: "Some of our nursing agencies won't even put an IV in for that procedure…" (MAiD assessor/provider 18)
	Witnessing: "… we've had witnessings where the patients have to leave the hospital and get the forms signed on the sidewalk because they won't do it inside the hospital." (Family caregiver 8) (also a volunteer witness for MAiD)
	"I have a patient in [rural area] … He had no one to witness his form. He receives homecare on a daily basis, metastatic [cancer]. … a nurse visiting him daily … a palliative care coordinator … a palliative nurse practitioner who's visiting from [city]. All of them are forbidden by their agencies to witness. … I messaged these people, because they're all friendly people of mine, and I said 'Please take this to your supervisor. This is now legal. You are a paid caregiver. You are allowed to sign this legally.' 'Oh, no, I'm sorry, it is our policy.' The [hospital], they have a policy, nobody who's an employee of the [hospital] is allowed to sign this form. I said 'You've created a barrier now. You've added a barrier to the law'…" (MAiD assessor/provider 26)
	Discretionary decisions
	"They … came up with a thousand and one excuses not to follow the rules and to – they seemed bound and determined to avoid it at all costs. … They were obstructive right until the bitter end." (Family caregiver 24a)
	"… after a year of allowing forms and assessments, they [the hospice] wouldn't allow him to sign his form on the premises and said he would have to leave the premises. Which is a huge area. It's a hospital and nursing home and a hospice in one area. So I said to them 'Are you telling me you want this guy to go in his electric scooter, in the rain and winter, and go a kilometre and a half to leave the property? Which newspaper would you like to talk to?'" (MAiD assessor/provider 24)
	"I had another patient transferred to hospice and I got someone on the phone, and they said, 'We'll let you in the building.' 'Okay, thanks.' But I'm not sure if that's a policy thing. They said, 'We will not provide MAID.' It's on their application to the hospice, the patients have to sign that they will not even discuss MAID when they are admitted to a hospice." (MAiD assessor/provider 26)
	"We've done very well at working with our institutional conscientious objections. … in some places sometimes they have to be transferred back, but other places, believe it or not, actually will allow us to assess and provide." (MAiD team member 9)
	Locations with little to no problems
	"I'm very lucky where we are. The only encounter that I did have was early on when one of our facilities did not have a policy about MAID in place at all one way or the other." (MAiD assessor/provider 12)
	"… I know it happens in other provinces. I know other [specialists] just say "Well, I work in a Catholic place, so I don't have to do it, like I have never been involved." I must say I've been to the hospice a few times in Halifax and one of the first times I was there, there was obviously a nurse that was uncomfortable with me being there and I got a bit of a cold shoulder. But that happened once and never again." (MAiD assessor/provider 2)

Table 4 (continued)

Theme	Illustrative quotes (additional examples to what is provided in the text)
3. Lack of transparency regarding institutional position	*Lack of transparency regarding institutional position* "They pretended – or they said this was the first time they'd ever faced this situation in the home. So they came up with a thousand and one excuses not to follow the rules and to – they seemed bound and determined to avoid it at all costs." (Family caregiver 24b) "She'd been at [institution] for coming on three years. So, basically, as soon as we found out that it was a law now, that we could have that, we started working on that process … So she'd been approved for a little while and then I think she decided that we would give it a couple of months, and in that couple of months we tied up everything … And then we found out that [institution] would not allow her to have the procedure, her provision in her home." (Family caregiver 28) "They were unorganised, both in terms of the technical procedures and what you had to go through, but also and more important culturally equipped to deal with it. Their staff didn't know how to react. They had no protocol of what to tell or not to tell other residents on the floor who knew that something was going on." (Family caregiver 12) "On the face of it, it doesn't seem like that big of an issue. Like, okay, no problem, you don't allow assessments or assisted deaths, they'll just go to another spot. But like patients don't know. They don't know that these healthcare institutions have those regulations because, at least in [province], they're not being upfront about it. So a patient just walks into a hospital thinking that it's a hospital. So then they're there and now they have to leave, but if they leave then you're withdrawing them from their care team that they already know and trust … you're causing pain and suffering on the transfer. … They're applying for MAID to end their enduring suffering and you're adding to their enduring suffering by having them leave for the assessment and the death." (MAiD team member 6)
4. Impacts on patients	*Physical pain and other suffering caused by forced transfers* "… they're still being transferred to a different part of the hospital. … there's still that stigma that you still have to go to a different part of the hospital. … So it's not perfect. It's pretty good, but it's not perfect." (MAiD assessor/provider 10) "…the transfer was very uncomfortable. So, unfortunately that was really bad. To have someone move off of a location where they've lived for 10 years in a long-term care facility, that is just ridiculous and hard." (MAiD assessor/provider 12) "I had a case where he was in the hospice and he had to be transported out. … to be transported to this place, the poor man had been in so much pain." (MAiD assessor/provider 17) *Constrained choice* "But where it comes into play for me … is when I'm seeing patients from a palliative care perspective and I ask them what their goals are and they say 'I want to stay home as long as possible, but if things get too bad I want to have MAID and if things get too bad I want to go to an inpatient setting.' Well, you can't have both. You have to make a choice. So if things get too bad and you need to be admitted because your family's not coping or your symptoms aren't being managed well enough, then you basically give up MAID. You don't have to. But the reality is if you're sick enough to need inpatient care, it's not going to be to your best interest to then be transferred to [major hospital] to have the procedure done at that point. So again I've never dissuaded somebody from making the choice that's right for them, but they need to be informed and the reaction I get is always, 'Are you kidding me?' So it's disheartening." (MAiD assessor/provider 1) "[The patient had been] … languishing for like three weeks after having made a MAID request because they happened to find themselves, by virtue of an ambulance, choosing [a Catholic hospital] over a secular institution. They just happened to find themselves in a place that didn't affirm their autonomy to make decisions around their end-of-life care. So yeah, it's unconscionable, it's bonkers, it's unjust, it's nonsensical. It causes distress for patients, it causes distress for clinicians." (MAiD assessor/provider 15) *Compromised access* "… I might be able to provide for them at this hospital, I'd get emergency privileges to do it, but they wouldn't have the people around them who had been really caring for them in a very tender and supportive way for a long time. So, I've had patients who have then made the decision to just let nature take its course and they missed out on MAID because of that." (MAiD assessor/provider 5) "The transfer services aren't - I mean they're not made for MAID. We don't book - we don't have a system where you arrive at 10:00 and then you pick up the patient. They come when they're ready. So then that means that families are disconnected from each other in the last hours of the person's life because the family's left to go to the new spot but the patient is still waiting over here. We've had instances where the patient's lost capacity because they got too much pain medication on route…" (MAiD team member 6) *Mitigating factors for individual patients* "We have had some patients … where the physician has gone in unbeknownst to the staff, done a MAID assessment and then the patient's been transferred home to have the procedure." (MAiD assessor/provider 1) "She got MAID is what happened, because I like barrelled right through that. Because … the woman asked for MAID. I am her physician. It is my job to make sure she gets it." (MAiD assessor/provider 14) "I did do an assessment there. I didn't ask permission. I just went in as a visitor." (MAiD assessor/provider 23) "We were running a secret MAiD operation … Behind their backs." (Family caregiver 12) "And the home came up with basically, the same form with their letterhead on top, and said my mum has to fill all of this out. And I put my foot down and said 'No, absolutely not. This government form is effectively the same thing as your form. You're welcome to have a photocopy of the government form, otherwise leave us alone.'" (Family caregiver 24a)

Table 4 (continued)

Theme	Illustrative quotes (additional examples to what is provided in the text)
5. Impacts on health professionals	*Emotional impacts* “I had one patient, they [the staff] went to the media and they went to the police to try to have me arrested.” (MAiD assessor/provider 3) “…the people on the frontline, the doctors and nurses on the frontline are loving and wonderful people who suffer great moral distress when they have to do this [participate in forced transfers].” (MAiD assessor/provider 17) “I said, you know, that I would continue to do assessments without any problem, and they threatened me with a College report. And I said ‘Oh, I’ve had lots of talks with the Registrar of the College … we’ve had good, long conversations about this and they do not support your position at all. They believe that doctors should be able to see patients and talk and they don’t support hospital privileging interfering with this.’ So then we made an agreement.” (MAiD assessor/provider 22) “We [publicly advocated] saying ‘… we are very concerned that there is a lack of knowledge and access for this.’ So I got a death threat.” (MAiD assessor/provider 26) “That was the longest death I’ve had [due to a complication from the forced transfer and lack of support from the objecting hospital] … when [the patient] finally died and the [family] had left the room, I just collapsed. I started bawling and … - I was trying to be quiet because this is not my grief, right. And I just started weeping and the paramedic came in and was like ‘It’s okay’. It was awful, just awful. I really felt I’d failed [the patient]. You know, I’d described the procedure and ‘it’ll be over in five minutes’. And then for this to happen, an ordeal like that, when if I could have requested [support] of the hospital this could have been avoided.” (MAiD assessor/provider 26) *Impact on professional relationships* “But there has been times where we’ve had to like not go there. Or we’ve had to really just like be battling it. And I knew going into it I was going into a hornet’s nest, and that happened. You know you’re meeting with hostility. No one’s going to help me. No one’s going to help me find what I need. No one’s going to give me the address to put on the death certificate. No one’s going to help me. So, I knew that and I could come prepared to be friendly, to be open, to be – you know, it’s all in the approach, right.” (MAiD assessor/provider 3) *Administrative burdens and lack of remuneration* “They were aware of the law. They were willing to proceed according to the letter of the law. But the palliative care nurse was told while they would not stop her from assisting it wouldn’t be done during her work hours, nor would it be part of her assigned work. She wouldn’t be paid for being there.” (Family caregiver 10)
6. Catalysts for change	*Description of changes over time* “…it was very different three years ago than it was now. So I did a lot of first provisions in hospice. They weren’t allowing them in hospice and they weren’t allowing the provision at all, and then they weren’t allowing admissions to do it. Over time it’s better and it’s evolved.” (MAiD assessor/provider 3) “In the beginning, yes that is definitely the way it was, that there were no assessments or let alone provisions happening in the hospitals.” (MAiD assessor/provider 5) *Positive experiences + normalisation over time* “…the underlying kind of drive comes from the public. It comes from people’s stories and it comes from publication of their stories and sharing of their narratives.” (MAiD team member 5) “Our laws changed because of patients. The patients challenge the system, change the law. The patients came to the community events that I spoke to. I couldn’t give rounds at the hospital that first month. I asked three or four different departments, can I come and give rounds on MAID. Nobody took me off on it, but I got three invitations in the community. Patients wanted to know. Patients took my information, went to their doctor’s office and said, hey, this exists, you don’t know about it, you find out about it, buddy, because I want – patients drive this change, and I think – and I watched it happen. Patients drove the change in the palliative care communities that were amenable to it. I know, several palliative care doctors that said, I respect what you do, I respect my patient’s choice, this is not something I’m going to ever do. A year later that doctor did an assessment for me. So it’s patient driven.” (MAiD assessor/provider 8) “I think they’ve come to some understanding that this is something that people who are Catholic wish to have, and it’s part of their healthcare, and they do recognise that it’s a legal right.” (MAiD team member 11) *Advocacy in response to negative impacts on patients* “… we vocally fought … and got the local press onside. We had a campaign. … [the institutions] wouldn’t have just dropped them [the restrictions] if we hadn’t fought that.” (MAiD assessor/provider 6) *Education and relationship building*

Table 4 (continued)

Theme	Illustrative quotes (additional examples to what is provided in the text)
	"But I think the upfront work that the health authority did - so I have to say the [health authority] did a really good job of doing a lot of background institutional work and meeting with the nurses, the nurse practitioners, the long-term care workers. I mean very early on we had an educational session for all the physicians who worked in long-term care who were itinerant, you know who work in like three or four of the facilities, of saying 'Here's people who might be interested in this. Here's what it looks like,' and meeting with the nurses and social workers and care aides. Then with pretty well every institutional one that I did, even though we didn't have the religious objective, I mean I sat down probably in about seven different long-term care facilities with the staff and said 'Okay, well, Mrs Smith' or Mrs Jones or whoever it is 'has just died. Does anyone have any questions about how that process rolls out? How's everyone feeling about it?' You know, it's difficult when they're trying so hard to make that person's life bearable and then they all of a sudden die. It's like, no, you didn't fail. It's just that this person really had come to the end of their rope and they wanted to take some control back. So that was helpful. Because, unfortunately, a lot of the care workers worldwide are Filipino and Christian, right. I think in every single western, English-speaking country this is the reality. That's hard for someone whose Christian values and sense of caring and duty are very, very strong. And I think it's really worthwhile investing that time in the care workers." (MAiD assessor/provider 12) "… a lot of that [allowing assessments on site] can be attributed to [team lead name] and our team, really. Because they worked super hard just making sure that there was education around what we were trying to do, education around responsibilities for objection, around transfer of care and what they mean to a critically ill, dying patient. So, I think that [team lead name] needs to be credited with all of that … [they] moved this along single-handedly." (MAiD team member 1) *Institutional dynamics* "…the medical director, family doctor, palliative care doctor, and she told me they were the first hospice in the country to have a policy … She wrote the policy, so it was her initiative. She was not – that was not a requirement. I think it would be true of all the private facilities, long term care facilities, I doubt any of them have policies on medical assistance in dying." (MAiD assessor/provider 11) *Regulatory mechanisms and leadership* "I would say it's gotten a lot better. So it does sometimes come down to the directors and the medical leads, but I think that they have had a clear message from the health authority and from the province. It's different if you are a member of the [British Columbia] Master Denominational Health Agreement, but if you are not and you are a publicly-funded facility then you do not have a legitimate argument to not support a resident who lives in your facility if they – you know, you are then blocking access to care." (MAiD team member 5) "We said right at the outset that access to MAID was a *Charter* right for Canadian citizens and we were a public body. And, therefore, we would have no part of any of our facilities where MAID would not be permitted. It would happen where the patients are. We would have no death destinations and we'd have no opt out sites. So that got me a bit of heat early on… It turned out that was very much the best decision that we made right at the beginning because it set the atmosphere for the whole thing. We spent a lot of time educating." (MAiD team member 8) "…there are some champions within the health authority… [who] really pushed it ahead. We thought it was going to go to a court battle and it didn't, the health authority worked it out." (MAiD assessor/provider 10) "…the health authority worked really hard to understand what they [the Catholic institution] wanted." (MAiD team member 11)

However, even in institutions with less restrictive positions, MAiD access could still be a problem. Some objecting institutions that allow MAiD assessments still refused to provide information about MAiD or tell patients it was an option. Participants reported this was related to the institutional position on MAiD, and in some cases also reflected individual conscientious objection of health professionals within the institution. For example:

> *"I don't think patients of [Catholic hospital] know that's an option for them, because nobody's telling them…there is an active access issue because providers in that institution are not telling people that it's an option." (MAiD assessor/provider 11)*

> *"I'm a little surprised that the palliative care team that came to visit us didn't tell us about MAiD. … That team very much didn't bring up MAiD or that that was an option, and very much sort of proceeded in this, you're-going-to-die-naturally-at-home way, was the sense that we got. So that was, in retrospect, a little surprising to me because that was definitely not what he wanted or intended." (Family caregiver 16)*

Another barrier to access that participants attributed to institutional objection was the creation of additional logistics that slowed down or blocked a patient's ability to access MAiD. A family caregiver described a long-term care facility that sought to have the patient use the institution's form instead of the government one:

> *"… that was one of these other brick walls they tried to throw up, is 'No, we won't accept her form. You have to use our form and our lawyers have to sign it,' and we're like "No, they don't." So they just kept coming up with nonsense to try and dissuade her…" (Family caregiver 24b).*

Many objecting institutions, particularly palliative care facilities, shifted from not allowing any aspect of MAiD to permitting assessments within a few years of MAiD becoming legal (discussed further in Theme 6). This change was attributed to several factors including institutions observing the impacts of forced transfers on patients, negative media attention, and the institution appreciating that an assessment is a conversation and believing "*that it's only actually killing someone that's not okay*" (MAiD assessor/provider 6).

Some participants highlighted that changes in institutional positions with respect to the scope of objections did not occur in a linear fashion, making them harder to navigate. For example:

> *"… our hospital/hospice/nursing care home vacillated on what they allowed. First, they allowed nothing. Then they allowed a request form. Then they allowed assessments but only if we did it undercover. Then they wouldn't allow forms. Then they would allow them again." (MAiD assessor/provider 24)*

There was considerable institutional discretion in how MAiD requests were handled, and some participants emphasised that decisions about scope were often made on an ad hoc basis, resulting in the scope of objections between and within some institutions seeming inconsistent and arbitrary (Table 4).

Theme 3. lack of transparency regarding institutional position

Participants described varying degrees of transparency about institutional positions. On one end of the spectrum were institutions with explicit policies against MAiD, which were clearly communicated to patients, health professionals, and care coordination teams, and were publicly available. For example:

> *"They said, 'We will not provide MAiD.' It's on their application to the hospice, the patients have to sign that they will not even discuss MAiD when they are admitted to a hospice." (MAiD assessor/provider 26)*

In contrast, a family caregiver indicated that many institutions' positions are not publicly promoted: "*I don't think anyone on their website says we do or do not provide assisted dying…*" (Family caregiver 6).

A few participants emphasised that there was a lack of transparency about the extent to which institutions would facilitate, or require, MAiD transfers. A physician noted:

> *"…if you ask some of the Catholic hospitals they will say, no, that they're very compassionate and arrange these things [transfers for the purpose of MAiD]. My personal experience is that that's not the case at all and that's just nice talk. I mean I've recently had a couple of patients that have been in Catholic hospitals and there was no way we could get them moved to another hospital that allowed MAiD." (MAiD assessor/provider 4)*

Similarly, a family caregiver described how it was only just prior to the planned MAiD provision, despite that patient having been approved for MAiD months earlier, when, "*…we found out that [the long-term care facility] would not allow her to have the procedure, her provision in her home*" (Family caregiver 28).

Theme 4. impacts on patients

Institutional objections had several negative impacts on patients, across three broad domains: pain and other types of suffering relating to forced transfers; constrained choice regarding the patient's end-of-life experience; and access being obstructed altogether.

Pain and other suffering related to forced transfers

The first major impact of institutional objection was pain and other suffering related to forced transfers out of objecting institutions. To sign forms and for MAiD assessments, patients were transferred to a variety of locations including other health care institutions, cafes, and public parks. For MAiD provision, patients were transferred home, to other institutions including hospitals and clinics, or to other locations such as funeral homes.

Forced transfers, when they occurred, had several consequences for patients. A physician described considerable pain experienced by a patient who was transferred out of a hospice for MAiD:

> *"He had dozens of bone metastases from prostate cancer. I can't imagine the agony of a bumpy ambulance ride for his death. It was just – [long pause] you know, we make oaths to do no harm, and I certainly felt that was a harm to this man." (MAiD assessor/provider 26)*

Participants also described the emotional consequences forced transfers had on patients, including feeling stigmatised. A physician described a patient's experience of stigma as being worse than the pain of the transfer:

> *"... the ambulance ride was going to be painful for him. But he said ... 'Honestly, the hardest thing about this whole thing is this, having to come to a different hospital like I'm doing something wrong.' So, it was like even in the absence of pain, in the absence of everything, just feeling like I'm doing something wrong." (MAiD assessor/provider 10)*

Another emotional impact was imposing additional logistical roadblocks (which participants perceived were due to the institution's objection to MAiD) which negatively impacted the patient's MAiD experience:

> *Family caregiver 1: "There's enough pain as it is. To then throw up these roadblocks on top of it is just cold..."*
> *Family caregiver 2: "...that's harm that can't ever be undone." (Family caregivers 24a and 24b)*

Constrained choice and other impacts on the person's end-of-life experience

A second major impact of institutional objection on patients was constrained choice and other negative impacts on the patient's end-of-life experience. For example, some patients were forced to choose between MAiD and being admitted to hospice. A nurse practitioner noted:

> *"...in this [regional] community...it's a huge barrier. We can't go into hospice. In fact, hospice tells patients when they're interviewing them that if they are considering MAiD they will not be allowed to come into hospice. ... some families cannot cope with palliative care at home." (MAiD assessor/provider 23)*

Another example of constrained choice was that some patients were compelled to access MAiD in less-than-ideal locations. Participants described developing suboptimal solutions when a person did not have a residence to be transferred to, including transfers to an abortion clinic, HIV hospital, a boardroom, and a basement. A physician described struggling to find a place in a rural area for a patient who did not want to have MAiD at home for the sake of his young children:

> *"I am worried about the one gentleman ... I'm not sure where he'll go. I heard that provincial parks will allow MAiD. So I was going to contact ... [name of provincial park] and see if we could go there, but it seems bizarre. I'd be willing to bring him to my backyard, you know. It's strange not having any place to offer these people when they could legally probably die in the Tim Hortons [coffee and donut shop] parking lot, you know, or the middle of the street, but not in a hospital or a hospice. It makes no sense to me. I find it immoral." (MAiD assessor/provider 26)*

Obstructed access

A third impact on patients was that access to MAiD was at times precluded, for a variety of reasons. For some, it was simply too hard to pursue MAiD in the context of the institution's objection. A physician commented: *"the persistence required to even get an assessment or have a conversation ... about MAiD in a Catholic institution ... is enormous"* (MAiD assessor/provider 15).

In other cases, patients were too sick to be transferred, some experienced a medical complication and died during the transfer, and some lost capacity due to medication needed to make the patient comfortable during the transfer. For other patients, MAiD access was compromised because they did not want to leave the facility where they had been living and where they knew the staff. A physician commented:

> *"I have had a number of patients that I assessed and were approved for MAiD in the hospital, but they said I've been living in this palliative care ward now for weeks and in some cases months, these are my family, I don't want to leave them. I don't want to go where there are strangers, where people don't know me …" (MAiD assessor/provider 5).*

Mitigating factors

Participants described several factors which mitigated these negative impacts on patients, including patient assertiveness. For example, *"she was bound and determined this was what she wanted"* (Family caregiver 24b). Also significant were family caregivers who advocated for the patient and were willing and able to facilitate the patient's choice. For example:

> *"… they [the long-term care facility] actually told us she wasn't allowed to access assisted dying there. And we said 'That's absolutely wrong. This is her home. She is legally – you are legally obliged to allow her to access it there.' So again we had to fight that fight." (Family caregiver 24a)*
>
> *"…when that time came when we were scrambling to get a bed, because there's not very many spaces available, we were told by a friend who had connections with hospice who said 'If your intention is to have MAiD, don't mention that in your hospice intake.' … in general we were told, 'Just keep that quiet just in case you come across somebody who's not supportive. You can't say that your intention is to enter hospice to have MAiD.' So we didn't say anything. Once we got there, then the conversations were okay…" (Family caregiver 6).*

MAiD assessors/providers and MAiD team members also played an important role in mitigating harm, using their knowledge of where to steer patients who are considering MAiD. For example:

> *"I always make sure to say, 'But if you even think you might at some point in the future want an assisted death, do not go here and do not go there. Go here.'" (MAiD assessor/provider 15).*

MAiD assessors/providers also described advocating considerably for patients, contacting hospital administrators and the media in egregious cases. Family caregivers spoke about the incredible personal dedication of clinicians, describing one physician as someone *"…who would move mountains to serve somebody however and wherever they need to be"* (Family caregiver 28). Some participants discussed assessors and witnesses who entered facilities posing as a visitor or family member for the purpose of signing forms or doing an assessment (though others expressed discomfort with this practice). For example:

> *"…we used all sorts of other tactics to get around it but, at the end of the day, they insist that patients obviously leave the facility to have MAiD." (MAiD assessor/provider 27)*

Another mitigating factor was pre-existing care pathways set up to navigate the objection. One example was a partnership between a long-term care facility that refused to provide MAiD and a MAiD coordination team at a hospital cluster to facilitate the MAiD process: *"…you had someone who you could discuss [MAiD] with, without having to involve the long-term care home"* (Family caregiver 12). Another example mentioned by several participants was a faith-based hospital with a dedicated separate area attached to it where MAiD provision was permitted.

Theme 5. impacts on health practitioners

Participants highlighted three main impacts on health professionals caused by institutional objections: emotional impacts; impacts on professional relationships; and administrative and workload impacts.

Emotional impacts

First, participants described significant emotional impacts on health practitioners from dealing with institutional objections, including frustration, anger and disgust, moral distress, and feeling stigmatised. A physician described feeling as if they had "failed" the patient who had a prolonged death after a forced transfer. Another physician discussed feeling outraged that their patient had experienced a series of forced transfers for assessments and provision:

> *"I was outraged by this one and I blew up. … Because we're supposed to be all about patients and how is this possible?" (MAiD assessor/provider 17)*

Another emotional impact on health professionals was stress from being subject to threats including complaints to various authorities, such as their professional regulatory body (College) and the police, and in one case, a death threat (Table 4). Participants indicated that although stressful, none of the complaints to the various authorities eventuated in sanctions.

Professional impacts

Second, participants discussed impacts on professional relationships caused by institutional objections, including employer-employee relationships. A key subtheme was situations involving a perceived conflict between the institution's position and the views of staff. A number of participants described institutions with staff that were supportive of MAiD who did not agree with the institution's position. For example:

> *"...most of the clinicians that I know who work in Catholic institutions would gladly provide MAiD, it's just that they're not empowered to." (MAiD assessor/provider 15)*

As mentioned in Theme 1, the institutional position was often attributed to opposition by a key stakeholder such as a medical director or board of directors. Another professional impact was tensions with other health professionals, such as experiencing hostility and a lack of assistance in a facility from employees who appeared to share the institutional position.

Administrative and workload burdens

Third, health practitioners took on additional administrative and other workload burdens to navigate institutional objections. Some staff were allowed to participate in MAiD, but only in their own time and without institutional support. For example, a palliative care nurse whose employer did not support MAiD was informed they could participate but only outside work hours, and therefore unremunerated. Several participants describing having to scramble to find locations for their patients to receive MAiD assessments and/or provision. A nurse practitioner commented:

> *"The fact that she actually ended up having MAiD how she wanted in the community was a shit ton of work on my part and the connections that I had. I'm not saying that to toot my own horn. It literally was she just happened to be seen by the right person, and that's sad." (MAiD assessor/provider 1)*

A MAiD assessor/provider in a rural area recounted that this additional workload was considerable because none of the local hospitals, hospices, or long-term care facilities would allow MAiD. The physician commented:

> *"... this is taking a lot of my time and mental head space I'd rather be spending on my kids than writing letters to CEOs of hospitals." (MAiD assessor/provider 26)*

Theme 6. catalysts for institutional change

A final theme was catalysts for institutional change. As noted in Theme 2, participants highlighted that in some (but not all) settings, institutional objections relaxed somewhat in the six years since Bill C-14 was passed, reducing negative impacts on patients.

> *"Those Catholic hospitals that at the beginning would never let you in the door, now they let you in the door to assess people." (MAiD assessor/provider 21)*

> *"I would say that 90% of [faith-based institutions in the province] are very, very supportive and they have now moved to allowing assessments but not provision. So there's less and less feedback from patients and family about adversity within that setting." (MAiD team member 5)*

The position in non-faith based palliative care settings was reported to have changed more than in faith-based palliative care settings. A physician noted:

> *"... some of those facilities have now moved a little bit more towards the middle or even allow assessments and provisions to happen. Each of those facilities have found their level. ... the whole spectrum exists in a hospice or palliative care facility. So there's been a lot of movement in that community. Not so much in the religious based ones, though." (MAiD assessor/provider 8)*

Greater acceptance of MAiD over time

Participants attributed changes in institutional positions to a variety of catalysts. One prominent catalyst was greater acceptance of MAiD over time, due to positive patient experiences, growing comfort in the medical community, and destigmatization of MAiD. A physician commented:

> *"I think they [decision-makers in an objecting faith-based hospice] ... were accustomed to seeing people suffer quite badly ... they saw how humane MAiD was and how grateful the patients and the families were." (MAiD assessor/provider 4)*

Likewise, a physician in Ontario described how institutional change was prompted by individual patients seeking MAiD as an end-of-life choice:

> *"Those Catholic hospitals ... now they let you in the door to assess people. So it's changing because they recognise that this has become ... a standard of prac-*

> *tice and they need to get on board and give people options." (MAiD assessor/provider 21)*

Another related factor was growing comfort with MAiD in the medical community. This was driven in part by clinicians witnessing MAiD assessments and observing peers they respected engage in MAiD work. For example:

> *"Once they [other clinicians] experience it and they see how gentle and … the gift that you give a family with the provision and that opportunity, I don't know, it's hard to stay too closed about it for too long, at least in my experience." (MAiD assessor/provider 3)*

> *"Some of the palliative care doctors that were very opposed at the beginning are now the staunchest allies." (MAiD assessor/provider 4)*

Another participant noted that, as in other areas of social change, broader societal acceptance of MAiD has grown with time and experience, reducing stigma:

> *"As time has gone by and as society has come to understand – much in the way that when medical marijuana was legalized, society did not end. … They saw the same thing for abortion. … They saw the same thing for MAiD and people are understanding now that society didn't end … time is a big thing. … Acceptance of the procedure and getting a sense that it is actually tremendously well-regulated … that there's a process, that there's due diligence, that there's two assessments, that the person has to meet criteria, that this is overseen is an important thing as well. And then word of mouth, right … you don't have to go too far before you meet someone who [has a relative that had MAiD] … it's less taboo." (MAiD team member 13)*

Advocacy to promote patient access and address the harms of institutional objection

A second catalyst for change was advocacy to address the negative effects of institutional objection on patients. In addition to mitigating harm on an individual patient (discussed in Theme 4), advocacy for individual patients also contributed to broader institutional change. Advocacy was undertaken by patients, family caregivers, MAiD assessors/providers, and organizations such as Dying with Dignity Canada and CAMAP. A physician commented on the important role of on-the-ground advocacy by patients and clinicians:

> *"… between the patients driving it on one end and the clinicians who are in the community itself driving it – that's what causes change in this country, those two forces." (MAiD assessor/provider 8)*

Advocacy was particularly effective when amplified by media reports. For example, a physician recounted how media attention on a particular case impacted an institution's discretion:

> *"… I talked to the family, and they said "Oh, yes, we're going to the press" … we went to the press that this poor man had to be transported … this was outrageous and awful. And guess what, ever since then every single patient at that facility has been assessed as requiring an in-hospital assessment [as opposed to being transferred off site]." (MAiD assessor/provider 22)*

Education and relationship building

A third catalyst was education and relationship building with objecting institutions. Participants highlighted proactive work by MAiD teams in some health authorities, who met with institutional decision-makers and staff. For example:

> *"… I think the upfront work that the health authority did … [they] did a really good job of doing a lot of background institutional work and meeting with the nurses, the nurse practitioners, the long-term care workers." (MAiD assessor/provider 12)*

Individual MAiD assessors/providers also described participating in education and relationship building, through speaking with staff in objecting institutions about what the MAiD process entailed and the impacts of transfers.

Institutional dynamics

Institutional dynamics were another catalyst for institutional change. Participants described how greater acceptance over time by clinicians within an institution contributed to changes in institutional policy. For example, a physician described how attitudes changed towards MAiD in a hospice that allowed external assessors to provide MAiD assessments:

> *"I could go in there, do an assessment, speak to a patient, leave. I would come in almost like a specialist. … I followed the rules happily, respected each other, did the work. It went from that, which it stayed at for a couple of years. Then of course the inevitable, which happens all the time. The palliative care doctors … they're the most patient centred doctors on the planet, they are very attached to some of their patients, they've known them for a while, they're*

> *quite connected, they work hard with them, and those patients start begging them for help and they start asking them for assisted deaths. Some of those clinicians started feeling like … this is my patient, I can help this patient. So they started to want to – there is that one case, like this one I'm going to support. So they'd asked me and I showed them how to do the assessment form then they would do it. Then they would only do it maybe once or twice a year, and then all of a sudden they're like, well I can do this, this patient of ours, I can do it. All of a sudden we've got now maybe half of them are willing to do assessments." (MAiD assessor/provider 8)*

Participants also cited leadership by dedicated individuals and support from staff or clinicians at various levels within an institution who supported MAiD access. Participants discussed champions in organisations, such as medical directors, who developed policy to support MAiD, and decisions by boards or CEOs to support MAiD (or establish processes to foster patient-centred care). For example:

> *"I met with the CEO of the hospital. … I had [CEO] behind me, he said 'Yeah, this is – let me be clear, this is happening at this hospital, and it happens the way it needs to happen and that's all there is to it.' Obviously, there were political pieces that had to be done very carefully…" (MAiD assessor/provider 9).*

Regulatory mechanisms and health system structures

Finally, some participants cited the role of regulation and health system structures in fostering institutional change. This included government policy and agreements, and policy set by MAiD teams in some areas. For example, a MAiD team member noted:

> *"… this health authority and [names of key leads] and the director at the time were very clear about access to care." (MAiD team member 5)*

Another MAiD team member noted the importance of the provincial regulatory framework in British Columbia, which required long term and residential aged care facilities to provide information about MAiD:

> *"The provincial government did say quite clearly that information is to be made easily accessible to all residents in these facilities. So they're not allowed to restrict information access." (MAiD team member 8)*

Similarly, participants from Nova Scotia described how an objecting hospital's position changed through the negotiation of a separate space attached to the hospital that persons could use for MAiD. This was achieved through advocacy by several key regulatory stakeholders.

Participants perceived that the absence of more formal regulatory mechanisms and top-down decision-making in fostering system change resulted in insufficient protection for patients from institutional objections. Despite descriptions of strong support by higher authorities in some locations, in others, participants felt that the regulatory environment still lacked sufficient protection for patients. For example:

> *"I wish the Ontario government would say 'No, you will all provide' … You get a dollar of our money, then you will provide all services…" (MAiD assessor/provider 26).*

Similarly, a participant from British Columbia noted that government agreements would need to be amended to make changes:

> *"… in some provinces like the one that I'm in, there is actually a contractual agreement from the '90s that allows faith-based facilities to dictate what happens on the premise. So we probably can't break that contract or it needs to be re-looked at." (MAiD assessor/provider 8)*

However, some participants acknowledged that this and other government-led change was highly political: *"I can understand why the politicians don't want to touch it…"* (MAiD team member 8).

Discussion

There are relatively few studies focused on stakeholders' experiences of institutional objection to MAiD in Canada, [8] and internationally [26]. In our broader study on MAiD decision-making, institutional objection was a frequently cited issue, with 27/32 MAiD assessors and providers, 9/11 MAiD team members, and 9/31 family caregivers having direct experiences of it. This study identified six themes related to institutional objection, drawing on reports of family caregivers, MAiD assessors and providers, and members of MAiD teams in British Columbia, Ontario, and Nova Scotia. Several themes resonate with the small body of existing literature, particularly the bases for institutional objection and impacts of forced transfers on patients. However, this research also provides novel insights, including factors leading to improved patient access to MAiD in response to institutional objections. Another unique finding is how some institutional objections have eased in the six years since MAiD was legalized federally in Canada, and the catalysts for that change. Despite these positive changes, participants reported institutional objection remains a significant problem in some settings, with a number of ongoing challenges. This study provides lessons for other jurisdictions, such as Australia, New Zealand, Spain, and various US states, where MAiD laws are more recent and are in the process of being implemented.

Patient harm demonstrates need for supports to access MAiD

Institutional objection spans a variety of practices and causes a range of harms to patients and their families. Consistent with other research, [8, 26] transferring a patient for MAiD assessments and provision was reported to cause pain and other emotional and psychosocial impacts. In addition to assessments and provisions, this study found a wider range of practices institutions refuse to engage with, including signing and witnessing request forms, IV insertion, and referrals for specialist consultations. Suffering due to institutional objection is therefore not only attributable to forced transfers, but also to less visible sources of stress including stigma, logistics, and administrative burdens. Institutional objections also constrained choice about how, when and where MAiD could be accessed, and disrupted existing therapeutic relationships, interfering with key parts of quality care [38].

This study identified several factors that mitigated negative impacts on patients and practitioners (discussed in Themes 4 and 5), which echo findings in previous research in Canada, [8] and Victoria, Australia [26]. Access to MAiD in an objecting institution often depends on individuals who are willing and able to drive the process and, in some cases, challenge the institutional position. This requires considerable effort and tenacity on the part of patients, family caregivers, and health professionals.

However, despite such efforts, a relative power asymmetry remains between individuals and institutions which can impede access to MAiD. For patients this is exacerbated given they are suffering from a grievous and irremediable condition. Further, not all patients have the ability, energy, supports, or resources to advocate for themselves. Additionally, patients may often have no choice about where they are treated. An objecting institution may be the closest or only health facility in the patient's area (a particular problem in rural settings) and may be the only facility to provide specialized care, such as palliative care [20, 22]. In some cases, patients may not be aware of the institution's position and how this may constrain their choices [39, 40]. Power asymmetries can also exist for health professionals, particularly if they are employed by an objecting institution or if they work in a region where the only hospital is a faith-based institution that will not grant them privileges, impeding their ability to advocate for patients. Our findings, therefore, suggest a need for regulatory structures and MAiD programs that support patient access in the face of institutional objections.

The need to increase transparency and clarity regarding MAiD access in objecting institutions

A factor that compounded impacts on patients and created challenges for health professionals was that institutional decision-making often lacked transparency and was subject to considerable discretion. At times, participants reported it was unclear what the institutional policy was, whether discretion would be exercised in favour of the patient to access MAiD, and how to navigate around barriers. This is consistent with literature demonstrating a lack of transparency in the positions of faith-based institutions, [39, 40] and uncertainty about who is safe to trust within those institutions [25]. "Pathway ambiguity" (i.e. a lack of clarity around care processes and challenges in care coordination) is problematic in MAiD in general, [25, 38, 41] and our findings suggest institutional objections contribute to this problem.

While robust care coordination can mitigate pathway ambiguity, the variable expressions of institutional objections may pose challenges to the effective coordination of the MAiD process. Other research has demonstrated that poorly coordinated care can be disruptive to the patient, the family, and the clinical team [38]. Our study highlights the benefit of a proactive approach to MAiD teams making contact with institutions and their staff and engaging in relationship building and education. However, our results also emphasize the success of this approach is highly dependent on local setting and the willingness of higher-level authorities to set clear policy promoting MAiD access. Some geographic areas do not have robust care coordination processes or willing institutions. A lack of transparency impedes patients' ability to make choices about their care. Ideally, institutions should be required to disclose their position transparently and proactively, and systems should promote consistent and clear decision-making.

Diversity within institutions suggests support needed for conscientious participants

This study identified two primary bases for institutional objections to MAiD: religious values and a philosophy of palliative care that sees palliative care as incompatible with MAiD. Both are well documented bases for institutional objection in the empirical [8, 24–26, 29, 45] and theoretical literature [3, 4, 7]. A further finding of this study was that participants perceived that institutions' objections to MAiD were often driven by top-down decisions, rather than a view universally shared by staff.

In other aspects of healthcare, such as reproductive medicine and contraception in faith-based hospitals, a lack of congruence between an institution's position and staff views contributes to professional conflicts and moral distress [42, 43]. While evidence on this issue in the MAiD context (both in Canada and internationally) is still emerging, the same challenges appear to exist. In a study of physicians and nurse practitioners, Brown et al. (2021) found some participants were frustrated by institutional objection, while others were comforted by the institution's stance [44]. Research on perspectives of palliative care unit and hospice staff suggests some palliative care practitioners view MAiD as a departure from "usual" practice, [45, 46] while others believe patients should have a right to access MAiD in hospice [45].

Our findings confirm that some health professionals involved in transfers from objecting institutions experience moral distress by being compelled to be involved as they see these transfers as not in patients' interests. Participants also reported a diversity of views from health professionals employed by objecting institutions, including those who conscientiously object to MAiD and those who would want to assess or provide (or otherwise support the MAiD process), but for the institutional position. Practical and professional supports are needed to support this diversity of views. Difficult professional dynamics due to conflicting views within an institution have emotional consequences for providers, and can affect provider willingness to participate in MAiD [27, 28]. While there is substantial literature on support for conscientious objectors to MAiD, our findings underscore the need for laws, policies, and practices to go beyond just protections for health professionals who conscientiously object and also extend to conscientious participants [27].

Implications for system change: the value of a multi-pronged approach underpinned by regulation

A new finding of this research is that some of the problems associated with institutional objections in Canada have improved over time, at least in some places. Participants reported increased acceptance of MAiD from previously objecting institutions, and a wide range of catalysts that contributed to changes in institutional positions. The catalysts we identified reflect both bottom-up forces, such as patient demand for MAiD and voluntary efforts by clinicians to effect system-wide change, and top-down ones, including regulatory architecture and strong policy positions from local authorities. These findings suggest a multi-pronged approach contributes to improved access and patient and provider wellbeing.

Bottom-up catalysts were critical in effecting change in the first six years since MAiD became legal. Just as family perspectives on MAiD may become more favourable with direct experience, [47] this study suggests that so can health professionals' and institutions'. The impact of observing positive patient experiences with MAiD, examples of integration between MAiD and palliative care, and patient demand for the option, led some institutions to soften their positions. Additionally, the influence of clinical leaders and peers who support MAiD led to greater acceptance and engagement in MAiD by individual clinicians, which in turn contributed to changes in institutional culture.

However, the persistence of institutional objections within faith-based institutions (relative to the changes observed in some secular palliative care settings) suggests that institutional objections rooted in religious values or ideology may be less amenable to change. This is another factor that suggests a stronger regulatory response may be needed, which reduces the need for bottom-up advocacy by patients, family members and health practitioners. Advocacy by very unwell patients and their families in response to a roadblock caused by institutional objection is a significant burden, and many patients may be simply unable to advocate due to factors including how unwell they are. The absence of top-down regulation may impose a significant burden on clinicians to undertake advocacy and negotiate patient access. Given that the model of assisted dying in Canada relies on clinician involvement to facilitate patient access, reducing burdens on clinicians is also important in ensuring provider sustainability and, in turn, patient access [27, 48].

While many changes happened "organically" over time, our findings suggest top-down policies and regulatory mechanisms are critical in supporting patient access in response to institutional objection. Locations where MAiD assessors and providers and MAiD team members indicated they had encountered few issues with institutional objections were ones where the health authority or medical director of an institution had proactively established a strong position supporting access. Further, while our study design cannot provide insights into prevalence of institutional objection, participants in Ontario generally reported more widespread challenges than in British Columbia and Nova Scotia. There is considerable variation in MAiD regulation and service delivery across Canada, both between and within provinces and territories. As noted in the introduction, while the MAiD law is set out in the federal *Criminal Code*, healthcare in Canada is implemented by provinces and territories with Nova Scotia, and to some extent, British Columbia implementing stronger regulatory support for patient access to MAiD. The Nova Scotia Health Authority has required all publicly-funded facilities to allow access to MAiD

[12]. Participants reported that British Columbia has facilitated access through provincial policy requiring the provision of information and, requiring non-faith-based institutions receiving greater than 50% of their funding from the government to allow access to MAiD (though the provincial MAiD policy and the Master Agreement between the province and the Denominational Health Care Facilities Association allow publicly-funded faith-based institutions to refuse to allow the provision of MAiD within their walls) [15]. Obviously, where there is legislation or policy requiring access, access is less impeded.

This may mean that a stronger top-down regulatory response to institutional objection is needed in areas where problems with MAiD access remain an issue. Although participants described significant improvements in patient access in many geographic areas, institutional objection remained a problem in many places, particularly rural and remote regions where no local institutions supported MAiD. However, even where more formal regulatory instruments and top-down policy exists, our findings indicate some objecting institutions introduce more subtle barriers to access, such as adding bureaucratic roadblocks not required by law or provincial policy. Bottom-up reporting of experiences by patients, families, and clinicians will remain important in highlighting and overcoming more surreptitious forms of institutional objection impeding access to ensure genuine non-obstruction and facilitate patient access.

Limitations

A strength of this study is it includes the perspectives of multiple family caregivers (reporting on the experience of patients they were supporting as well as their own experiences), MAiD assessors and providers, and MAiD team members. Drawing on these three cohorts across three provinces provides a robust basis to identify both individual and systems issues. A potential limitation is the perception of family caregivers may differ from those of patients, and can be influenced by grief, bereavement and their relationship with the patient [35, 49]. Although we attempted to recruit patients seeking MAiD, this is a difficult cohort to reach. While family members have been demonstrated to reliably report on the quality of end-of-life care and on observable symptoms, [50] more research involving direct patient voices is needed.

An additional potential limitation is that our family caregiver sample was predominantly female. Further research on how gender may play a role in patient advocacy may provide additional insight into the dynamics between institutions, patients, and families. Another limitation is that all family caregiver interviews which reported patients experiencing an institutional objection ultimately involved the patient accessing MAiD. While MAiD assessors and providers also commented on cases when patients did not access MAiD due to institutional objection, further research on family or patient perspectives when patients are prevented from accessing MAiD is needed.

Our sample may also be more supportive of MAiD and more opposed to institutional objection given recruitment involved study advertisements circulated by Dying with Dignity Canada (a key patient education and interest group) and CAMAP (the national professional organization for MAiD). However, subsequent purposive sampling for diversity and the inclusion of members of MAiD teams may have helped to ensure a range of views were included in the sample. Even so, more research is also needed from the perspective of objecting institutions, and from healthcare professionals who work in them (including those with a conscientious objection to MAiD). Our study suggests that the ethos for an institution is often determined by a top-down decision, but how this operates and may change over time warrants further investigation. Similarly, more insight into how institutions develop and apply their MAiD policies, and how this affects patients, family, and staff in the institution, is warranted.

Finally, since the regulatory environment regarding institutional objection and implementation of MAiD into the healthcare system varies by province and territory, additional research exploring the impacts of institutional objection in other Canadian provinces and territories may reveal different or additional experiences and catalysts for change. More data on prevalence of institutional objections and patient transfers, and the impact of geography on patient access, would also be valuable.

Conclusion

The ethical justifiability of institutional objection is contested, and this study raises questions about how best to address harms caused by institutional objections. These findings shed light not only on Canadian MAiD regulation and practice but are also relevant to other jurisdictions which have legalized MAiD or are implementing it or considering doing so. Should objections be regulated by the state or left to individual institutions to negotiate? If the state chooses to regulate institutional objection, should this be achieved through law or policy or some other mechanism, and what model of regulation is appropriate (e.g. permitting institutional objection wholesale, not allowing it or some type of reasonable accommodation model that aims to balance patient and institutional interests) [3]? The wide range of harms identified, both to patients and practitioners, suggest that at least some limits to institutional discretion are warranted and that top-down regulatory involvement may be the best way to facilitate patient access to this lawful end-of-life choice.

Abbreviations

MAiD	Medical assistance in dying

Supplementary Information

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Supplementary Material 1

Supplementary Material 2

Supplementary Material 3

Supplementary Material 4

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Authors' contributions
Data was collected by EC, RJ and JD. EC wrote most of the first draft of the manuscript, with other sections completed by RJ. EC and RJ analyzed the data, with iterative input from JD, LW, and BPW to finalize the themes. EC, RJ, JD, LW and BPW all made substantive revisions to iterative drafts of the manuscript. EC finalized the text, which was approved by all authors. All authors read and approved the final manuscript.

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Data availability
The interview guides are available in Additional Files 1, 2, 3, and 4. Due to confidentiality undertakings given to research participants as a requirement of the study's ethical approval, the data generated and analyzed in this study are not publicly available. Requests to discuss this should be directed to the corresponding author.

Declarations

Ethics approval and consent to participate
Ethics approval was provided by the Dalhousie University Research Ethics Board (REB #2021–5688 and #2020–5313) and Queensland University of Technology Human Research Ethics Committee (UHREC #2000000270). This research was conducted in accordance with the requirements of this ethics approval. All participants gave free and informed consent to take part in this research.

Consent for publication
Not applicable.

Competing interests
BPW and LW were engaged by the Victorian, Western Australian and Queensland governments to provide the legislatively mandated training for doctors involved in voluntary assisted dying in those states. EC and RJ were employed on these projects. BPW is a member of the Queensland Civil and Administrative Tribunal, the quasi-judicial review body which has jurisdiction over some voluntary assisted dying matters. LW is a member of the relevant oversight body in Queensland, the Voluntary Assisted Dying Review Board. JD was part of several initiatives that contributed to MAiD law reform in Canada: the Royal Society of Canada Expert Panel: End-of-Life Decision Making; the plaintiff's pro bono legal team in Carter v Canada (Attorney General) [2015] 1 SCR 331; the Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying; and the Council of Canadian Academies Expert Panel on Medical Assistance in Dying. JD is also a member of a Working Group developing a module for the federal MAiD National Curriculum (funded by Health Canada, developed by the Canadian Association of MAiD Assessors and Providers) and a member of the MAID Practice Standard Task Group (mandated by Health Canada to develop a model practice standard for the regulation of MAiD by provincial/territorial health professional regulatory bodies) (neither initiative addresses institutional objection). JD is also on the Advisory Board for the Completed Life Initiative, a national MAiD advocacy and education initiative in the United States. All views expressed in this article are those of the authors and not the organizations they are affiliated with.

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POLICY REPORT

Facilitating regional and remote access to voluntary assisted dying in Western Australia: targeted initiatives during the law-making and implementation stages of reform

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ETHICS APPROVAL

This policy report only analyses publicly available information and does not require ethical approval

ABSTRACT:

Australians living in regional and remote communities face several barriers when accessing high quality health care. Voluntary assisted dying (VAD), a new and sensitive end-of-life option, presents a new challenge for residents living in these communities. Western Australia (WA) is the second Australian state to implement VAD laws and, to date, is the jurisdiction with the greatest need to address access inequities in regional and remote communities due to its vast area. This article identifies and explores initiatives introduced by the WA Government to address regional and remote access inequities in each of the two stages of the reform process: the stage of the reform process leading up to passing the law ('law-making stage'), and the stage of the reform process after the law was passed and prior to it commencing operation ('implementation stage').

The analysis reveals that several initiatives were implemented during each of the law-making and implementation stages of reform. Initiatives introduced in the law-making stage through inclusion in the legislation itself included dedicated guiding

principles promoting equality of access for regional and remote residents, broadened qualification requirements for medical practitioners who can participate in VAD, allowing nurse practitioner administration, and mandating that statistics relating to regional and remote access are recorded and reported. Other initiatives dedicated to facilitating regional and remote access were not specifically provided for by legislation but were introduced during the implementation stage of the reform process. These include the establishment of a Statewide Care Navigator Service that administers a Regional Access Support Scheme and ensuring that the Statewide Pharmacy Service is accessible to regional and remote residents. Other initiatives intended to facilitate regional and remote access were provided for in legislation but given further content during the implementation stage. These include an access standard (contents determined by the CEO during implementation) and telehealth (supporting guidance around lawful use issued by the WA Government during implementation).
This policy report reveals that WA took a considered and targeted focus to address regional and remote access in both the law-making and implementation stages of reform. Given VAD in WA is still in the early stages of its operation, it is too soon to determine how effective these initiatives have been in promoting regional and remote access to VAD in WA. Careful evaluation of these initiatives will be crucial to monitor their effectiveness and to assess whether additional measures are needed. Reflecting on the WA experience will also be valuable for other states as they legalise VAD and develop (and adapt) their own access initiatives.

Keywords:

access, end of life, implementation, initiatives, law, reform, regional, voluntary assisted dying, Western Australia.

FULL ARTICLE:

Context

Australia is a vast country, with approximately 28% of its population living in regional and remote areas[1]. Access to high quality health care is a well-documented challenge for this population when compared to metropolitan counterparts[2]. This population typically has higher levels of disease and injury, lives shorter lives, and experiences more challenges in accessing health services, including end-of-life and palliative care[3]. While regional and remote access to health services is an issue in all Australian jurisdictions, these issues are particularly acute in Western Australia (WA) due to its vast area and population distribution, which comprises many communities with limited access to medical practitioners[4].This policy report will focus on regional and remote access in WA, in the context of voluntary assisted dying (VAD).

VAD is a relatively new end-of-life choice that is available to terminally ill competent adults who can satisfy narrow eligibility criteria. The existence of regimes for lawful assisted dying have expanded significantly around the world in the past 20 years[5].In Australia, at the time of writing, VAD had been legalised in six states (Victoria, WA, Tasmania, South Australia, Queensland and New South Wales) and has commenced operation in Victoria and WA. While there is some variation across states, the legislative models are broadly similar. The practice is highly regulated, and access is only possible with the approval of at least two medical practitioners who have undertaken the legislatively mandated training and possess the necessary level of qualifications and experience (and, in Victoria and South Australia, one of the medical practitioners must have expertise in the patient's disease, illness or condition). The VAD substance is dispensed by a pharmacy, and self-administration (by the person) and practitioner administration (by eligible health practitioners) are permitted.

Victoria's VAD laws, the first VAD laws in Australia, commenced operation in June 2019. One of the practical challenges in Victoria is finding an eligible medical practitioner willing to assist in the VAD process[6,7]. This challenge is particularly acute for those in regional and remote communities[6,8,9]. In Victoria, approximately 35% of practitioners are from regional and remote areas, and only a small proportion of them are specialists[10]. The lack of qualified medical practitioners has often meant terminally ill patients have been forced to travel to metropolitan Melbourne to be assessed. For patients who are too gravely ill to travel, this can mean they are unable to access VAD[6].

Under all VAD legislative models, health practitioners can conscientiously object to being involved. The implications of conscientious objection may be disproportionately great for individuals seeking VAD in regional and remote communities due to the already smaller cohort of eligible medical practitioners[9,11,12]. These communities tend to be disproportionately serviced by internationally trained practitioners[13], who have been found to more likely claim a conscientious objection to 'contentious' medical practices such as abortion[14]. Similarly, reputational and community stigma have been found to deter health practitioners from participating in VAD, which is particularly acute in the regional and remote context given practitioners typically live in the same community in which they practise[6,9,15].

A further barrier for regional and remote access to VAD is the restriction on the ability of health professionals and patients to communicate through telehealth. This restriction potentially applies in the VAD context because of Commonwealth criminal law, which makes it an offence in some circumstances to discuss 'suicide' via a 'carriage service' (such as telehealth). While this law was enacted before state VAD laws were passed, and it targeted different activities, it has potentially criminalises certain aspects of the VAD process that are permitted under state VAD laws and causes significant access issues for regional and remote residents [7,10,16-20].

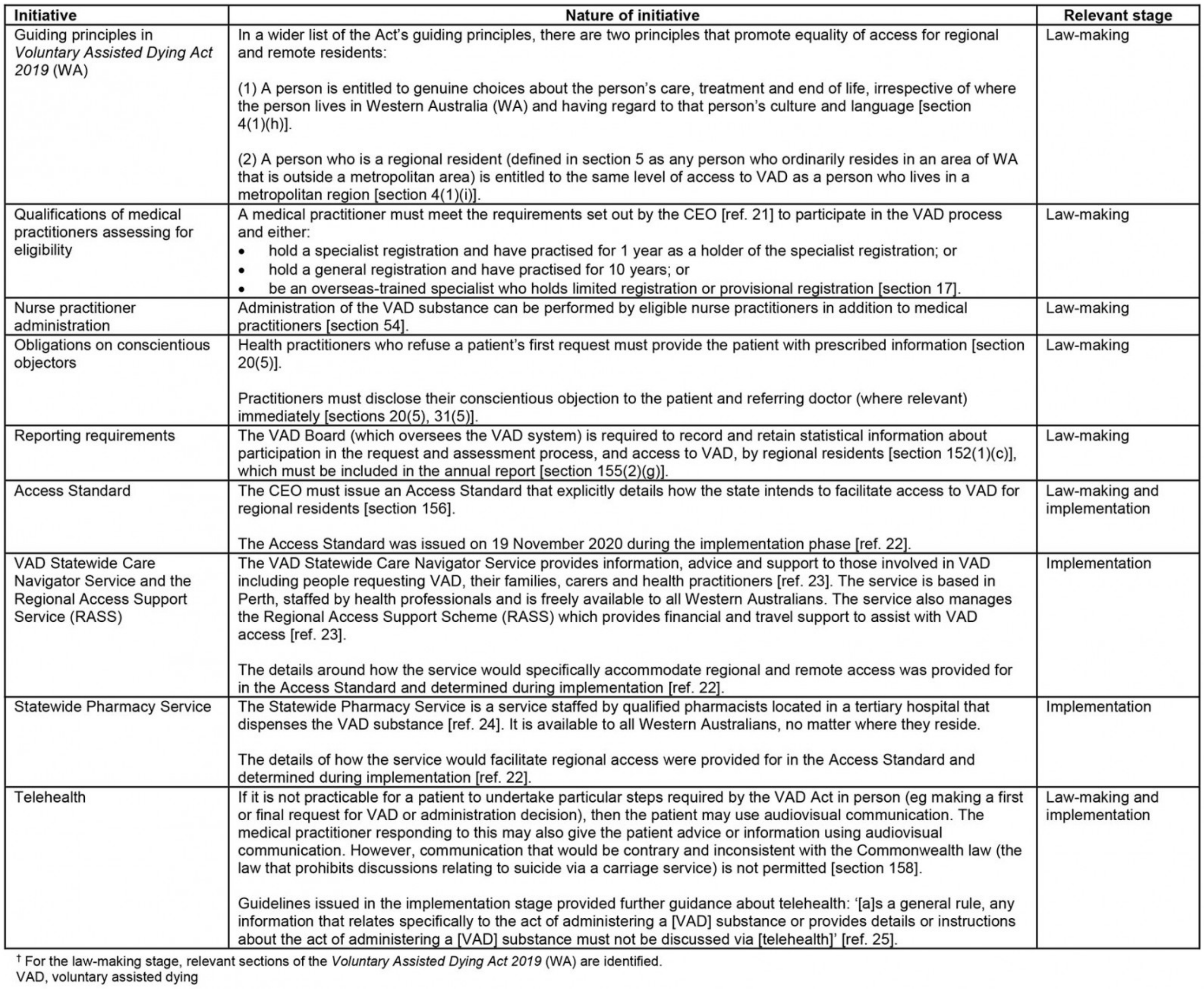
Equity of access to VAD for individuals living in regional and remote communities will be a challenge for any Australian jurisdiction legalising VAD, and states have taken a variety of approaches to mitigate this inequity. However, recognising such challenges would be pronounced in the WA context – due to the state's geography and population distribution – the WA Government implemented a range of initiatives intended to facilitate access for all potentially eligible individuals to VAD, regardless of where they reside. This policy report explores initiatives used to facilitate regional and remote access in WA, reflecting on the lessons learned and the implications of such initiatives for future implementation of VAD in other Australian jurisdictions and internationally.

Regional and remote access initiatives

The focus of this policy report is on regional and remote access initiatives that have been identified through four sources: VAD legislation or policy, parliamentary debates, the Ministerial Expert Panel (MEP) report (which advised the WA Government on designing the VAD system)[4], and academic literature. These initiatives, identified in Table 1, and described more fully in the commentary that follows, occurred at two different stages of the reform process. The first is the law-making stage (up to 19 December 2019, when the law was passed by Parliament) and the second is the implementation stage (from 19 December 2019 to when the law started in force on 1 July 2021).

Because the WA law began operation in July 2021, the design and implementation phases could draw on early insights from Victoria. However, as was repeatedly noted in the MEP's report, the vast differences between Victoria and WA, particularly in relation to WA's geography, population distribution and cultural diversity, demanded further measures to support the needs of regional and remote communities[4].

Table 1: Overview of initiatives[21-25†]



Initiative	Nature of initiative	Relevant stage
Guiding principles in *Voluntary Assisted Dying Act 2019* (WA)	In a wider list of the Act's guiding principles, there are two principles that promote equality of access for regional and remote residents: (1) A person is entitled to genuine choices about the person's care, treatment and end of life, irrespective of where the person lives in Western Australia (WA) and having regard to that person's culture and language [section 4(1)(h)]. (2) A person who is a regional resident (defined in section 5 as any person who ordinarily resides in an area of WA that is outside a metropolitan area) is entitled to the same level of access to VAD as a person who lives in a metropolitan region [section 4(1)(i)].	Law-making
Qualifications of medical practitioners assessing for eligibility	A medical practitioner must meet the requirements set out by the CEO [ref. 21] to participate in the VAD process and either: • hold a specialist registration and have practised for 1 year as a holder of the specialist registration; or • hold a general registration and have practised for 10 years; or • be an overseas-trained specialist who holds limited registration or provisional registration [section 17].	Law-making
Nurse practitioner administration	Administration of the VAD substance can be performed by eligible nurse practitioners in addition to medical practitioners [section 54].	Law-making
Obligations on conscientious objectors	Health practitioners who refuse a patient's first request must provide the patient with prescribed information [section 20(5)]. Practitioners must disclose their conscientious objection to the patient and referring doctor (where relevant) immediately [sections 20(5), 31(5)].	Law-making
Reporting requirements	The VAD Board (which oversees the VAD system) is required to record and retain statistical information about participation in the request and assessment process, and access to VAD, by regional residents [section 152(1)(c)], which must be included in the annual report [section 155(2)(g)].	Law-making
Access Standard	The CEO must issue an Access Standard that explicitly details how the state intends to facilitate access to VAD for regional residents [section 156]. The Access Standard was issued on 19 November 2020 during the implementation phase [ref. 22].	Law-making and implementation
VAD Statewide Care Navigator Service and the Regional Access Support Service (RASS)	The VAD Statewide Care Navigator Service provides information, advice and support to those involved in VAD including people requesting VAD, their families, carers and health practitioners [ref. 23]. The service is based in Perth, staffed by health professionals and is freely available to all Western Australians. The service also manages the Regional Access Support Scheme (RASS) which provides financial and travel support to assist with VAD access [ref. 23]. The details around how the service would specifically accommodate regional and remote access was provided for in the Access Standard and determined during implementation [ref. 22].	Implementation
Statewide Pharmacy Service	The Statewide Pharmacy Service is a service staffed by qualified pharmacists located in a tertiary hospital that dispenses the VAD substance [ref. 24]. It is available to all Western Australians, no matter where they reside. The details of how the service would facilitate regional access were provided for in the Access Standard and determined during implementation [ref. 22].	Implementation
Telehealth	If it is not practicable for a patient to undertake particular steps required by the VAD Act in person (eg making a first or final request for VAD or administration decision), then the patient may use audiovisual communication. The medical practitioner responding to this may also give the patient advice or information using audiovisual communication. However, communication that would be contrary and inconsistent with the Commonwealth law (the law that prohibits discussions relating to suicide via a carriage service) is not permitted [section 158]. Guidelines issued in the implementation stage provided further guidance about telehealth: '[a]s a general rule, any information that relates specifically to the act of administering a [VAD] substance or provides details or instructions about the act of administering a [VAD] substance must not be discussed via [telehealth]' [ref. 25].	Law-making and implementation

† For the law-making stage, relevant sections of the *Voluntary Assisted Dying Act 2019* (WA) are identified.
VAD, voluntary assisted dying

Guiding principles

During the law-making process, dedicated principles to promote equity of access for regional and remote residents were introduced (Table 1). Principle (1) was recommended by the MEP in response to consultation feedback that there should be dedicated guiding principles related to equality of access[4]. Principle (2) was introduced during the parliamentary debates to acknowledge the government's commitment to providing regional and remote residents equal access to VAD[26].These principles, while not creating specific legal obligations, guide the interpretation of the Act and were relied on to introduce access initiatives for regional and remote residents.

Qualifications of medical practitioners

Due to access concerns about availability of medical practitioners, the MEP recommended that criteria for practitioners to participate in the VAD process be less restrictive than in Victoria[4].The MEP suggested that relevant experience and skills of practitioners were more pertinent than specialist qualifications and noted that many senior doctors working in country hospitals did not have specialist qualifications[4].The MEP recommended that, unlike in Victoria, the legislation should not require participating practitioners to hold a fellowship from a specialist medical college or be a vocationally trained GP[4]. Nor did it recommend that at least one of the practitioners have 5 years' experience post-fellowship or post-registration, or one of the practitioners have relevant expertise and experience in the patient's disease, illness or condition (also Victorian requirements)[4]. WA practitioners must still satisfy the legislative requirements (Table 1) to participate in VAD.

Nurse practitioner administration

To increase the pool of clinicians available to administer VAD, the MEP recommended nurse practitioners' involvement[4]. By contrast, Victorian law only permits practitioner administration by medical practitioners. The MEP suggested that nurse practitioners' extensive training and scope of practice would make them suitable to participate in VAD, noting that nurse-led teams already provide specialist palliative care in regional and remote WA[4].

Conscientious objection

The MEP considered how conscientious objection could hamper access. While recommending conscientious objection to be permitted, the MEP wanted to ensure that patients were still provided with sufficient information about VAD to ensure access[4]. The access challenges posed by conscientious objection, particularly in regional and remote communities, are widely recognised[9,11,12]. Commentators have raised concerns about the Victorian VAD Act's conscientious objection provision (section 7), and its ability to compound access issues, due to the lack of obligations it imposes on conscientious objectors to refer patients on to willing practitioners or provide information about VAD[8,9]. WA, unlike Victoria, requires conscientious objectors to provide the patient with standardised information, which includes contact details of the VAD Statewide Care Navigator service and information about regional support packages[27].

Statistical information

The Act's requirement to collect and publish statistical information about regional access was an amendment moved during parliamentary debates. It was reasoned that given the commitment to facilitate equal access for regional and metropolitan residents (guiding principle (2) discussed above), parliament should support this initiative to ascertain to what extent this principle is realised in practice[26].

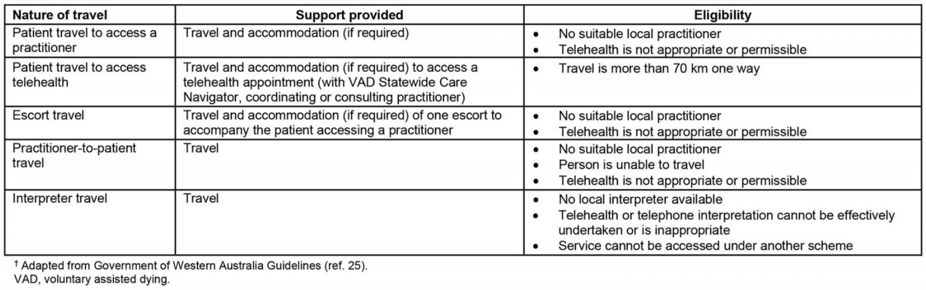
Access Standard

During parliamentary debates, the VAD Bill was amended to introduce an Access Standard, with its content to be determined during implementation. The amendment was moved due to concerns about the access inequities some WA residents face, particularly regional and remote residents[26]. The Access Standard was intended to assist people seeking VAD to understand how they can do so and reflected the Act's principles about equitable access[26]. It was issued in November 2020 and indicated that regional and remote access would be facilitated via the VAD Statewide Care Navigator Service, Regional Access Support Scheme (RASS), VAD Statewide Pharmacy Service and by the state providing clarity about, and monitoring developments in relation to, telehealth[22]. These specific initiatives are discussed further below.

VAD Statewide Care Navigator Service and Regional Access Support Scheme

When considering possible access issues, the MEP recommended establishing a VAD Statewide Care Navigator Service[4]. While the Navigator Service facilitates VAD access statewide, the Access Standard specified that the service would include provision for regional and remote residents to receive information and face-to-face support (if required)[22]. The Access Standard also established the RASS to facilitate access by supporting persons living in regional and remote areas to travel in order to access a practitioner, or support a practitioner to visit the person through payment of travel expenses and remuneration[22]. Further detail about the scheme's travel support is provided in Table 2.

Table 2: Regional Access Support Scheme travel support[25†]



Nature of travel	Support provided	Eligibility
Patient travel to access a practitioner	Travel and accommodation (if required)	• No suitable local practitioner • Telehealth is not appropriate or permissible
Patient travel to access telehealth	Travel and accommodation (if required) to access a telehealth appointment (with VAD Statewide Care Navigator, coordinating or consulting practitioner)	• Travel is more than 70 km one way
Escort travel	Travel and accommodation (if required) of one escort to accompany the patient accessing a practitioner	• No suitable local practitioner • Telehealth is not appropriate or permissible
Practitioner-to-patient travel	Travel	• No suitable local practitioner • Person is unable to travel • Telehealth is not appropriate or permissible
Interpreter travel	Travel	• No local interpreter available • Telehealth or telephone interpretation cannot be effectively undertaken or is inappropriate • Service cannot be accessed under another scheme

[†] Adapted from Government of Western Australia Guidelines (ref. 25).
VAD, voluntary assisted dying.

VAD Statewide Pharmacy Service

Although a Statewide Pharmacy Service was contemplated during the law-making process, its operation was only determined during implementation. In the parliamentary debates, a hub-and-spoke model was considered optimal, with a central pharmacy service at a tertiary hospital with several regional pharmacy hubs[26], but was ultimately not adopted. The Access Standard provided that the service would actively engage with regional and remote residents to ensure safe, timely and appropriate supply of the VAD substance and ensure regionally based 'Authorised Disposers' could facilitate convenient substance disposal for these residents[22]. The service has also set (and to date met) 5 days as the key performance indicator for supply of the VAD substance, compared to 2 days for metropolitan WA[28].

Telehealth

The MEP's consultation process revealed some support (albeit not universal) for telehealth to enable regional and remote access to VAD[4]. The MEP recognised that telehealth already played a significant role in delivering specialist palliative care in regional and remote communities and acknowledged that electronic information exchange would enable reliable and secure access to VAD statewide[4]. The MEP indicated that access to telehealth would primarily be addressed during implementation, but recommended that there should be no impediment to appropriate use of telehealth in the legislation[4].

The importance of telehealth for regional and remote access, and concerns about the impact of the Commonwealth Criminal Code, were raised in the parliamentary debates[26]. The WA Government indicated that it was in continuing discussions with the Commonwealth and committed to adopting alternative implementation strategies to assist with access if telehealth was not permitted[26].

The Access Standard provided that the state would continue to monitor developments in the Commonwealth Criminal Code and provide clarity around what audiovisual communications could be appropriately utilised[22]. As already discussed, the WA Government issued guidance (via its clinical guidelines) during implementation making it clear that some discussions about VAD should not occur via telehealth[25].

Lessons learned

This policy report has considered an existing challenge (regional and remote access to health care) in the context of a new and sensitive end-of-life option, VAD. This report has focused on WA, the jurisdiction to date with the greatest need to address regional and remote access, and one that has taken specific steps to do so.

Currently, there are limited data available about regional and remote access to VAD in WA, given the official report of WA's VAD operations is yet to be published. However, in June 2022, the WA Minister of Health stated in Parliament that, as of 31 May 2022, there were 68 fully trained medical practitioners eligible to provide VAD, 46 of whom came from Perth (including the Peel region), with the remaining 22 coming from regional and remote areas[29]. The Minister also indicated that 171 individuals have accessed VAD, 21% of whom were located in regional areas[29].The RASS has reportedly been used multiple times to provide access to individuals in regional and remote areas[30]. Despite its acknowledged usefulness, it has been noted that the lack of local practitioners in regional and remote regions means that residents in these areas face greater burdens[30]. Incentives such as remuneration for training have been proposed to help increase the number of providers[31], and there is emerging evidence that the RASS has been used to partly compensate regional practitioners for undertaking the training to assist a particular patient when there are no trained practitioners available in the area[32].

Despite these early indications, it is still unclear how regional and remote access will fare in WA. However, as already noted, there was a considered and targeted focus on regional and remote access in both the law-making and implementation stages of the WA system. Evaluation of the effectiveness of WA's access initiatives and opportunities to improve will be critical. It is significant that regional and remote access is the subject of legislatively mandated data collection and reporting because this facilitates transparent assessment of progress on this issue. Providing health care generally is challenging for regional and remote residents and VAD should not be expected to be any different. However, careful evaluation can assess the effectiveness of the specific measures employed by the WA Government and identify the need for additional measures, if required.

WA is not the only Australian state with regional and remote challenges – indeed all states have them. Significantly, Queensland and Tasmania (two other states that have passed VAD laws that have not yet started) have the most decentralised populations, with the largest proportion of regional residents in the country[33]. Alongside South Australia and New South Wales, these states have made efforts to facilitate regional and remote access in their respective legislation and will likely introduce further initiatives during implementation. There is an opportunity for these implementation exercises to benefit from the WA experience as well as international assisted dying regimes where regional and remote access issues have similarly been identified[12,34]. However, each jurisdiction is different, so any initiative must be adapted to the context in which it will operate.

Importantly, in Australia, some VAD access issues for regional and remote communities are beyond the control of state governments. For instance, VAD systems depend on having sufficient willing and available practitioners. Additionally, restrictions on using telehealth cannot be addressed by state governments and depend on Commonwealth action. Despite the limitations of telehealth, especially in the VAD context, telehealth has traditionally been used to help mitigate access barriers, with a range of different telehealth models being used across regional and remote Australia[35]. Given the burdens this restriction on telehealth creates in the context of VAD, the Commonwealth should amend its Criminal Code[16,17].

Note in proof

Since the acceptance of this article, VAD laws are now also operational in Tasmania, Queensland and South Australia. In November 2022, Western Australia's Voluntary Assisted Dying Board released its first annual report, which details uptake of VAD requests, including among regional patients (https://ww2.health.wa.gov.au/~/media/Corp/Documents/Health-for/Voluntary-assisted-dying/VAD-Board-Annual-Report-2021-22.pdf [https://ww2.health.wa.gov.au/~/media/Corp/Documents/Health-for/Voluntary-assisted-dying/VAD-Board-Annual-Report-2021-22.pdf]). Furthermore, the requirements for remunerating regional practitioners for undertaking VAD training has subsequently been broadened, so its availability is no longer limited to cases where practitioners undertake the training to help a particular patient.

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Declared conflicts of interest

The authors disclose that Ben P. White and Lindy Willmott were engaged by the Victorian, WA and Queensland Governments to design and provide the legislatively mandated training in each of these states for medical practitioners (and nurse practitioners and nurses as appropriate) involved in voluntary assisted dying. Casey M. Haining was employed on the Queensland VAD training. Lindy Willmott is a member of the Queensland Voluntary Assisted Dying Review Board.

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ORIGINAL RESEARCH

Accessing voluntary assisted dying in regional Western Australia: early reflections from key stakeholders

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ABSTRACT:

Introduction: Most Australian jurisdictions have passed voluntary assisted dying (VAD) laws, with some regimes already in operation. Inequitable access to assisted dying in regional communities has been described internationally. Although regional access to VAD has been identified as a concern in Australia, to date it has been understudied empirically. Western Australia (WA) was the second Australian jurisdiction to pass and implement VAD laws. Due to the vast geography of WA (and the potential for such geography to exacerbate regional access inequities) several initiatives were introduced to try to mitigate such inequities. This article aims to explore the effectiveness of these initiatives, and report on regional provision of VAD in WA more generally, by drawing on the early experiences and reflections of key stakeholders.

Methods: A total of 27 semi-structured interviews were conducted with 29 participants belonging to four main stakeholder groups: patients and families, health practitioners, regulators and VAD system personnel, and health and professional organisation representatives. Interviews were transcribed verbatim and analysed using inductive thematic analysis.

Results: Data analysis led to the description of four main themes: the importance of the Regional Access Support Scheme, the need for local providers, the role of telehealth in VAD provision and the impact of distance.

Conclusion: Early experiences and reflections of key stakeholders suggest that while many of the regional initiatives implemented by WA are largely effective in addressing regional access inequities, challenges for regional VAD provision and access remain.

Keywords:

access, end of life, initiatives, qualitative, regional, stakeholders, voluntary assisted dying, Western Australia.

FULL ARTICLE:

Introduction

All six Australian states have now passed voluntary assisted dying (VAD) laws. At the time of writing, VAD laws have commenced in three states (Victoria, Western Australia (WA) and Tasmania), with the other state laws coming into effect before the end of 2023, following a designated implementation period. Despite jurisdictional variation, each regime enables terminally ill adults to access VAD provided they satisfy legislative eligibility criteria as assessed by two qualified medical practitioners. If a person is deemed eligible, the VAD substance will be dispensed by the Statewide Pharmacy Service and will either be administered by the person (self-administration) or by an eligible practitioner (practitioner administration).

As is the case with many health services, inequitable access to VAD within regional communities is a pressing concern and has been described internationally[1]. Empirical evidence from Victoria (the first Australian jurisdiction to implement VAD laws) has revealed that regional patients have experienced access difficulties, mainly attributable to the lack of local providers[2].This has necessitated terminally ill patients to travel to metropolitan Victoria to access VAD[2,3].

Access has also been hampered in Victoria due to the prohibition of the use of telehealth in the VAD context[3-10]. Guidance issued by the Victorian Government stipulates that all ‘discussions, consultations and assessments with patients, family and carers regarding [VAD] must occur face-to-face’ (p. 15)[11].This guidance reflects concerns that the use of telehealth in the VAD context may breach the Commonwealth *Criminal Code Act 1995*, an Australian federal law that makes it an offence to use a ‘carriage service’ (eg phone, fax, videoconference, email) to discuss ‘suicide’. Victoria’s guidance adopts a conservative approach that is arguably unnecessarily restrictive given commentators have suggested that aspects of the VAD process can occur via telehealth without contravening the federal law[4,5]. Providing general information about the availability of VAD, providing contact details of a VAD provider and conducting eligibility assessments are unlikely to breach the law, but any discussion and processes relating to the prescription or dispensing of the VAD substance might be a breach[4,5]. A more nuanced position has been adopted in WA’s *Voluntary Assisted Dying Act 2021*, where telehealth is permitted to some extent, subject to the Commonwealth Criminal Code[12].

As the second Australian jurisdiction to pass VAD laws, WA drew on the Victorian experience and committed to ensuring equitable access[13]. Such a commitment stemmed from concerns that the geographically vast nature of WA would likely compound access inequities for regional residents (ie persons who reside outside the metropolitan region)[13]. Accordingly, several initiatives were introduced during the law-making and implementation stages of the WA legislation to facilitate access[14]. Such initiatives included:

- introducing legislative guiding principles promoting equity of access
- broadening (in comparison to Victoria) the qualification requirements for participating medical practitioners
- permitting nurse practitioner administration
- mandating data collection in relation to regional access to facilitate monitoring
- issuing an access standard (which details how WA will facilitate regional access)
- introducing obligations on conscientious objectors
- ensuring statewide VAD services (Statewide Care Navigator and Statewide Pharmacy Service) are accessible to all WA communities
- permitting the use of telehealth (insofar as is permitted by the Commonwealth Criminal Code)
- establishing a Regional Access Support Scheme (RASS), which provides financial and travel support for patients, a patient’s escort, practitioners and/or interpreters to support regional patients[14].

In addition to state-based work led by the WA Government (described above), there is also evidence of local efforts. The WA Country Health Service (WACHS), which is the state’s only public regional health service provider (with services spanning over 2.5 million km^2)[15], is committed to supporting VAD provision within its catchment[16]. In addition to supporting patients and employees within its health services, it also works with the other state VAD services (Statewide Care Navigators and Statewide Pharmacy Service) to support safe regional travel and VAD provision across regional WA more broadly[17]. WACHS, with the coordination assistance of a designated VAD regional lead, provides VAD service personnel with local information and resources (eg fleet vehicles, charter flights and accommodation) to support their regional travel[17].

Given VAD in WA has only been a lawful end-of-life choice for a short time, there is limited insight into regional VAD provision. However, the VAD Board’s first annual report gives some indication of how provision is tracking (Table 1)[18]. The report reveals that the demand for VAD in WA has been much higher than expected, and that the proportions of regional and metropolitan patients seeking and accessing VAD largely mirror the proportions in the WA population[19]. First requests were made by persons residing in each region of WA, and participating practitioners had a practice address in all regions except the Wheatbelt, the region within regional WA with the third-highest number of VAD first requests[18]. The RASS was utilised, and indeed facilitated regional access to some extent, being relied on in all but one region (Mid West)[18].The Statewide Pharmacy Service travelled to every WA region and met VAD substance supply targets (five business days), except on one occasion due to a flight cancellation[18].

Given the limited insight into regional provision to date, this article augments the VAD Board report findings and reports on the early experiences of regional provision in WA based on the reflections of key stakeholders.

Table 1: Key statistics for voluntary assisted dying in Western Australia in the first year of operation (figures correct to 13 June 2022)[18,20]

Description		Number (%)
Medical practitioners who have completed the mandatory training		70
Metropolitan		47 (67.1)
Regional		23 (32.9)
Number of nurse practitioners who have completed the mandatory training		2
Number of medical practitioners who have acted as a coordinating, consulting and/or administrating practitioner		50
Number of patients assessed as eligible to access VAD following completion of a First Assessment		353
Metropolitan		278 (78.8)
Regional		75 (21.2)
Number of VAD deaths (*N*=190)		
Metropolitan	Practitioner administration	102 (53.7)
	Self-administration	37 (19.5)
Regional	Practitioner administration	45 (23.7)
	Self-administration	6 (3.2)
Number of requests that met the defined Regional Access Support Scheme criteria†		108
Number of patients supported by the Regional Access Support Scheme		50

† 104 (96%) of these were a request for travel of a practitioner to a patient.
VAD, voluntary assisted dying.

Methods

This study utilised purposive sampling with different groups of stakeholders: health practitioners (HP), patients and families (PF), regulators and VAD system personnel (RS), and health and professional organisation representatives (Table 2). A variety of recruitment strategies were adopted including advertising via social media and advocacy organisations, and utilising professional networks and publicly available contact details of individuals known to be involved in the VAD process to contact prospective participants. Snowball sampling was also used.

Semi-structured interviews were conducted by CMH (present during all interviews), LW and BPW between March and September 2022 via the videoconferencing platform Zoom or by telephone (see Table 3 for demographics). Separate interview guides were used to accommodate the different types of stakeholders. Each guide contained questions that invited participants to reflect on how the WA VAD regime was operating in practice, and the ability of the WA Act to meet its policy goals and VAD regulation more broadly. Field notes were written following each interview. The interviews were audio-recorded and then transcribed by a professional transcription company. Transcripts were de-identified by CMH, and each participant was sent a copy of their de-identified transcript and invited to review and amend their transcript to ensure comprehensiveness of the data collected.

Transcripts were imported into NVivo v1.6.1 (QSR International: https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home [https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home]). To analyse the data, the authors used inductive thematic analysis as described by Braun and Clarke (2006)[21]. CMH initially familiarised themselves with the data by listening to the audio recording of each interview and reading through each transcript. CMH then developed a preliminary coding framework. The coding framework was reviewed and revised by LW and BPW, drawing on their previous experience and recollection of the data. The data was then coded according to the revised framework. CMH grouped relevant codes into preliminary themes, and then reviewed and extracted the data relevant to the regional context. CMH then defined and named the themes (and subthemes) arising from the extracted data. These were then verified and endorsed by both LW and BPW and are reported here.

Table 2: Participant categories for stakeholder interviews related to voluntary assisted dying regime in Western Australia

Participant category†	Description
Health practitioners (HP)¶	• Health practitioners who have experience with providing VAD
Patients and families (PF)	• Individuals seeking access to VAD (whether or not approved) or • Individuals granted access to VAD or • Family members who have supported (or are supporting) a family member through the VAD process (whether or not the VAD request was ultimately approved)
Regulators and VAD system personnel (RS)	• Individuals who shape the regulation of VAD (either across the entire state or within a particular health service network), including overseeing it, regulating it (or end of life more broadly) and providing education about it
Health and professional organisation representatives (O)	• Individuals who belong to a particular organisation including health organisations (eg community nursing, aged care organisation) or professional organisations (eg advocacy organisations)

† There is overlap between these categories of participants. For example, a Statewide Care Navigator and a Statewide Pharmacy Service representative may fulfill a regulator and VAD system role but can also be classified as health practitioners. In reporting this study, each interviewee has been allocated to only one category (based on the primary focus of their role), but insights were sought from participants across all relevant roles.
¶ Health practitioners comprise medical practitioners only, because the authors were unable (despite active efforts) to recruit other health practitioners (nurse practitioners) who are legally permitted to administer the VAD medication in WA.
VAD, voluntary assisted dying.

Table 3: Participant demographics for stakeholders in the voluntary assisted dying regime in Western Australia

General demographics		**Number**
Participant group	Health practitioners (HP)	7
	Patients and families (PF)	5
	Regulators and VAD system personnel (RS)	10
	Health and professional organisation representatives (O)	7
Gender identity	Male	12
	Female	17
Age group (years)	30–39	4
	40–49	6
	50–59	4
	60–69	11
	≥70	4
Primary location (region)	Metropolitan	26
	Regional and remote	3
Health practitioner characteristics		
Voluntary assisted dying role	Coordinating (primary doctor who manages process) only	1
	Both coordinating and consulting (second opinion on eligibility)	6
Number of cases	<10	1
	10–20	2
	21–30	1
	>30	3
Number of years in profession	10–20	2
	21–30	2
	>30	3
Main speciality	General practice	3
	Rural generalist	1
	Anaesthetics	1
	Emergency medicine	1
	Other	1
Regional experience[†]		6
Patient characteristics[¶]		
Diagnosis	Cancer	3
	Emphysema	1
	Pulmonary fibrosis	1
VAD experience	Unable to commence the VAD process	1
	Lost capacity during the VAD process	1
	Approved for self-administration	2
	Completed VAD process through practitioner administration	1

[†] Participants who had at least one experience with regional provision.
[¶] These demographics reflect participants who were patients themselves or patients described by a family member.
VAD, voluntary assisted dying.

Ethics approval

Ethics approval was granted Queensland University of Technology Human Research Ethics Committee (Ref 20000002700). Informed consent was obtained before each interview.

Results

A total of 27 interviews with 29 participants were conducted (two interviews had multiple participants, and one interview was done in two parts due to participant availability). Interview times ranged between 58 and 144 minutes. Data analysis revealed four main themes: the importance of the RASS, the need for local providers, the role of telehealth in VAD provision and the impact of distance. Each of the main themes (and relevant subthemes) are summarised in Table 4 and described below, including as quotes from interview participants.

Table 4: Main themes identified through thematic analysis of stakeholder interviews

Theme	Subtheme
Importance of the Regional Access Support Scheme	Source of financial support for providers
	Reflections on the service's efficacy
	Not practical for all metropolitan practitioners
Need for local providers	The benefits of local provision
	The challenges of limited local providers
	Barriers to local provision
	Initiatives aimed at increasing local provision
Telehealth's role in VAD provision	Context in which telehealth is used
	Limits placed on the use of telehealth
Impact of distance	Mail
	Travel

VAD, voluntary assisted dying.

Importance of the RASS

The RASS was designed to improve access to VAD for patients living outside of metropolitan areas.

Source of financial support for providers: The RASS permits the provision for funds to be disbursed to support regional patients to access VAD.

> *The Regional Access Support Scheme can pay for a person to travel to a doctor. It will pay for a support person to travel with them, or it will pay for a practitioner to travel to the person, or everyone can travel and meet at a middle location that's mutually convenient, and it will also pay for interpreters to travel … It will pay for things like accommodation, flights, that sort of thing, and it also pays for the practitioner's time lost. So, [the VAD Care Navigators] can pay them as a set fee. It's less than four hours or over four hours. There's no kind of I was there for an hour and a half and it's an hourly rate. [RS8]*

The RASS is one of the limited opportunities for VAD practitioners to be adequately compensated, which was identified as critical in incentivising uptake.

> *It's a fabulous service [and it] remunerates practitioners far more than they're able to be remunerated doing work locally, but it requires of those practitioners significant time commitment and availability to fly to a region, do their assessment and fly back. [RS9]*

> *The rural solution in WA would not have worked without the RASS on the current payment schedule. [HP6]*

One participant commented on the reverse inequity that the RASS results in, identifying that the same resources were not allocated to palliative care.

> *It just seems to be so inequitable because we are having resources spent on sending people out to the regional areas to do assessments and getting the lethal substance out there, but we won't get those resources being used for palliative care. [O7]*

Reflections on the service's efficacy: Participants who had engaged with the RASS were largely positive about it. Many highlighted that the RASS has largely served its policy purpose and embodied a commitment to person-centred care.

> *The [RASS] in WA has been a success in what it's demanding. That issue of geographic equity is being addressed and we're doing moderately well. [HP6]*

> *[W]e're dealing with patients getting near to the end of their lives, they don't want to travel. They're too sick to travel. Logistically it's a … nightmare. There's a whole host of reasons why that wouldn't be possible for the person. And I think again that speaks to our practitioners, where they have been willing to do so, about the real need to provide that person-centred care. And for many people being at home in [their] own bed and not stuck in a hotel in [metropolitan WA] is actually a really huge part of that. [RS8]*

Participants also indicated that the RASS was a well-managed and efficient system.

> *[T]hey organise all your travel, they pay for your travel and any food you need and that sort of stuff, and they're very efficient and very flexible … I thought it was very good. [HP2]*

One participant, while praiseworthy of the RASS, did suggest that it can create additional administrative burdens for practitioners.

> *So, it's fine. It's just the administration side of things that I'm not very good at … I don't have any office staff, so I don't have anyone who can actually put through bills for me. So, I had to make up my own billing invoice online. [HP5]*

Not practical for all metropolitan practitioners: Despite the positive sentiments about the RASS, participants indicated that it was impractical for some practitioners due to the time commitment required. Furthermore, the success of RASS was perceived to be due to the availability of a subset of VAD providers.

> *I would consider doing that if it was paid more … I can earn money sitting here seeing my normal patients. I'm not going to rush down to [regional WA] and take a day off to do that when it's so poorly paid, and it takes a long time. [HP4]*

> *[I] have a little less flexibility because I have quite a lot of committed contract hours during the working hours of the week … [A subset of providers have] done lots of them … without [these] providers, we would be struggling to say we were providing equitable access to country areas. And, as you know, WA is a … big place. [HP6]*

Need for local providers

Despite the positive reception of RASS, the scheme does not obviate the need for more local providers.

The benefits of local provision: Some participants described that the regional setting was conducive to VAD provision. The nature of such communities meant that regional health practitioners often had a pre-existing therapeutic relationship with the patient and professional relationships with local health service staff, which assists the process to operate more smoothly.

> *[What is] good [with] a hospital [in] [regional town X] is we're fairly close to each other, we all know each other well. So, the boss of the hospital who's my boss, I know very well personally, obviously, as I do the palliative care team, the pharmacist and the nurses on the wards who[m] the patient might need to pass through … [This] can actually make the process flow quite easily, which has been a massive advantage. I don't know how I'd cope with that in a bigger city where I don't know the hospital staff, and I don't work in the hospital … Having that level of trust and working as a team has made things so much easier. [HP7]*

> *[The] consulting practitioner is a visiting palliative care specialist who goes around the region. So, [they have] often met a lot of these patients. So, that makes things a whole lot easier when [they are] meeting someone via [videoconference], especially if they're unwell, to be able to make a correct decision, but also, it's easier in terms of the rapport from the patient's perspective. [O1]*

Local practitioners sometimes relied on informal 'buddy systems'. It was observed by one participant that professional colleagues could provide eligibility assessments as consulting practitioners, while still satisfying the requirement for an independent assessment.

> *I got [the Care Navigator's] advice … like being such a small place, we're all friends. I [didn't] want it to look like an inside job … I want[ed] it to look [like], from the 'pub test' [colloquialism for a hypothetical test of public reaction to an issue] so to speak, … an independent decision. So, I did actually ask the Care Navigator 'Is this okay?' and they said 'Yes, it's fine.' [HP7]*

The role of designated VAD regional leads and the importance of having one in each region were also highlighted.

> *I think because the regions operate very, very differently and distinctly … [it was] thought that [there should be] a regional contact across each of our seven regions, and that regional contact would be the person that, if there were any questions, would be able to answer and direct the person on to the appropriate service, which would usually be the Care Navigator Service. [RS7]*

The challenges of limited local providers: Participants reported that there were challenges in meeting demands because of limited local providers (particularly in the early days). Consequently, local providers have been required to manage large patient loads, which has been found to be taxing on both the provider and the patient.

> *I'd sort of like to see that we had more practitioners available, just so that the singular general practitioner is not the sole practitioner of VAD. That might make things a lot easier, for [them] certainly, and perhaps also for availability for the patient. [O1]*

The potential for inequitable access in towns that only have a single GP serving was also identified, particularly if the doctor is a conscientious objector. Such a context renders the importance of the statewide VAD services to facilitate referrals.

> *We have GPs that work alone in practice[s] in small towns all the way across the state … when you're living in a town with one doctor … it can never be equitable. So, the Statewide [Care Navigator] Service … [is] so incredibly important to connect [a] person with someone that can assist them. [RS7]*

Barriers to local provision: Participants identified that while there are several barriers that discourage practitioners from becoming VAD providers, additional barriers tend to exist for regional practitioners.

> *I think that rural practitioners may be busier and may just think, oh, I don't have time for this. [HP1]*

> *Most of the practitioners are in small practices in country towns, and we've known from the outset that in those settings a lot of clinicians didn't want to be identified as Dr Death. [HP6]*

> *A lot of them, as I found out from a situation in [Regional WA Town], are … new doctors, like perhaps recently from overseas, who actually do not qualify to do the training yet, they haven't spent the time in the Australian situation. So, some of them would love to and they just have to wait another four years until they're allowed to do the training. [HP1]*

Initiatives aimed at increasing local provision: Participants reflected on the initiatives implemented to increase the number of local providers both pre- and post-implementation of the WA Act.

Pre-implementation measures Reflecting on Victoria's issues with regional provision, the framing of the WA legislation aimed to widen the cohort of eligible VAD providers. Unlike in the Victorian regime, the WA legislation does not require one of the medical practitioners assessing the patient to have 'expertise and experience' in the person's disease[11], which has been interpreted as requiring one of the practitioners to be a specialist in the person's disease. WA's less prescriptive approach was favoured among participants.

> *I think in the Victorian legislation [one of the] practitioner[s] ha[s] to be in the same specialty as the disease of the patient … so if it was a neurological problem, they had to see a neurologist, if was a haematological problem they would have to see a haematologist. That's not always possible, particularly in the huge state that we have here. You know, if there is somebody up in … [regional WA], there isn't necessarily going to be a neurologist on tap that is interested in VAD. [HP4]*

Moreover, unlike in Victoria, appropriately qualified and trained nurse practitioners are permitted to administer the VAD substance to an eligible person in WA. This innovation was intended to mitigate access issues by creating a larger pool of practitioners available to participate in this aspect of the VAD process[13,14]. However, only two nurse practitioners in WA have done the requisite training to date[20]. Some participants surmised that the lack of uptake among nurse practitioners was attributable to their limited role in the VAD process.

> *When the Act was drafted there was discussion about just allowing nurse practitioners to be part of the process in total. So, allowing them to do the assessments and to be a provider for a patient. And that kind of got watered down to, well, they*

> *can have the role of administering practitioner, and that'll help particularly in rural and regional areas. I don't think we've seen that. [RS1]*

Participants suggested revising the role of nurse practitioners or implementing a GP–nurse collaborative partnership may be effective in addressing access inequities.

> *I think the way that [it could] work is if you had teams of, for example, GPs and nurse practitioners who would deal with a patient collectively. So, they're both there from the beginning, but the GP does the assessment bit … knowing that the nurse practitioner would be available for the administering role. Or [the legislation] needs to be revised so that nurse practitioners can actually do the whole process. [RS1]*

Post-implementation measures Participants also reflected on the continued awareness-raising efforts undertaken by the WA Government to increase the amount of local VAD providers.

> *We did talk a lot about having a plan because we wanted to increase the number of people trained. We're doing a regional roadshow, for example, it's going around the regions, and [we're thinking about] what incentives might well occur to encourage people. [RS3]*

There is also evidence of payments being made to local providers for completing the mandatory training (using RASS funds), to incentivise provision. Initially, payments were only available when linked to a particular patient but have since been expanded.

> *[The WA Government] insisted that [practitioners had to] already have a case waiting initially … [but] because [of the] busy doctor's life, got a case here, got to do that training. We need[ed] them to train beforehand. So [the WA Government has] loosened up on that. [RS4]*

Telehealth's role in VAD provision

The Commonwealth Criminal Code (CCC) places some restrictions on what aspects of the VAD process (and related communications) can occur electronically[4,5,12]. The legislation and guidance issued in WA is that telehealth can be used for some aspects of the VAD process (subject to the constraints of the CCC)[12]. Participants reported that telehealth was used in the VAD context to some extent.

Context in which telehealth is used: Many participants identified that permitting telehealth for some aspects of the VAD process was useful.

> *One of the key aims of the WA legislation was to minimise the restriction on access that would occur for rural or remote patients. I think that the ability to have videoconference interactions has achieved that goal as much as you can without a million practitioners around WA doing this. [HP3]*

Telehealth was often used in consulting assessments and was occasionally used by coordinating practitioners for some aspects of the VAD process (insofar as permitted). In many cases, telehealth was used in conjunction with the RASS to help minimise travel time.

> *What I have tended to do there is take a first request and first assessment by videoconference … and I have access to that sort of seven days a week … I've tended to … then travel to see them for the final request … The Navigator Service and the Regional Access Support Scheme have made that very easy. [HP3]*

Limits placed on the use of telehealth: Many participants reflected on the challenges that arise in practice due to the CCC.

> *While we can talk about some stuff … over audiovisual connection, there are some [stuff] that can only be covered face to face. So, until that changes, we'll always be making two visits to [regional WA] for one person … I mean I do think at some point … you probably do need face to face … because these are such important discussions to have and the things that people want to tell you and ask you are so important. But when you're talking about a state as big as WA and somebody might be three-and-a-half hours' drive from where we are, it's just not practical to do that every time … it would be simpler if that was changed. [HP1]*

> *[The Commonwealth Criminal Code is] exceptionally challenging, particularly for some of our rural patients, to wait for a hard copy prescription which can't be scanned [and] emailed like a standard prescription. [RS10]*

Impact of distance

Participants reflected on the fact that the vast geography of WA created logistical difficulties and delays.

> *I think there will always be challenges for WA given its … population distribution geographically in terms of getting to the country and remote areas. [O6]*

Mail: Participants reflected that the need to use postal mail introduced delays. However, postal mail was necessary on occasions because certain documentation (such as a prescription or protocols) are unable to be transmitted electronically because of the CCC.

> *When you live regionally, everything takes at least another 24 hours. So, if you lived in the city, I'm sure everything would be done in a way shorter timeframe … Even if it's … [a] priority post that's coming from a regional area to the city, that's not going to happen overnight. [O1]*

> *[W]hat we've found … is often when sending an item from one rural location to another, it will need to go from a rural area, back to [Metropolitan WA] and then back out again. We've seen that with mail, we've seen that with medications. [RS10]*

Travel: Due to distance concerns, various personnel involved in the VAD process (eg health practitioners, Statewide Care Navigator Service and Statewide Pharmacy Service) would often need to fly to a particular region. This was quite demanding, due to the paucity of available flights and the flexibility this necessitates.

> *When it comes to flights, particularly with the scarcity of flights to some areas, it has been challenging to meet [the patient's] desires in some of those situations … Often practitioners and patients have been very flexible, which is great. [RS10]*

Some participants described that VAD personnel would often commit to late-night/weekend commutes. In some cases, long drives were required in the absence of flights.

> *There was a patient in [regional WA] for whom, because the team could not get a flight, the practitioner and the Care Navigator drove 1,900 kilometres over a weekend to support the administration to the patient because that's when the patient wanted to have it … [T]here are some amazing stories of commitments, focus on [a] patient['s] wish, dealing with logistic nightmares … [The VAD Care Navigator] must have travelled a million kilometres already in my view. [HP6]*

Discussion

This article reports on early reflections of regional VAD provision and access in WA. The findings suggest that active efforts taken by the WA Government to facilitate access during the law-making and implementation phase of the WA legislation have, at least to some extent, been successful. Most significantly, participants emphasised that the RASS has been instrumental in facilitating regional access, and participants were largely complimentary of its operation. Other examples of initiatives that have facilitated access include the removal of the 'expertise and experience' requirement and facilitating greater use of telehealth.

Notwithstanding the positive reflections, the findings did identify challenges with regional provision. Consistent with the Victorian experience[2], the lack of local providers was considered by participants as a barrier. It is concerning that, although each region has had requests for VAD, not all regions have local providers[18]. It is promising that the number of local providers has increased over time, and the government is taking active measures to raise awareness and incentivise practitioners to become VAD providers, but there is still a dearth. Although the RASS can facilitate VAD provision, there were sometimes delays due to practitioner availability and travelling constraints. Furthermore, if it is the case that the RASS is largely serviced by a small subset of VAD providers, this raises concerns about the scheme's sustainability. Increasing the number of local providers will inevitably reduce the reliance on the RASS and likely reduce delays.

The findings also suggest that some of the early challenges faced by regional communities may be addressed through law reform. Most significant are the challenges that arise due to the CCC. While participants largely found the use of telehealth to be beneficial, restrictions on its use were considered unnecessarily burdensome, which is consistent with the Victorian experience[10]. Similarly, the requirement to mail particular documents (eg prescriptions, protocols), due to the CCC's prohibition on such documents being emailed (or transmitted by other electronic means), was described by participants as burdensome due to the inevitable delays it caused. The sentiments from participants largely echoed calls for reform of the CCC[4,5] (including those from the WA VAD Board[18]) to remove such challenges.

Participants also identified areas for reform in relation to nurse practitioner involvement. Internationally, the ability for nurses to participate in VAD provision has been identified as a mechanism to address some access barriers, particularly in the context of limited providers in rural settings[1]. Several participants suggested that low nurse practitioner involvement could be in part attributable to their role being confined to acting as an administering practitioner (unlike in Canada, where nurse practitioners can also undertake eligibility assessments). Given this initiative has not been successful to date in WA, further reflection is needed to increase nurse practitioner involvement with VAD.

Finally, although most participants identified significant challenges for residents of WA accessing VAD, there are opportunities to use strengths of regional health care to enhance access. For example, participants identified the benefits of personally knowing other medical practitioners and health administrators in the local area. There may be scope to harness these existing relationships to establish local networks to support access to VAD.

Limitations

First, although this study includes the views of a variety of stakeholders, there were ultimately limited participants in each group, and therefore data saturation was not reached and hence some perspectives may not have been captured by this study. Second, not every participant was able to reflect on the regional experience, so the findings reported in this article are limited to a subset of the sample. We note that although three participants were themselves based in regional WA, others interviewed were able to meaningfully comment on these issues. For example, five out of the six interviewed VAD metropolitan medical practitioners travelled to provide VAD regionally. Similarly, many regulators and VAD system personnel had active roles in regional engagement to enhance access. Finally, as some of these findings relate to WA-specific initiatives, the results may have limited relevance to other settings.

Conclusion

This article has provided an overview of the early operation of VAD provision in regional WA. The findings suggest that although there have been several successful initiatives that have helped to facilitate regional VAD provision, challenges to equitable access remain. Efforts intended to incentivise local provision need to be sustained, and consideration needs to be given to areas of reform that can help address some of the perceived barriers to regional provision. Further research needs to be undertaken to monitor regional provision over time.

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Conflicts of interest

The authors disclose that Ben White and Lindy Willmott were engaged by the Victorian, Western Australian and Queensland governments to design and provide the legislatively mandated training in each of these states for medical practitioners (and nurse practitioners and nurses as appropriate) involved in voluntary assisted dying. Casey Haining was employed on the Queensland project. Lindy Willmott is a member of the Queensland Voluntary Assisted Dying Review Board.

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