Regulating voluntary assisted dying in Australia: some insights from the Netherlands

Over two decades of Dutch experience can inform deliberations about the nature of a regulatory framework in Australian jurisdictions

The Victorian *Voluntary Assisted Dying Act 2017* (VAD Act), which commenced on 19 June 2019, permits voluntary assisted dying (VAD) in limited circumstances in Victoria. In addition to Victoria, the Western Australian government is currently developing its own VAD legislation, and Parliamentary committees have been established in Queensland and South Australia to consider reform. Although repeated attempts to reform the law have been generally unsuccessful,[1] it now appears legislation may be more likely to pass.[2]

For other Australian states, the Victorian law may be seen as a departure point for designing legislative reform. When the Victorian Bill was debated in Parliament, it was heralded as "the safest, and most conservative model in the world" with 68 safeguards.[3] These safeguards were designed to protect vulnerable individuals, but also to navigate the politics of controversial legislation. Our goal in this article is to inform the VAD debate in Australia with insights from the Netherlands. There, euthanasia and physician-assisted suicide (the terms used for VAD in the Netherlands) have been regulated for over 25 years through a combination of prosecutorial guidance, the Termination of Life on Request and Assisted Suicide (Review Procedures) Act (since 2002) and, more recently, the Euthanasia Code 2018.[4] Australian legislators can learn much from the many Dutch experiences and studies of the practical operation of their laws. Here we focus on three issues: the requirement of pre-authorisation, the choice between self-administration and practitioner administration by a doctor, and the importance of transparency and evaluation studies.

Pre-authorisation requirement for VAD

Pre-authorisation of VAD is one safeguard in the Victorian legislation. The coordinating doctor must review all relevant documentation, complete a final review form and apply for a permit from the Secretary of the Department of Health and Human Services. In doing this, the doctor must be satisfied the Act's requirements have been met, including a first request by a patient, eligibility assessments by two doctors, a written declaration by the patient, the appointment of a contact person, and the making of a final request. The Secretary must then determine whether to issue a permit within 3 business days (regulation 7, Voluntary Assisted Dying Regulations 2018).

Our concerns about pre-authorisation are twofold. The first is the extra time this process will take. Existing safeguards require at least 9 days between a patient's first request and the final request (although this can be abridged if the patient is likely to die within the 9 days), and at least one day between the second doctor's assessment and the final request (section 38, VAD Act). Permitting a further 3-day delay for consideration by the Secretary may cause hardship for a terminally ill patient who is suffering and unnecessarily impede access to VAD. The second point concerns the utility of the Secretary's review. It appears that the review's purpose is ensuring all paperwork has been appropriately completed rather than reviewing individual cases, including checking the reliability of eligibility assessments. If so, this raises doubts about the effectiveness of such a safeguard, particularly given the delays it will cause.

In the Netherlands, although patients need not be terminally ill to be eligible, the majority of patients who receive euthanasia or physician-assisted suicide have a short estimated life expectancy: a week or less for 36%, 2–4 weeks for another 36%, 1–6 months for 19% and more than 6 months for 8%.[5] Another study showed that for over half of patients (62%), the time between the first explicit request and the time of administering euthanasia or assisting in suicide was 1 month or less.[6] Dutch data also reveal that for about a quarter of all euthanasia requests, the patient died before the physician decided whether or not to grant the request or between granting the request and performing euthanasia.[7]

These data combined suggest that the pre-authorisation requirement may adversely affect patients, especially more severely ill ones, from receiving an assisted death. This may be particularly problematic when a limited life expectancy is an eligibility criterion, as it is in Victoria, especially as it is known that physicians tend to overestimate life expectancy in seriously ill patients.[8] In the Netherlands, legislators considered pre-authorisation as a safeguard before enacting its legislation. However, because of the above described risk of assistance to die not being available to the most severely ill, the focus of safeguards shifted instead to consultation of a second doctor. Over time, the consultation process has been strengthened by a national program to provide trained and experienced independent doctors as consultants (Support and Consultation on Euthanasia in the Netherlands [SCEN] doctors).[9,10]

Administration by patient or doctor

The default method of VAD under the Victorian framework is self-administration. While a doctor may be present, this is not required. Practitioner

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administration by a doctor is permitted only if the patient "has lost the physical capacity to self-administer or digest" the medication (section 53, VAD Act). The legislation also does not allow a doctor to assist a patient to die who has unsuccessfully attempted self-administration; for example, when a patient vomits the medication.

We have concerns about the Victorian approach, and instead favour patient choice between practitioner administration and self-administration, but under medical supervision. While self-administration promotes autonomy to the extent that patients are completely in control of the timing of their death and do not have to work around the convenience of a medical practitioner, we argue that allowing a choice of method promotes patient autonomy to a greater degree. As evidenced by the Dutch experience (below), this approach would also improve patient safety and ensure a chain of custody for lethal medication.

In the Netherlands, while both euthanasia (practitioner-assisted) and assisted suicide (self-administration) is permitted, the incidence of self-administration is very low. In 2017, 6306 cases of euthanasia, 250 cases of assisted suicide, and 29 cases involving a combination of both were reported to review committees in the Netherlands.[11] Indeed, the guidelines of the Royal Dutch Medical Association originally indicated a preference for assisted suicide because it confirmed the patient request, but ultimately omitted this because it did not happen in practice. Practitioner administration is preferred in the Netherlands for a range of reasons. First, about half of the patients are too weak to self-administer. Second, doctors prefer to control the process or take responsibility for effective provision of VAD.[12] Third, and related to the second reason, complications occur more frequently in self-administration; in about 10% of cases there are technical difficulties, such as difficulty in swallowing, and in about 9% of cases there are complications such as vomiting.[13] As a final point of contrast, the Dutch guidelines state that if self-administration fails (eg, the patient cannot finish the drink, vomits or does not die within a certain time frame), the doctor has an obligation to administer the medication.[14] Some of the 29 reported cases of a combination of assisted suicide and euthanasia in 2017 are likely to be such cases.

Transparency and evaluation

The Victorian legislation contains a range of oversight and review mechanisms but two are particularly important for current purposes. The first is the Voluntary Assisted Dying Review Board, which has oversight of the legislative scheme. The Board reviews each death and provides an annual report to Parliament regarding the operation of the legislation (section 108, VAD Act). It must also retain statistical information about the numbers of permits issued and deaths through VAD, as well as information in relation to matters such as patient characteristics (section 117, VAD Act). This information will be publicly available. A second important aspect of review is the statutory requirement for the Minister for Health to review the operation of the legislation after 5 years (section 116, VAD Act). Much can be learnt from the Netherlands regarding both transparency and evaluation of the legislative framework.

Transparency of the sensitive practice of euthanasia has always been an important policy goal in the Netherlands. Transparency is important to ensure community confidence and trust that the VAD system is operating as it should. To this end, the Regional Euthanasia Review Committees publish annual reports,[11] and provide anonymised judgements of reported cases (including in English) on their website.[15] In addition, the government funds an evaluation of the law by independent researchers every 5 years. The research considers the nature of the review processes by the Committees, any litigation that has occurred, as well as the way the law works in practice. This has resulted in a wealth of empirical data, including some of those cited in this article. This evaluation and research is important not only for transparency, but also to drive improvements in practice. One example is the code of practice written by the Committees, following a recommendation of the evaluation study, to support consistency in practice by doctors in assessing patient eligibility.[4]

Conclusion

As other Australian states consider reform to permit VAD, debate about how best to regulate this practice will continue. In particular, how can a system best facilitate safe and timely access to VAD for eligible patients but ensure that others who are not eligible do not have access?[16] While Victoria's VAD legislation will of course be considered, its potential limitations must be weighed. Drawing on Dutch experience and data, we raise safety and access concerns both in relation to the need for pre-authorisation of VAD and limiting access to practitioner administration of the VAD medication. Regardless of the model adopted, accountability in how the system operates is essential. A key learning from the Dutch experience is that rigorous evaluation of VAD is critical to promote transparency in decision making in the system and to drive practice improvements.

Competing interests: Ben White and Lindy Willmott have been engaged by the Victorian Government to design and provide the legislatively mandated training for doctors involved in voluntary assisted dying. Lindy Willmott is also a member of the board of Palliative Care Australia, but this article only represents her views.

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