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Models of care for voluntary assisted dying: a qualitative study of Queensland's approach in its first year of operation

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ABSTRACT

Objective. Voluntary assisted dying (VAD) began in Queensland in January 2023 but little is known about its practical operation. This research examined models of care for providing VAD in Queensland. **Methods.** Semi-structured interviews were conducted with 24 participants involved with VAD delivery across Queensland's 16 Health and Hospital Services (HHSs). Participants included HHS VAD Coordinators, nurse practitioners and nurses who acted as administering practitioners, and Queensland VAD Support and Pharmacy Service (QVAD SPS) staff. **Results.** Five themes about Queensland VAD models of care were developed: VAD is accessed almost exclusively through the public sector via HHSs, influenced by a Health Service Directive; local models of care vary; nurses play significant roles facilitating access to and providing VAD; QVAD SPS has been instrumental supporting HHSs and ensuring statewide access as back-up VAD provider; and VAD services need more resourcing. **Conclusions.** The Queensland approach to providing VAD has been largely successful in ensuring patient access across the state. However, it differs from previous Australian VAD models with access predominantly through the public sector, greater roles played by nurse practitioners/nurses, and VAD being provided by QVAD SPS. Under-resourcing and consistency in provision of VAD services remain challenges.

Keywords: euthanasia, health system funding, health systems, health workforce, implementation, models of care, physician-assisted dying, voluntary assisted dying.

Introduction

All Australian states and the ACT have voluntary assisted dying (VAD) laws. The Northern Territory is actively considering reform.[1] There is a broad 'Australian model' with narrow eligibility criteria and many procedural safeguards (Box 1).[2] However, states have implemented VAD laws differently.

In Queensland, where VAD has been available since January 2023, Queensland Health issued a Health Service Directive (HSD) requiring each of its 16 Health and Hospital Services (HHSs) to provide a VAD service (Box 2).[3] Each HHS was required to establish 'a model of care to provide timely, publicly funded voluntary assisted dying services for eligible people' including 'all steps of the voluntary assisted dying process'. The HSD did not prescribe a model of care or its implementation. HHSs did not receive dedicated funding for providing VAD.[4]

Another key implementation feature is the Queensland VAD Support and Pharmacy Service (QVAD SPS).[4] It differs from other states in that it:

- Combines in a single service:
  - a care coordinator service established under the Act 'to provide support, assistance and information to people'[5] – QVAD Support;[6] and
  - a statewide pharmacy service to supply VAD medication – QVAD Pharmacy.[7]

Box 1. **Brief overview of Australian VAD laws**[A]

Eligibility criteria

- A person must be an adult, have decision-making capacity, be seeking VAD voluntarily and without coercion, meet residency requirements, have a qualifying disease, illness or medical condition, and be experiencing suffering.
- The medical condition must be advanced and progressive, and one that will cause death, in most jurisdictions, within 6 months or 12 months for neurodegenerative conditions. (Queensland has a global 12-month timeframe; the ACT does not have a timeframe and refers to people 'approaching the end of their life'.)

Request and assessment process

- A person must make three separate requests for VAD.
- Eligibility criteria must be assessed by at least two independent medical practitioners (one can be a nurse practitioner in the ACT).

Other example safeguards

- Restrictions on how VAD may be raised with patients, including Victoria and South Australia prohibiting registered health practitioners from initiating a discussion about VAD.
- Mandatory training for health practitioners involved in assessing and providing VAD along with required minimum qualifications/ experience.
- Oversight Boards which review individual cases of VAD and report publicly on collected aggregate data.
- Four states require prospective approval of VAD from a Board or government official.

[A]Because of differences in Australian VAD laws, this Box provides only a general overview and does not address some local variations.[2]

Box 2. **Extracts from Health Service Directive 'Access to voluntary assisted dying'**[3]

Purpose

This directive outlines the mandatory requirements for Queensland Health Hospital and Health Services to safely and effectively:

- manage and respond to requests for information about and access to voluntary assisted dying, and
- deliver voluntary assisted dying services.

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Outcomes

Hospital and Health Services will achieve the following outcomes:

- Each Hospital and Health Service establishes a model of care to provide timely, publicly funded voluntary assisted dying services for eligible people.
- People who request information about voluntary assisted dying receive appropriate information and support from the Hospital and Health Service.
- Eligible people who request access to voluntary assisted dying are supported through the process by the Hospital and Health Service and receive safe, high quality, person-centred care.
- Hospital and Health Service employees are informed, educated, competent, and aware of their rights, responsibilities, and local policies and procedures in order to meet their legislative obligations.

....

Access requirements

Hospital and Health Services must establish a model of care to provide timely, publicly funded voluntary assisted dying services for eligible people. This includes services required to enable a person to complete all steps of the voluntary assisted dying process, from first request to administration of the voluntary assisted dying substance. It is not a requirement that voluntary assisted dying services are provided at every Hospital and Health Service facility, however, consideration should be given to a person's preferences around location of service delivery and place of death. These services must be delivered under the governance of the Hospital and Health Service.

....

- Has interdisciplinary staff with nursing and social work care coordinators, pharmacists and a psychologist, led by a palliative care physician.
- Includes practitioners, primarily nurses, authorised to provide VAD as part of QVAD Support (Queensland law permits doctors, nurse practitioners and nurses to be 'administering practitioners').

This is the first empirical study of Queensland's VAD system, examining models of care for providing VAD using qualitative interviews with HHS VAD coordinators, nurses providing VAD and QVAD SPS staff.

Methods

Recruitment

Recruitment used purposive sampling across two phases. Phase one (part of a wider study) recruited nurses who provided VAD as 'administering practitioners'. QVAD SPS forwarded study details to all eligible nurses. Most of these nurses were also a VAD Coordinator in their HHS or worked for QVAD SPS. Phase two sought VAD Coordinators from remaining HHSs (whether or not a nurse who had provided VAD) and the wider QVAD SPS team for statewide insights. Phase two participants were recruited at a clinical symposium and via direct email to remaining HHS VAD Coordinator email addresses. Snowball recruitment was used throughout. Recruitment ceased on data saturation (information redundancy).[8]

Data collection

Twenty-four semi-structured interviews occurred between October 2023 and March 2024 by BPW, AW and LW (with one a designated lead). BPW attended all, AW all except one and LW four interviews. All but one were Zoom video conferences (one via telephone) and lasted between 34 and 92 min. Interviews were audio-recorded and transcribed verbatim. Participants could amend their transcript (member checking),[9] and some provided supplementary information (e.g. VAD death numbers).

Our interview guide (Supplementary material file S1) was based on analysis of the Queensland VAD system,[2,10] similar research from other jurisdictions[11–14] and research team discussions. Open-ended questions explored system operation, with novel features of Queensland's implementation specifically explored.

Analysis

NVivo 14 (QSR International) was used to store and code transcripts and supplementary information. Thematic analysis was applied using codes developed deductively (based on previous research and field knowledge, e.g. role of VAD coordinators and impact of resourcing, and iterative discussion of early themes) and inductively.[15] Interviews were coded by AW using a framework developed with BPW and LW and periodically refined. BPW and AW undertook iterative analysis during data collection including discussions and/or shared journalling about key implications after each interview and periodic review of data as a whole (e.g. after the first nine interviews). Themes developed were discussed and tested by all authors.

Ethics

Study approval was by Queensland University of Technology Human Research Ethics Committee (2000000270). Participants provided informed consent.

Results

Twenty-four participants were interviewed with representation from 15 of the 16 HHSs (Table 1). Interviewees were primarily nurses (19) with two doctors and three other health professionals. Five themes were developed about Queensland VAD models of care.

Table 1. Characteristics of interviewees (n = 24).[A]

Characteristic	Number of participants
Age (years)	
31–39	7
40–49	5
50–55	11
56–75	1
Gender	
Female	22
Male	2
Profession	
Nurse practitioner/nurse	19
Social work/allied health	3
Doctor	2
Location of primary practice	
Metropolitan	12
Regional	7
Rural/remote	5
Work setting	
HHS VAD coordinator	14
QVAD SPS	5
Other roles[B]	5

[A]One interview was conducted with an additional participant but no system perspective was obtained, so that participant is not included in this study.
[B]Other roles were: members of HHS VAD teams actively involved in providing VAD (but not a VAD Coordinator), and one nurse participant who was not part of a VAD team but had a relevant clinical leadership role in their HHS which led to VAD provision.

Voluntary assisted dying is accessed almost exclusively through the public sector via Health and Hospital Services, influenced by the Health Service Directive

Participants described the vast majority of VAD being accessed through the public sector, including rural general practitioners (GPs) working within a HHS or specifically employed by it for VAD work. A QVAD SPS participant, drawing on the fact that its service issues all VAD medication in Queensland, put the figure at 'about 90%'.

Participants identified the HSD's influence because it mandated a local model of care for public access to VAD in each HHS. Participants perceived the HSD positively because it required at least some engagement in all HHSs.

> I think the directive was good. I think it was great. I think that that really socialised VAD. We had to have a policy in place. We had to have a guideline in place to really set up those systems of governance.

Local models of care vary

An outcome of the HSD not prescribing how a model of care should be implemented is 'huge variety' in models.

> However it [the HSD] wasn't prescriptive in any way. And some HHSs embraced this better than others. Some HHSs provided funding for dedicated authorised medical practitioners and authorised nurses as well as administrative staff. And other HHSs did not provide that support.

All HHSs had a VAD Coordinator who served as a contact point. This was generally a nurse, with some allied health such as social workers. But the nature of these roles varied. Some Coordinators had a navigating role supporting patients, families and health professionals while others played only an arms-length facilitative role (e.g. just connecting patient with doctors).

The VAD workforce within HHSs also varied. Some Coordinators were designated appointments with allocated VAD workloads. Some HHSs also had a team supporting VAD that may include medical, nursing or administrative appointees (and occasionally all). However, some HHSs did not have a dedicated workforce, and VAD Coordinators performed their role without workload recognition and on top of existing job/s.

> They simply said, 'Just add this [VAD Coordinator] to your job as [current position]'.

> So what happened was in some of these smaller – and in larger ones as well – that people who were already fully employed were also given the title of, 'You're the VAD service provider as well'.

> So we have no funding …. We've got no admin. We've got nothing. We just do it.

Participants reported variation in governance and oversight. Some described clear reporting lines and strong support from HHS management. Others described a lack of clarity about reporting – 'no-one knows what I do' – and unsupportive or disinterested HHS leadership.

Nurses play significant roles in facilitating access to voluntary assisted dying and providing it

Nurse practitioners and nurses play a significant role in VAD in Queensland. HHSs generally opted for a nurse-led response (most VAD Coordinators are nurses), with one participant observing this was a cost-effective path to HSD compliance.

Nurses, generally as VAD Coordinators, often led the establishment of HHS VAD processes. They often facilitated VAD applications to reduce administrative and logistical burdens on doctors, freeing them to undertake exclusively medical roles like eligibility assessments.

Appointing nurses as Coordinators or within HHS VAD teams resulted in nurses acting as administering practitioners. Fifteen of 19 nurses interviewed had undertaken practitioner administration. Some nurse participants described accompanying patients through the VAD process and at all appointments (including eligibility assessments), culminating in them being the administering practitioner.

For some participants, practitioner administration was a core role, with a few providing this more than 20 times. In some HHSs where practitioner administration is common, some reported this role being primarily undertaken by nurses.

> I see everybody that comes through, all the referrals come through. I go and visit them at home or in a ward … [W]herever they are, I'll go and see them and talk them through the whole process from the beginning. Make that initial introduction because I'll be the one that supports them through the process. … We have a different model here in VAD. We agreed way at the beginning with the SMOs [senior medical officers] that it made sense for me to do the things that I can do. And for them to spend time doing the things that they can do that I can't do. So that's why I ended up having so many administrations. It makes sense for me to do the administering. It's better to use your time to do the coordinating and the consulting and the final requests that I can't do.

Queensland Voluntary Assisted Dying Support and Pharmacy Service has an integral role in supporting Health and Hospital Services and as back-up voluntary assisted dying providers to ensure statewide access

QVAD SPS is an integral part of Queensland's approach to VAD. Participants were glowing about its work, including support provided to HHSs and VAD Coordinators, and patients and families through QVAD Support.

> This [HHS] service wouldn't have survived without QVAD Support.

Some particularly valued that QVAD SPS was interdisciplinary with care coordinators and pharmacists in the same team.

Although assisting all HHSs, much QVAD Support work focused on 'gap-filling' where VAD was not available locally. Participants also spoke about QVAD SPS's efforts to build this capacity in these regions.

> Probably the first three months of the year, we didn't have anyone here, we had no authorised doctors … so it was basically just QVAD Access that we were using, so they were flying doctors up, and almost every week. We were really busy right from the beginning, there was no lead in period, it was just right from the start.

This gap-filling role included QVAD SPS staff acting as administering practitioners. Administration was not an intended QVAD Support function but this was needed in HHSs without local capacity, or in complex cases whereadditional experience was beneficial. This role was often fulfilled by QVAD SPS nurses (linked with above theme), and was sometimes acknowledged as challenging given limited time to establish patient relationships.

> It's been gap-filling for want of a better term when a patient's priority has been that they've needed it, and nobody else has been able to go and do it. They reach out to us and then we'll, one of us is asked, obviously, no one's forced into doing anything, if we would like to go and do an administration. And then we travel and do the administration.

More resourcing is needed within Health and Hospital Services

Many participants were concerned VAD was under-resourced in their HHS. Some described HHSs 'ticking the box of the HSD' so it had VAD in theory, but the practice was quite different.

> There's absolutely no money here for us … no one wants to pay for it. … It's law, it's legislation, you have to provide the service. So find some money and get on with it, basically.

There were also reports that Coordinators and other clinical VAD roles had insufficient time for the work volume, particularly given higher than expected demand. Participants in HHSs with dedicated medical VAD roles (compared with nurse-only models) appreciated this structural access to doctors, who are needed for VAD eligibility assessments, as this facilitated timely progress for patients through the VAD approval process. A few HHSs with large VAD workloads valued administrative support given the paperwork and time-intensive nature of assessment processes.

Linked with under-resourcing was the temporary nature of VAD appointments. Many participants reported job insecurity made them vulnerable and risked VAD service continuity. However, some described recent improvements in resourcing within their HHS including making roles permanent and allocated VAD time within workload.

> I am just hellishly lucky that our health service realised that they would need to make permanent positions and have done so. Albeit a bit slightly slower than we hoped. But all the other health services, they're still working on temporary contracts and things because nobody's got any money and nobody wants to give any money from any other service to run this service. So I think that was a real miss that there should have been some way of ongoing funding for this. You can't really demand that health service runs a service but then just say, 'But we're not going to give you any financial assistance to do so'. But then you can't not run a service because then we're breaking an HSD.

These factors led to some participants feeling burnt out and overloaded, commonly compounded by the isolation of being a 'lone practitioner'. Many reported no alternative support in their HHS: 'I haven't [been able to] have a holiday'. However, many described feeling supported by QVAD SPS with the VAD process and personally (including through its community of practice). Another protective factor was the rewarding nature of supporting patients to have their choice of VAD.

Discussion

VAD access in Queensland has been shaped by implementation, especially the HSD and QVAD SPS. Significantly, the vast majority of VAD (~ 90%) is accessed through the public sector. This appears to be different from other states. While available data is not definitive, GP VAD participation can be a useful proxy given GPs primarily work in the private sector. Data in VAD Review Board reports varies (e.g.

registered for VAD training versus *participating* in VAD) but GPs account for 81% of practitioners in Tasmania,[16] 60% in South Australia,[17] 59% in Victoria,[18] and 45% in Western Australia,[19] suggesting VAD access is spread across public and private sectors elsewhere. Also noteworthy is Queensland's statewide VAD availability. Queensland has VAD practitioners in each HHS area[4] while Victoria and Western Australia report areas without them.[18,19]

Both features of access in Queensland – public sector access and statewide availability – were reportedly driven by the HSD mandating each HHS have a local model of VAD care. The HSD is a stronger policy response than adopted in previous states with VAD. For example, Victoria's 'VAD model of care pathways for health services' allowed services, including public health services, to choose their level of involvement in VAD.[20] The least involved pathway was to provide only 'information and support',[20–23] the pathway chosen by most organisations in the first 2 years of operation.[24] The resulting inequities in patient access to VAD due to variations in approaches by institutions is problematic.[25]

The role of nurse practitioners and nurses in Queensland is also striking. For example, 15 of our sample had provided practitioner administration, consistent with Queensland Board data that 14 nurse practitioners and nurses had undertaken this role in the first 6 months.[4] By contrast, the only report of nursing engagement as administering practitioners (permitted in WA, Tasmania and NSW) is in WA with one nurse practitioner providing practitioner administration over the last 2 years.[19]

Again, the HSD likely leads to greater nursing participation, particularly as administering practitioners. HSD obligations were usually met by HHSs through nursing appointments, generally as VAD Coordinators. This greater nursing involvement with patients through accompanying them in the VAD process may remove the known barrier to undertaking practitioner administration of not having a prior patient relationship.[19] The 'gap-filling' role of QVAD Support has also contributed to greater nursing participation in VAD as its nursing staff acted as administering practitioners when needed, although generally without the same opportunity to establish patient relationships.

The QVAD Support service has also had wider and significant impact on access, particularly in ensuring statewide availability. Its ability to provide assessments and/or administration to meet unmet demand in HHSs has been pivotal. Although not an anticipated function of QVAD Support, this was needed to ensure statewide access despite the HSD and other initiatives like the QVAD Access travel scheme (similar to other states).

This research also identified challenges for Queensland's VAD implementation. A key issue is resourcing, particularly in HHSs where the model of care was reportedly tokenistic. Limited guidance in the HSD about the content of models of care led to significant variation. Greater direction about minimum requirements for a local VAD service may be beneficial, informed by research about optimal models of care.

Further, a larger VAD workforce is needed, even in HHSs with well-established VAD services, to meet 'significant'[4] demand and for workforce sustainability, a recognised issue nationally.[4,13,19,26,27] Initiatives in some HHSs of increased medical appointments and making VAD roles permanent are important to consider. Resourcing and sustainability are also important for QVAD SPS as their practitioner administration roles are time and resource intensive. Additional HHS VAD capability may assist with reducing this load, as may QVAD SPS's efforts to build local capacity.

Resourcing also includes seeking opportunities for greater private sector participation, particularly through primary care. While reliable public sector access should be preserved to ensure equity, access is enhanced when VAD is available in a range of settings. GPs are the first port of call for many patients,[12] but a key barrier is the lack of remuneration, particularly from Medicare.[26] More research on the lack of VAD provision outside the public sector in Queensland is needed.

Limitations

A study strength is recruitment reach with participants from 15 of 16 Queensland's HHSs, as well as a considerable number of QVAD SPS staff. However, participants were all employees of Queensland Health and so had limited insight into VAD in the private sector (albeit a very small component of VAD in Queensland). Another strength is that this is the first reported study of Queensland VAD practice. However, the VAD system's first year of operation represents a point in time and (as participants noted) the system is evolving. Finally, most participants were nurses and perspectives of other key participants, particularly doctors, are needed (Ley Greaves L, Willmott L, Feeney R, White BP, unpubl. data).

Conclusion

Despite Australian states having similar VAD laws,[2] implementation has a significant impact on VAD practice. Key differences in Queensland's VAD system stem from its HSD mandating all HHSs to have a model of care for public access to VAD and its distinctive QVAD SPS. This has led to enhanced statewide access to VAD and through the public sector, and an increased role in VAD for nurse practitioners and nurses. However, resourcing and consistency in VAD provision remain challenging. More research is needed as to what constitutes an optimal model of care for VAD services.

Supplementary material

Supplementary material is available online.

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Data availability. The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions. The interview guide is available in Supplementary material file S1.

Conflicts of interest. Ben P. White and Lindy Willmott have received funding to conduct research on VAD from the Australian Research Council, state governments (including the Queensland Government) and philanthropic organisations. They were also engaged by three Australian state governments (Victoria, Western Australia and Queensland) to develop the legislatively mandated training for health practitioners providing VAD in those states. Lindy is a member of the Queensland Voluntary Assisted Dying Review Board, the oversight body in Queensland. Rachel Feeney was engaged as a clinical consultant for the VAD Training Education Module for Healthcare Workers in Queensland. Laura Ley Greaves was employed by a Queensland HHS for the purpose implementing VAD and has also been engaged in VAD training projects.

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