Participating doctors' perspectives on the regulation of voluntary assisted dying in Victoria: a qualitative study

Lindy Willmott¹, Ben P White¹, Marcus Sellars^{1,2}, Patsy M Yates³

The known: Victoria is the first Australian state to enact voluntary assisted dying legislation. The *Voluntary Assisted Dying Act 2017* (Vic) includes many safeguards to ensure that only eligible patients receive assistance to die.

The new: Doctors who have participated in voluntary assisted dying have mixed views about the operation of the system and its safeguards. Restrictions on initiating conversations with patients and limiting interactions to face-to-face meetings cause concern, as do practical problems related to system software and documentation requirements.

The implications: The Victorian voluntary assisted dying system should be reviewed to improve its processes and its access to eligible patients. Other Australian states can learn from the Victorian experience.

oluntary assisted dying became lawful in Victoria in June 2019 when the *Voluntary Assisted Dying Act* 2017 (Vic) (the Act) commenced operation.¹ To 31 December 2020, there had been 224 deaths under the Act.² Other Australian states have already or are likely to legalise voluntary assisted dying in the near future.³⁻⁷

The Victorian legislation aims to facilitate access to voluntary assisted dying, but only for eligible patients. ^{8,9} The Act achieves this balance with 68 safeguards, making it the "safest, and most conservative model in the world". ¹⁰

Doctors are central to voluntary assisted dying. They assess patient eligibility, either as coordinating practitioners (the first doctor who assesses the patient) or consulting practitioners (the second doctor, who provides an independent eligibility assessment). Doctors accompany a patient on their complex journey from the initial discussion of voluntary assisted dying to the final provision of the medication. Their perceptions of the operation of the legislation in practice are therefore critical.

In this article, we report the perspectives of doctors who have participated in the voluntary assisted dying process in Victoria during the first year of its operation.

Methods

We report our study according to the Consolidated Criteria for Reporting Qualitative Health Research. ¹¹ Eligible doctors were those who had been involved in voluntary assisted dying in Victoria since the *Voluntary Assisted Dying Act 2017* (Vic) commenced operation, as either coordinating or consulting doctors for patients who had requested voluntary assisted dying. Potential participants could be identified because doctors are legally required to complete a specific training program before assessing the eligibility of patients for voluntary assisted dying;

Abstract

Objectives: To investigate the perspectives of doctors involved with voluntary assisted dying in Victoria regarding the *Voluntary Assisted Dying Act 2017* (Vic) and its operation.

Design, setting, participants: Qualitative study; semi-structured interviews with 32 doctors who had participated in the voluntary assisted dying system during its first year of operation (commenced 19 June 2019). Doctors were interviewed during April–July 2020.

Results: Three major themes related to problems during the first year of operation of the Act were identified: the statutory prohibition of health professionals initiating discussions with their patients about voluntary assisted dying; the Department of Health and Human Services guidance requirement that all doctor-patient, doctor-pharmacist, and pharmacist-patient interactions be faceto-face; and aspects of implementation, including problems with the voluntary assisted dying online portal, obtaining documentary evidence to establish eligibility, and inadequate resourcing of the Statewide Pharmacy Service.

Conclusions: Doctors reported only limited concerns about the Victorian voluntary assisted dying legislation, but have had some problems with its operation, including implications for the accessibility of voluntary assisted dying to eligible patients. While legislative change may resolve some of these concerns, most can be ameliorated by improving the processes and systems.

doctors who had consented to contact about future research were invited by email to participate in our study. In addition, we used both purposive and snowball sampling to capture a range of experiences, including number of cases of voluntary assisted dying, role (coordinating, consulting doctor), years of medical experience, speciality, location (regional, metropolitan), age, and sex.

We developed an interview guide (online Supporting Information), based on our analysis of the policy goals underlying the Act⁹ and discussion by the research team, to explore participants' perceptions of a range of regulatory matters, including eligibility assessments, request and assessment processes, reporting obligations, administering the medication, and whether the legislation achieved its policy goals of balancing safeguards and providing access to eligible patients.

Author MS conducted semi-structured interviews with each participant during 14 April – 24 July 2020 on the video conferencing platform Zoom or by telephone. Recruitment ceased when theoretical saturation was reached. All interviews were digitally audio-recorded and transcribed verbatim. Individual transcripts were provided to participants to view and amend (member checking).

We used NVivo Plus 12 (QSR International) to store, code, and search transcripts. Author MS applied thematic analysis ¹² to code the transcripts line by line and to inductively identify concepts

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describing participants' experiences and perspectives of how the Act was operating in practice. Similar concepts were subsequently grouped as themes, and, with the assistance of authors LW and BW, MS developed a coding structure to capture concepts related to participants' experiences and perspectives on global regulatory aspects of voluntary assisted dying. Despite the breadth of topics covered in the first round of coding (including concerns about assessing patient eligibility), and to avoid an overly simplified overall description of the participants' views, ¹³ MS undertook a second round of coding, using a coding framework that mapped each of the global regulatory aspects of voluntary assisted dving (developed with LW and BW, based on their previous research into mapping these domains⁹). These two rounds of coding permitted analysis in relation to both specific aspects of the regulatory framework identified as problematic (reported here) and broader thematic trends (to be reported separately).

Our results were independently verified for the presence of themes by LW and BW, and discrepancies were resolved by consensus. After key themes were identified, LW re-examined the data and manually coded themes.

Ethics approval

The Queensland University of Technology Human Research Ethics Committee approved our study (2000000033). Informed consent was obtained before each interview.

Results

As of 18 June 2020, 106 of 228 doctors who had undergone training for assessing the eligibility of patients for voluntary assisted dying had consented to being contacted about future research (46%) and were invited to participate in the study. Seventeen doctors responded that they were not eligible for participation because they had not been involved in voluntary assisted dying. Of the 106 doctors who consented to being contacted about future research and those contacted through snowball sampling, 12 vocationally registered general practitioners and 20 medical specialists participated in our study (Box). Participants had been involved in a median of six cases (interquartile range [IQR], 3–13.5 cases). The median duration of the interviews was 62.5 minutes (IQR, 55.2–72.5 minutes).

We identified three major themes related to problems during the first year of operation of the Act: the prohibition of health professionals initiating conversations with their patients about voluntary assisted dying; the requirement for face-to-face engagement only (based on the intersection of the Act with the Australian *Criminal Code Act 1995*);¹⁴ and broader implementation problems. Sample comments by participants are included in the online Supporting Information.

Prohibition of health professionals initiating conversations about assisted dying

Section 8(1) of the Act prohibits initiating a discussion about voluntary assisted dying:

A registered health practitioner who provides health services or professional care services to a person must not, in the course of providing those services to the person:

- a $\,$ initiate discussion with that person that is in substance about voluntary assisted dying; or
- $b \;\; \text{in substance, suggest voluntary assisted dying to that person.}^{1}$

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	Radiation oncology	2
No. 1	Haematology	1
Nepnrology 1	Nephrology	1
Anaesthetics 1	Anaesthetics	1
Palliative care 1	Palliative care	1
Surgery 1	Surgery	1
Location (region)	Location (region)	
Major city 19	Major city	19
Inner regional 12	Inner regional	12

Outer regional

The policy aim of this prohibition is to guard against undue influence by health professionals. Some doctors expressed concerns this could prevent a patient making an informed choice about treatment options, particularly patients from non-English speaking backgrounds or people with poor health literacy; that is, people less likely to learn about voluntary assisted dying from the media or other sources. Some doctors felt "morally compromised", "deceitful", or "intellectually dishonest" withholding information about voluntary assisted dying. Other participants felt this prohibition was an appropriate safeguard against unduly influencing patients, as doctors "have a lot more influence than we realise". Because of this prohibition, doctors described patients as inevitably self-selecting. For some, this made the conversation easier, as only patients who at least knew a little about voluntary assisted dying could request it.

Requirement that all interactions be face-to-face

The guidance provided by the Victorian Department of Health and Human Services requires face-to-face consultations between doctors and patients, doctors and pharmacists (including discussions about the content of voluntary assisted dying prescriptions and the transmission of prescriptions to pharmacists), and between pharmacists and patients. The guidance reflects concerns that doctors and pharmacists might breach federal law should they use a "carriage service" (eg, telephone, email, or telehealth facilities) to discuss "suicide" (*Criminal Code Act 1995*, sections 474.29A and 474.29B), ¹⁴ even if acting lawfully under the Act. ^{16,17}

Many participants criticised the burden this requirement placed on doctors, pharmacists and patients, particularly patients in rural and remote areas, a burden exacerbated during the coronavirus disease 2019 (COVID-19) epidemic in 2020. Doctors spoke of the immense burden for very sick patients required to travel, sometimes for hours and several times, for eligibility assessments. Some also noted the burden on already busy doctors who travelled long distances to undertake assessments. Others saw merit in stipulating at least one face-to-face consultation in which they could assure themselves that the request for assisted dying was genuinely voluntary. They regarded telehealth interactions as having significant limitations, a "second rate solution" suitable only for complex cases in which face-to-face consultations were not possible.

Concerns were also expressed about requiring doctors and pharmacists to meet personally to transfer the prescription for the voluntary assisted dying medication; that is, not permitting the coordinating doctor to email it to the pharmacist. Requiring pharmacists to meet face-to-face with patients also had practical implications in terms of delays in providing voluntary assisted dying.

Implementation of the Act

Participants largely mentioned systems problems rather than the safeguards included in the Act. Three major sub-themes were identified.

First, process problems included its complexity, particularly the many forms required. However, some noted this became less of a challenge as their familiarity with the forms and requirements grew. Some doctors also expressed frustration about perceived "pedantic" checking of forms by Safer Care Victoria that did not clearly make the system safer. The frequent rejection of submitted forms caused delays, often with serious consequences for eligible terminally ill patients who had been assessed as having intolerable suffering.

This frustration was compounded by difficulties with the online portal through which doctors were required to lodge the various forms. They felt that the portal was badly designed, counterintuitive in its layout, and difficult to navigate. Concerns were also expressed about technical problems with uploading documents, with implications for busy clinicians. Some doctors suggested better training and guidelines on how to use the portal could reduce these difficulties. Despite widespread reservations about the process, some doctors noted that with time they became more efficient in navigating the portal.

Second, doctors described difficulties in generating required documentation for assessing eligibility, particularly proof that a person was an Australian citizen or permanent resident and had been ordinarily resident in Victoria for the 12 months before making a first request for voluntary assisted dying (*Voluntary Assisted Dying Act 2017* (Vic), section 9). Some felt this effectively locked out patients who had lived in Victoria throughout their adult lives but could not provide documentary proof of these requirements. For those able to provide proof, compiling it could cause delays. Obtaining documentation is especially difficult at the end of life, a chaotic time for many people.

Third, after a permit for voluntary assisted dying has been issued by the Department of Health and Human Services secretary, the Statewide Pharmacy Service liaises with the doctor when the required prescription is written and meets with the doctor or patient (according to what is appropriate) when the medication is delivered. While participants praised the quality of their interactions with the Statewide Pharmacy Service, they generally believed that it was inadequately resourced and that this caused considerable delays, both in writing and transmitting the prescription and in delivering the medication to the doctor or patient.

Discussion

All governments considering voluntary assisted dying reform must strike a balance between promoting patient autonomy through accessibility and restricting its availability to eligible people, thereby ensuring that the system is safe. Compared with those of other countries, the Victorian system is more highly regulated, as illustrated by the requirement to obtain a permit before providing assistance to die.⁸

Safety can be achieved with legislative safeguards or by system design. The safeguards embedded in the Victorian system indicate the focus on safety. Some participants commented that the detailed checks and balances provided them with the confidence to participate in the system. However, it is also important to reflect on how the system operates in practice. Making voluntary assisted dying accessible to eligible patients will not be achieved if doctors find the system too onerous to navigate or if some patients die before receiving the medication.

We found that doctors perceived some important shortcomings in the current system. The implementation of the Act was strongly criticised, particularly the usability of the system portal. These challenges were burdensome for doctors and families, and increased patient and family suffering, sometimes leading patients to abandon the process or their deaths before obtaining the medication. In a case that illustrates this point, a coordinating doctor applied to the Victorian Civil and Administrative Tribunal after several requests by Safer Care Victoria for further evidence of Victorian residency during the preceding 12 months of an applicant; the tribunal determined that, based on

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the information available by the time of its determination, the residency criterion had been satisfied. $^{18}\,$

Two of the authors of the current article have previously noted that it is important that any complexity in system design be internally facing; that is, not experienced by patients or doctors. Some strategies to improve the process for doctors could be simple, such as providing information about how the portal operates and the nature of the required documentation. Doctors reported that system useability increased with practice, but early support would have been useful.

The second major problem identified by participants was the Department of Health and Human Services requirement that all consultations be undertaken in person to avoid potential liability under federal law. Whether this concern is legally justified awaits authoritative legal determination, but doctors or pharmacists who engage in electronic communication about "suicide" are at legal risk, ²⁰ particularly as departmental guidance prohibits such interaction. The Commonwealth legislation should be amended to remove this risk and to avoid unnecessary burdens on doctors and terminally ill patients. While good medical practice dictates that many consultations should be in person, doctors should be permitted to exercise clinical judgement about the format of their consultations.

The final concern — the prohibition of initiating conversations about voluntary dying — refers to the content of the law rather than its implementation. This concern is consistent with good medical practice and published evidence for the importance of honest and open communication, including providing patients with a range of treatment options and information on their risks and benefits.²¹ However, participants differed on whether doctors should be permitted to initiate discussions, some believing the prohibition was an important protection against coercion, and suggested they would not be prepared to participate in the system without this prohibition. In Western Australia, the legal prohibition is narrower and does not prevent a treating doctor initiating discussion of voluntary assisted dying with a patient (section 10). But if they do so, they must also provide information about other treatment options, including palliative care, as well as the likely outcomes.

Implications and limitations

As with all new systems, the voluntary assisted dying system in Victoria could be improved. Section 116 of the Act

requires the Health Minister to review the legislation after four years of operation. Our findings suggest that the process should be improved and participating doctors better supported.

Our findings also provide useful insights for Western Australia and Tasmania during their implementation phases, and for other states considering similar legislation. However, the problems identified by our Victorian study may not arise in other jurisdictions with different approaches to implementation. Further, our findings are based on the perceptions, experiences, and expertise of the doctors we interviewed, and they may not be representative of all doctors involved in the voluntary assisted program process. For instance, we recruited no neurologists, although several participants had acted as coordinating or consulting doctors for patients with neurological illnesses.

Conclusion

Safeguards ensure that systems for providing voluntary assisted dying are safe for patients and their communities. Procedural processes and delays that ensure that only eligible patients have access to assisted dying and that their requests are genuinely voluntary and enduring can be justified. However, the system must also be efficient and help doctors navigate the process. It is therefore important to consider the perceived shortcomings reported by participating doctors. While some problems might be resolved by amending the legislative framework, others might be more readily remedied by practical support for doctors, including clear guidance about using the voluntary assisted dying portal, particularly during their initial use of the system, and adjustments in system design.

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Supporting Information

Additional Supporting Information is included with the online version of this article.