

## **'REGULATORY ACTION' BY PATIENTS AND FAMILY CAREGIVERS TO OVERCOME BARRIERS TO ACCESSING VOLUNTARY ASSISTED DYING: A QUALITATIVE STUDY IN VICTORIA, AUSTRALIA**

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*Voluntary assisted dying ('VAD') commenced in Victoria, Australia, in 2019. Drawing on qualitative interviews, we investigate how patients' and family caregivers' actions to overcome access barriers may be conceived of as 'regulatory'. We adopt Julia Black's definition of regulation as sustained, focused, and intentional action to alter behaviour. Participants performed various actions to overcome access barriers, primarily motivated by a desire to support VAD access for individual patients. However, many participants sought to make the VAD system better for others. Participants perceived their actions improved individual experiences of VAD and sometimes also altered the behaviour of key participants in Victoria's VAD system or impacted the system more broadly. Patients and family caregivers should have opportunities to be involved in regulation if they wish. However, consideration must be given to addressing VAD access barriers to reduce the burden on patients and family caregivers of having to take action to overcome these barriers.*

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## I INTRODUCTION

Victoria was the first Australian state to legalise voluntary assisted dying ('VAD') (known elsewhere as euthanasia, physician-assisted suicide, or medical assistance in dying) after passing the *Voluntary Assisted Dying Act 2017* (Vic) ('*VAD Act*'). Patients and family caregivers were central to the process of legalising VAD in Victoria, which reflects the shift towards placing consumers at the centre of healthcare decision-making, research, and reform.<sup>1</sup> VAD laws have now passed in all Australian states and the Australian Capital Territory,<sup>2</sup> and Australia joins a growing number of jurisdictions internationally to allow some form of VAD, including the Netherlands, Belgium, Canada, Spain, and various states in the United States.<sup>3</sup>

Two dominant policy goals of the *VAD Act* are to respect individual autonomy (to choose the manner and timing of death), and to safeguard vulnerable people and the community.<sup>4</sup> The potential risks if VAD regulation is unsafe or of poor quality are significant, and the importance of avoiding potential misuse of such laws, including coercion of vulnerable people to access VAD, were identified as critical when designing Victoria's VAD system.<sup>5</sup> Because of this, considerable emphasis in Victoria has been placed on the '68 safeguards' in the *VAD Act*.<sup>6</sup> The safeguards in the *VAD Act* include: strict eligibility criteria; a prohibition on registered health practitioners initiating VAD discussions with patients; a rigorous request and assessment process; and oversight throughout the process by the state's Voluntary Assisted Dying Review Board. Table 1 provides an overview of some key aspects of the *VAD Act*.

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- 1 Margaret M O'Connor et al, 'Documenting the Process of Developing the Victorian Voluntary Assisted Dying Legislation' (2018) 42(6) *Australian Health Review* 621, 622 <<https://doi.org/10.1071/AH18172>>.
  - 2 Katherine Waller et al, 'Voluntary Assisted Dying in Australia: A Comparative and Critical Analysis of State Laws' (2023) 46(4) *University of New South Wales Law Journal* 1421, 1423; *Voluntary Assisted Dying Act 2023* (ACT).
  - 3 Joachim Cohen and Kenneth Chambaere, 'Increased Legalisation of Medical Assistance in Dying: Relationship to Palliative Care' (2023) 13(2) *BMJ Supportive and Palliative Care* 178, 178–9 <<https://doi.org/10.1136/bmjspcare-2022-003573>>.
  - 4 Ben P White et al, 'Does the *Voluntary Assisted Dying Act 2017* (Vic) Reflect Its Stated Policy Goals?' (2020) 43(2) *University of New South Wales Law Journal* 417, 427 <<https://doi.org/10.53637/QEQJ5610>> ('Stated Policy Goals').
  - 5 Ibid 425–6; Department of Health and Human Services, Parliament of Victoria, *Ministerial Advisory Panel on Voluntary Assisted Dying* (Final Report, 21 July 2017) 44–5 <<https://content.health.vic.gov.au/sites/default/files/migrated/files/collections/research-and-reports/m/ministerial-advisory-panel-on-voluntary-assisted-dying-final-report-pdf.pdf>>.
  - 6 Rosalind McDougall and Bridget Pratt, 'Too Much Safety? Safeguards and Equal Access in the Context of Voluntary Assisted Dying Legislation' (2020) 21(1) *BMC Medical Ethics* 38:1–10, 1 <<https://doi.org/10.1186/s12910-020-00483-5>>.

Table 1: Overview of Key Aspects of the VAD Act

Aspect of Process	Summary of VAD Act Provisions
Discussions about VAD (Section 8 of the VAD Act)	<ul style="list-style-type: none"> <li>• Registered health practitioners cannot initiate discussions about VAD or suggest VAD to a person in the course of providing health or personal care services.</li> </ul>
Eligibility Criteria (Section 9 of the VAD Act)	<ul style="list-style-type: none"> <li>• To be eligible for access to VAD, a person must:               <ol style="list-style-type: none"> <li>1. be aged 18 years or more;</li> <li>2. be an Australian citizen or permanent resident;</li> <li>3. be ordinarily resident in Victoria for at least 12 months at the time of making a first request;</li> <li>4. have decision-making capacity in relation to VAD; and</li> <li>5. be diagnosed with a disease, illness or medical condition that is:                   <ol style="list-style-type: none"> <li>a) incurable;</li> <li>b) advanced, progressive and will cause death;</li> <li>c) is expected to cause death within 6 months (or 12 months, for neurodegenerative diseases, illnesses or medical conditions); and</li> <li>d) is causing suffering to the person that cannot be relieved in a manner the person considers tolerable.</li> </ol> </li> </ol> </li> </ul>
Request and Assessment Process <sup>7</sup> (Part 3 of the VAD Act)	<ul style="list-style-type: none"> <li>• A person may access VAD if:               <ol style="list-style-type: none"> <li>1. they have made three requests for VAD (a first request, written declaration, and final request);</li> <li>2. they have been assessed as eligible for access to VAD by two eligible medical practitioners who have completed mandatory training (called the coordinating medical practitioner, who completes the first assessment, and the consulting medical practitioner, who completes the consulting assessment);</li> <li>3. they have appointed a contact person;</li> <li>4. the co-ordinating medical practitioner has completed the final review, certifying the process was in accordance with the VAD Act; and</li> <li>5. they have been issued with a permit by the Department Head of the Department of Health and Human Services.</li> </ol> </li> <li>• The person must also understand specific information, and their request must be enduring, and they must be acting voluntarily and without coercion.</li> <li>• The written declaration must be witnessed by two independent, eligible witnesses.</li> <li>• The person must have decision-making capacity, including at the time of administration.</li> </ul>

7 All aspects of the request and assessment process must occur in person due to a prohibition on using telehealth issued by the Victorian Government, in response to the *Criminal Code Act 1995* (Cth) provisions. See Department of Health and Human Services (Vic), 'Voluntary Assisted Dying: Guidance for Health Practitioners' (Guidelines, July 2019) 4 <<https://www.health.vic.gov.au/publications/voluntary-assisted-dying-guidance-for-health-practitioners>>; Eliana Close et al, 'Voluntary Assisted Dying and Telehealth: Commonwealth Carriage Service Laws Are Putting Clinicians at Risk' (2021) 215(9) *Medical Journal of Australia* 406 <<https://doi.org/10.5694/mja2.51287>>.

Aspect of Process	Summary of VAD Act Provisions
Permit Approval (Part 4 of the VAD Act)	<ul style="list-style-type: none"> <li>• A self-administration or practitioner administration permit must have been issued in relation to the person by the Department Head of the Department of Health and Human Services before the person is authorised to access VAD.</li> </ul>
Administration (Parts 4 and 5 of the VAD Act)	<ul style="list-style-type: none"> <li>• The default method of administration is self-administration.</li> <li>• Practitioner administration is only permissible if the person is physically incapable of self-administering or digesting the VAD substance.</li> <li>• For practitioner administration, the person must make an administration request and administration must be witnessed by an independent witness.</li> <li>• The VAD substance is managed by a coordinated, statewide pharmacy service.</li> <li>• The contact person has obligations in relation to the VAD substance, including returning any unused or remaining VAD substance to the dispensing pharmacy.</li> </ul>
Oversight (Parts 6 and 9 of the VAD Act)	<ul style="list-style-type: none"> <li>• The VAD Act establishes the VAD Review Board as the oversight body to review VAD cases in Victoria. Forms must be completed and uploaded to an electronic portal at certain steps in the process and are reviewed by the VAD Review Board.</li> <li>• Some decisions made during the request and assessment process are reviewable by the Victorian Civil and Administrative Tribunal.</li> <li>• The contact person is contacted by the VAD Review Board to provide feedback and has other reporting obligations.</li> </ul>

While safety is undoubtedly critical, safeguards must also be balanced to ensure the system facilitates access to VAD for eligible people who wish to access this option, and achieve the other dominant policy goal of respecting autonomy.<sup>8</sup> Linked to this concept of respecting autonomy by supporting access is a third policy goal of the *VAD Act*: promoting high-quality care.<sup>9</sup> This includes supporting quality therapeutic relationships and patient-centred experiences in line with the preferences and choices expressed by the individual.<sup>10</sup>

There is very limited research examining patient and family experiences and perspectives on how Victoria's VAD system (which commenced on 19 June 2019) is operating in practice.<sup>11</sup> Existing studies highlight significant barriers to access

8 White et al, 'Stated Policy Goals' (n 4) 427; Margaret O'Connor et al, 'Implementing Voluntary Assisted Dying in Victoria, Australia' (2021) 36(3) *International Journal of Health Planning and Management* 602 <<https://doi.org/10.1002/hpm.3126>>; Ben P White, Lindy Willmott and Eliana Close, 'Victoria's Voluntary Assisted Dying Law: Clinical Implementation as the Next Challenge' (2019) 210(5) *Medical Journal of Australia* 207 <<https://doi.org/10.5694/mja2.50043>>.

9 White et al, 'Stated Policy Goals' (n 4) 424.

10 Ibid.

11 Ben P 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* 22:1–12 <<https://doi.org/10.1186/s12910-023-00902-3>> ('The Impact on Patients'); Ben P White et al, 'Access to Voluntary Assisted Dying: A Qualitative Study of Family Caregivers' Perceptions of Barriers and Facilitators'

faced by patients, and their family caregivers, seeking to access VAD.<sup>12</sup> These barriers include: difficulty finding doctors willing and trained to participate;<sup>13</sup> the prohibition on registered health practitioners raising VAD with patients;<sup>14</sup> the lengthy approval process and the consequent 'race' against time to access VAD, which is compounded by how unwell patients seeking VAD are;<sup>15</sup> the policy preventing the use of telehealth for VAD consultations due to the risk of breaching the *Criminal Code Act 1995* (Cth);<sup>16</sup> and institutional objections.<sup>17</sup> These barriers to access are also highlighted in reports issued by the VAD Review Board, including the sixth report for the period July 2021 to June 2022 and the seventh report for the period July 2022 to June 2023.<sup>18</sup> Additionally, patients and family caregivers have expressed issues relating to VAD access barriers in grey literature, such as stories and testimonies shared through prominent patient advocacy organisations, Dying With Dignity Victoria and Go Gentle Australia,<sup>19</sup> and in the media.<sup>20</sup> These concerns are also reflected in the emerging body of literature examining doctors' perspectives of Victoria's VAD system.<sup>21</sup> Overall, the early evidence from Victoria suggests that some patients experience significant barriers to access, with various

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(2023) 219(5) *Medical Journal of Australia* 211 <<https://doi.org/10.5694/mja2.52004>> ('Access to Voluntary Assisted Dying'); Ben P White et al, 'Barriers to Connecting with the Voluntary Assisted Dying System in Victoria, Australia: A Qualitative Mixed Method Study' (2023) 26(6) *Health Expectations* 2695 <<https://doi.org/10.1111/hex.13867>>.

12 White et al, 'The Impact on Patients' (n 11); White et al, 'Access to Voluntary Assisted Dying' (n 11).

13 White et al, 'Access to Voluntary Assisted Dying' (n 11) 212.

14 Ibid 213.

15 Ibid 212.

16 Ibid.

17 White et al, 'The Impact on Patients' (n 11) 4–6, 9; White et al, 'Access to Voluntary Assisted Dying' (n 11) 212–13.

18 Voluntary Assisted Dying Review Board, *Report of Operations: July 2021 to June 2022* (Annual Report, June 2022) ('2022 Annual Report') <[https://www.safercare.vic.gov.au/sites/default/files/2022-09/Voluntary%20Assisted%20Dying%20Review%20Board%20Report%20of%20Operations%20July%202021-June%2022\\_FINAL.pdf](https://www.safercare.vic.gov.au/sites/default/files/2022-09/Voluntary%20Assisted%20Dying%20Review%20Board%20Report%20of%20Operations%20July%202021-June%2022_FINAL.pdf)>; Voluntary Assisted Dying Review Board, *Annual Report: July 2022 to June 2023* (Report, June 2023) ('2023 Annual Report') <<https://www.safercare.vic.gov.au/sites/default/files/2023-08/VADRB%20Annual%20Report%202022-23.pdf>>.

19 'Personal Stories', *Dying With Dignity Victoria* (Web Page) <<https://www.dwdv.org.au/stories/>>; 'Testimonies', *Go Gentle Australia* (Web Page) <<https://www.gogentleaustralia.org.au/testimonies>>.

20 Madi Chwasta, 'Victoria's Voluntary Assisted Dying Program under the Spotlight after Regional Man's Long Wait', *ABC News* (online, 7 December 2022) <<https://www.abc.net.au/news/2022-12-06/zendaland-clark-voluntary-assisted-dying-victoria/101706420>>; Melissa Cunningham, 'Calls for Reform of State's Assisted Dying Law as Victorians Die in Peace and Heartbreak', *The Sydney Morning Herald* (online, 12 March 2023) <<https://www.smh.com.au/national/calls-for-reform-of-state-s-assisted-dying-law-as-victorians-die-in-peace-and-heartbreak-20230301-p5coh2.html>>.

21 Lindy Willmott et al, 'Participating Doctors' Perspectives on the Regulation of Voluntary Assisted Dying in Victoria: A Qualitative Study' (2021) 215(3) *Medical Journal of Australia* 125 <<https://doi.org/10.5694/mja2.51123>> ('Participating Doctors' Perspectives'); Ben P White et al, 'Prospective Oversight and Approval of Assisted Dying Cases in Victoria, Australia: A Qualitative Study of Doctors' Perspectives' (2024) 14(e1) *BMJ Supportive and Palliative Care* e1462 <<https://doi.org/10.1136/bmjspcare-2021-002972>> ('Prospective Oversight and Approval'); Jodhi Rutherford, 'Doctors and the Voluntary Assisted Dying Act 2017 (Vic): Knowledge and General Perspectives' (2020) 27(4) *Journal of Law and Medicine* 952; Cameron J McLaren and Greg Mewett, 'Update on Voluntary Assisted Dying in Australia' (2021) 215(3) *Medical Journal of Australia* 115 <<https://doi.org/10.5694/mja2.51152>>.

factors that mitigate the impact of those barriers on patients.<sup>22</sup> Of particular relevance here, the capability and assertiveness of patients and family caregivers were found to be factors mediating the negative impact of institutional objections on patients.<sup>23</sup>

Patients and family caregivers can make an important contribution to improving healthcare systems by sharing their voices and experiences.<sup>24</sup> Some scholars theorise that patient and family involvement (through advocacy, complaints, and other mechanisms) may even constitute ‘regulation’, namely ‘altering’ or ‘steering’ how the health care system operates and the behaviour of actors within it.<sup>25</sup> Regulation has historically often been thought of as law or formal rules enforced by the state aimed at governing behaviour, for example, the *VAD Act* in Victoria.<sup>26</sup> However, more recent scholarship acknowledges that other people, instruments, and forces beyond law or formal rules may influence how systems operate in practice and, therefore, constitute ‘regulation’.<sup>27</sup> The literature considering the potential role of patients and family caregivers as ‘regulatory actors’ is in its ‘infancy’.<sup>28</sup> A key author in this context is Judith Healy, who has argued that patients may be ‘regulatory actors’ by performing certain kinds of actions which she depicts on a pyramid.<sup>29</sup> Examples of actions provided by Healy that demonstrate how patients and family caregivers may steer behaviour include using ‘voice’ to make complaints about poor quality care (being ‘[v]ocal complainants’), and taking on roles, such as representatives on boards, and participating in decision-making about health services and individual healthcare (being ‘active partners’).<sup>30</sup> A singular agreed

22 White et al, ‘The Impact on Patients’ (n 11); White et al, ‘Access to Voluntary Assisted Dying’ (n 11).

23 White et al, ‘The Impact on Patients’ (n 11) 9.

24 Emma Richardson et al, ‘User Involvement in Regulation: A Qualitative Study of Service User Involvement in Care Quality Commission Inspections of Health and Social Care Providers in England’ (2019) 22(2) *Health Expectations* 245 <<https://doi.org/10.1111/hex.12849>>.

25 Judith Healy, ‘Patients as Regulatory Actors in Their Own Health Care’ in Peter Drahos (ed), *Regulatory Theory: Foundations and Applications* (Australian National University Press, 2017) 591 <<https://doi.org/10.22459/RT.02.2017>> (‘Patients as Regulatory Actors’); John Braithwaite, ‘Leading from Behind with Plural Regulation’ in Judith Healy and Paul Dugdale (eds), *Patient Safety First: Responsive Regulation in Healthcare* (Allen & Unwin, 1<sup>st</sup> ed, 2009) 24; Kristin Madison, ‘Patients as “Regulators”? Patients’ Evolving Influence over Health Care Delivery’ (2010) 31(1) *Journal of Legal Medicine* 9 <<https://doi.org/10.1080/01947641003598195>>.

26 Philip Selznick, ‘Focusing Organizational Research on Regulation’ in Roger G Noll (ed), *Regulatory Policy and the Social Sciences* (University of California Press, 1985) 363, 363.

27 Julia Black, ‘Critical Reflections on Regulation’ (2002) 27(1) *Australian Journal of Legal Philosophy* 1; Jacint Jordana and David Levi-Faur, ‘The Politics of Regulation in the Age of Governance’ in Jacint Jordana and David Levi-Faur (eds), *The Politics of Regulation: Institutions and Regulatory Reforms for the Age of Governance* (Edward Elgar Publishing, 2004) 1, 3–5 <<https://doi.org/10.4337/9781845420673.00009>>; Robert Baldwin, Martin Cave and Martin Lodge, ‘Introduction: Regulation’ in Robert Baldwin, Martin Cave and Martin Lodge (eds), *The Oxford Handbook of Regulation* (Oxford University Press, 2010) 3, 5–6 <<https://doi.org/10.1093/oxfordhb/9780199560219.003.0001>>; Christel Koop and Martin Lodge, ‘What Is Regulation? An Interdisciplinary Concept Analysis’ (2017) 11(1) *Regulation and Governance* 95 <<https://doi.org/10.1111/rego.12094>>.

28 Siri Wiig et al, ‘What Methods Are Used to Promote Patient and Family Involvement in Healthcare Regulation? A Multiple Case Study across Four Countries’ (2020) 20 *BMC Health Services Research* 616:1–15, 2 <<https://doi.org/10.1186/s12913-020-05471-4>> (‘What Methods Are Used?’).

29 Healy, ‘Patients as Regulatory Actors’ (n 25) 594.

30 *Ibid.*



definition of regulation is elusive, and other scholars may argue that some actions contemplated by Healy fall short of regulation.<sup>31</sup> According to Julia Black, another prominent regulatory scholar:

[R]egulation is the sustained and focused attempt to alter the behaviour of others according to defined standards or purposes with the intention of producing a broadly identified outcome or outcomes, which may involve mechanisms of standard-setting, information-gathering and behaviour-modification.<sup>32</sup>

We adopt Black's definition in this article. Where we use the term 'altering the behaviour of others', we do so in line with Black's definition of regulation.

Given the emerging evidence about barriers to accessing VAD in Victoria, the aim of this article is to investigate how patients and family caregivers who have been involved in seeking VAD act in response to their experiences, and the extent to which those actions might be conceived of as 'regulatory'. We seek to answer the research question: in what ways, if any, do patients and family caregivers act as 'regulatory actors' in voluntary assisted dying in Australia?

## II METHODS

### A Study Design

This study is nested within a broader international project investigating the regulation of VAD in Australia, Canada, and Belgium, the goal of which is to recommend an optimal model of VAD regulation.<sup>33</sup> This research is underpinned by a critical realist perspective.<sup>34</sup> We used Virginia Braun and Victoria Clarke's reflexive thematic analysis.<sup>35</sup> Aspects of reflexivity included: Ben P White ('BPW') and Ruthie Jeanneret ('RJ') conducting interviews together and debriefing after interviews to share thoughts in order to deepen the interpretation of data; maintaining a reflexive journal which was referred to throughout the data collection process; and iteratively testing results and findings in order to achieve a richer understanding of the data.

### B Eligibility and Recruitment

Individuals were eligible to participate in this study if they were over 18 and had been involved in VAD in Victoria as a patient or family caregiver. For patients,

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31 Madison (n 25); Black (n 27).

32 Black (n 27) 26.

33 Ben P White, Lindy Willmott and Eliana Close, 'Better Regulation of End-of-Life Care: A Call for a Holistic Approach' (2022) 19(4) *Journal of Bioethical Inquiry* 683 <<https://doi.org/10.1007/s11673-022-10213-8>>; 'Project', *Optimal Regulation of Voluntary Assisted Dying* (Web Page) <<https://research.qut.edu.au/voluntary-assisted-dying-regulation/project/>>.

34 Joseph A Maxwell, *A Realist Approach for Qualitative Research* (SAGE Publications, 2012).

35 Virginia Braun and Victoria Clarke, 'Using Thematic Analysis in Psychology' (2006) 3(2) *Qualitative Research in Psychology* 77 <<https://doi.org/10.1191/1478088706qp0630a>>; Virginia Braun and Victoria Clarke, 'Reflecting on Reflexive Thematic Analysis' (2019) 11(4) *Qualitative Research in Sport, Exercise and Health* 589 <<https://doi.org/10.1080/2159676X.2019.1628806>>; Virginia Braun and Victoria Clarke, *Thematic Analysis: A Practical Guide* (SAGE Publications, 2021) ('*Thematic Analysis*').

a person was eligible if they had requested VAD and started the assessment process, whether or not they had completed it or were approved as eligible. For family caregivers, a person was eligible to participate if they supported a patient meeting these criteria.

We recruited through two patient advocacy organisations, Dying With Dignity Victoria and Go Gentle Australia. We also utilised social media recruitment (including X, formerly known as Twitter) and snowball sampling.<sup>36</sup> We initially relied on convenience sampling, as individuals contacted us in response to study advertising shared through these platforms.<sup>37</sup> However, to ensure we recruited participants with diverse experiences and perspectives, we also used purposive sampling.<sup>38</sup> Primarily, we achieved this through advocacy organisations making direct contact with individuals known to them whose experiences and perspectives we were seeking for the research (for example, individuals from geographically diverse areas in Victoria).

### C Data Collection and Setting

Data were collected via qualitative semi-structured interviews conducted by RJ and BPW between 17 August 2021 and 25 October 2022. BPW led 17 interviews and RJ led 11 interviews, with the non-lead interviewer asking follow-up questions. BPW is an experienced qualitative researcher and led more early interviews, which formed part of RJ's research training. Interviews were conducted using Zoom (n=25), telephone (n=2), or in person (n=1). Zoom was primarily utilised due to considerations related to the COVID-19 pandemic. All interviews were audio-recorded; Zoom interviews were audio- and video-recorded, but the video was deleted to maintain participant confidentiality.

Interviews were semi-structured, which allowed flexibility, but conducted according to a robust procedure established in an interview protocol developed by the research team. An interview guide was used, which was discussed and iteratively updated. The research team debriefed after each interview to check for distress and reflect on the interview content. RJ and BPW maintained a reflexive journal throughout data collection.

Data collection ceased when the research team considered the dataset had sufficient 'information power' to meet the study aims and research questions.<sup>39</sup>

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36 Patrick Biernacki and Dan Waldorf, 'Snowball Sampling: Problems and Techniques of Chain Referral Sampling' (1981) 10(2) *Sociological Methods and Research* 141 <<https://doi.org/10.1177/00491241810100205>>.

37 Ilker Etikan, Sulaiman Abubakar Musa and Rukayya Sunusi Alkassim, 'Comparison of Convenience Sampling and Purposive Sampling' (2016) 5(1) *American Journal of Theoretical and Applied Statistics* 1 <<https://doi.org/10.11648/j.ajtas.20160501.11>>.

38 Ibid.

39 Braun and Clarke, *Thematic Analysis* (n 35); Virginia Braun and Victoria Clarke, 'To Saturate or Not to Saturate? Questioning Data Saturation as a Useful Concept for Thematic Analysis and Sample-Size Rationales' (2021) 13(2) *Qualitative Research in Sport, Exercise and Health* 201 <<https://doi.org/10.1080/02159676X.2019.1704846>>; Kirsti Malterud, Volkert Dirk Siersma and Ann Dorrit Guassora, 'Sample Size in Qualitative Interview Studies: Guided by Information Power' (2016) 26(13) *Qualitative Health Research* 1753 <<https://doi.org/10.1177/1049732315617444>>.



## D Data Analysis

Interviews were transcribed verbatim (standard conversational level) by a professional transcription company, which had signed a confidentiality undertaking. All participants were sent their transcript and could update or amend it (member checking).<sup>40</sup> Four participants provided supplementary information via email, which was included in the analysis.

Once member checked, all transcripts and supplementary information were deidentified and uploaded to NVivo (release 1.6.1). Data were analysed using Braun and Clarke's reflexive thematic analysis.<sup>41</sup> RJ and BPW independently coded the first five transcripts and discussed initial codes to achieve a richer understanding of the data.<sup>42</sup> After discussion, RJ and BPW both coded the remainder of the transcripts and supplementary information. After this initial round of coding to identify content related broadly to the research question, RJ coded the relevant data again line by line. Themes were developed using a combined deductive and inductive approach. The concept of patients and family caregivers as 'regulatory actors' was identified as a discrete area of interest and data were deductively analysed to determine whether it related broadly to this concept. Once this subset of data was identified, themes were developed inductively, as they are generated from the data rather than in relation to an existing hypothesis. Themes were iteratively developed, with reference to notes from the reflexive journal, and refined by all authors after engaging with the data. Both semantic (surface level) and latent (underlying) themes are reported. To ensure potential 'regulatory activity' was not missed, we were inclusive in our data analysis.

## E Rigour

Ethics approval was obtained from the Queensland University of Technology Human Research Ethics Committee (Reference #2000000270). Research was conducted in accordance with the requirements of this ethics approval. Free and informed consent to participate was obtained from each participant prior to their interview. Because all family caregiver interviews were conducted after the patient had died, consent was not obtained from the patients described by family caregivers. This study is reported according to the consolidated criteria for reporting qualitative research ('COREQ') checklist for qualitative research.<sup>43</sup>

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40 Simon C Kitto, Janice Chesters and Carol Grbich, 'Quality in Qualitative Research' (2008) 188(4) *Medical Journal of Australia* 243, 244 <<https://doi.org/10.5694/j.1326-5377.2008.tb01595.x>>.

41 Braun and Clarke, 'Using Thematic Analysis in Psychology' (n 35); Braun and Clarke, 'Reflecting on Reflexive Thematic Analysis' (n 35); Braun and Clarke, *Thematic Analysis* (n 35).

42 David Byrne, 'A Worked Example of Braun and Clarke's Approach to Reflexive Thematic Analysis' (2022) 56(3) *Quality and Quantity* 1391, 1393 <<https://doi.org/10.1007/s11135-021-01182-y>>.

43 Allison Tong, Peter Sainsbury and Jonathan Craig, 'Consolidated Criteria for Reporting Qualitative Research (COREQ): A 32-Item Checklist for Interviews and Focus Groups' (2007) 19(6) *International Journal for Quality in Health Care* 349 <<https://doi.org/10.1093/intqhc/mzm042>>.

### III RESULTS

In total, 28 interviews were conducted with 33 participants (one patient and 32 family caregivers) about 28 patient experiences of VAD (five interviews each involved two family caregivers, two interviews were conducted with different family members about one patient experience on separate occasions, one participant reported two patient experiences, and one family caregiver's interview occurred over two dates). All interviews were conducted after the patient's death, except for the sole patient interview. This interview was conducted after the participant was found eligible for VAD and had obtained the VAD substance, but before administration. Interviews ranged between 56 and 134 minutes, with a median of 90 minutes.

Table 2: Characteristics of Interview Participants

Characteristics	Number
Age (years), mean 56.6	
20–29	1
30–39	4
40–49	7
50–59	3
60–69	13
70–79	4
80–89	1
Sex	
Female	26
Male	7
Relationship to patient*	
Child (including stepchild, child-in-law)	17
Spouse (including de facto partner)	10
Parent	3
Sibling	2
Self	1
Friend	1
*One participant spoke about two patients and is included in two categories, so this data describes 34 relationships.	

Table 3: Characteristics of Patients Described by Interview Participants

Characteristic	Number
Age (years), mean 70.8	
20–29	1
30–39	1
40–49	0
50–59	3
60–69	7
70–79	8
80–89	6
90–99	2
Sex	
Female	13
Male	15
Location	
Metropolitan	16
Regional	12*
* One regional patient moved to a metropolitan area during the VAD process.	
Highest level of education	
Some high school	7
High school	9
University – diploma	1
University – undergraduate	7
University – postgraduate (including graduate diploma)	4
Primary disease, illness, or medical condition	
Cancer	18
Neurological	9
Other	1
Eligibility for VAD and death	
Assessed as eligible	24

Characteristic	Number
Patient died via self-administered VAD substance	19
Patient died via practitioner-administered VAD substance	3
Patient died but did not take VAD substance (natural death)	1
Patient waiting to take VAD substance	1
Patient died prior to eligibility assessment completed	3
Patient assessed as ineligible and died	1
Timing of voluntary assisted death (or engagement with process)	
July – December 2019	4
January – June 2020	6
July – December 2020	3
January – June 2021	10
July – November 2021	5

We generated four themes: (1) potentially ‘regulatory’ actions undertaken by patients and family caregivers; (2) motivations for actions; (3) perceived outcomes of actions; and (4) factors impacting actions, motivations, and/or outcomes.

These four themes are conceptually related and there is overlap (see Figure 1). For example, advocating for the patient’s choice for VAD (Theme 1) is ostensibly motivated primarily by a desire to support the patient’s choice (Theme 2). The outcome of successful advocacy and support is the patient can access their choice for VAD (Theme 3). Another example is that one participant made a policy reform submission (Theme 1), dually motivated by a desire to make the system better and

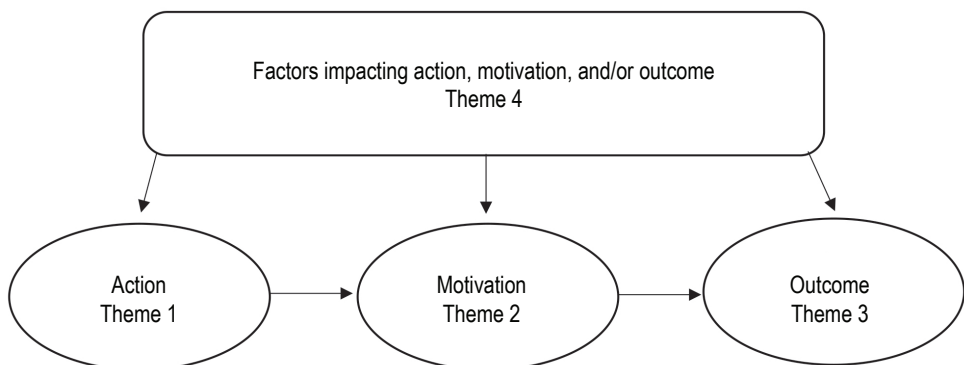


Figure 1: Conceptual relationship between themes

process grief (Theme 2), but which has been unsuccessful to date in bringing about change (Theme 3). The nature of this participant's experience, including barriers to access, impacted their actions and motivations (Theme 4). This overlap between themes is acknowledged throughout.

## **A Theme 1: Potentially 'Regulatory' Actions by Patients and Family Caregivers**

Participants in our study reported potentially 'regulatory' actions being performed by patients and family caregivers including exercising consumer choice, advocating for the patient, storytelling, making complaints and feedback, taking on a system role, and law reform efforts.

### **1 Exercising Consumer Choice**

Participants reported patients exercising (often, with the participant's support) consumer choice in relation to doctors and institutions. Patients and family caregivers intentionally chose one provider over another to enable them to access VAD.

With respect to consumer choice relating to individual doctors, some participants reported that doctors' willingness to participate in VAD was ascertained as part of the 'selection criteria' in choosing a doctor to care for the patient's primary illness or condition. Other participants described seeking out a particular doctor because they 'came highly recommended'<sup>44</sup> or were known to provide VAD. In contrast, in one case, the participants educated the doctor about VAD being a legal option as the doctor was unaware of VAD before it was raised by participants. In other instances, the doctor was aware of VAD but had not participated until asked to do so by the patient. Some participants reported requesting or asking their treating doctor to complete the mandatory training to assist them.

Patients, with the support of family caregivers, also exercised consumer choice by selecting an institution willing to provide VAD. For example, several participants described choosing an institution based on its known institutional policy about VAD: 'That place was chosen because they would allow it.'<sup>45</sup> Other institutions were avoided because VAD was prohibited in the institution.

### **2 Advocating for the Patient**

Many participants described advocating for patients to receive their choice for access to VAD and utilising their knowledge to ensure the patient received the best possible care. This was both specific to the VAD process and related to the general care of the patient, for example, researching the progression of the patient's illness in medical journals or invoking powers of attorney to decline unnecessary treatment or tests.

Participants also described negotiating for prioritisation in the VAD system to ensure access or minimise the time in which the patient was suffering. For example,

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44 Family caregiver interview 13.

45 Family caregiver interview 4.

one participant explained: ‘We had to call the state pharmacist and say: “You need to come really, really quickly because mum’s about to be transferred to [objecting institution] and you’re not allowed in [objecting institution].”’<sup>46</sup>

Participants commented that because the patients were so unwell, the advocacy by family caregivers on behalf of those patients was particularly important: ‘[M]um wasn’t able to do any of that [find a doctor who was able and willing to help with VAD]. So again coming back to that having someone to support someone. If you were someone who was on their own or what have you, you really would need a social worker or someone to help you ...’.<sup>47</sup>

### 3 *Storytelling*

Our participants shared their stories in many ways, including through participation in radio or news media interviews, written newspaper articles, podcasts, presentations, or documentaries. Participants also described sharing their VAD story via personal discussions and on social media with friends, acquaintances, and colleagues.

Sometimes, this was sharing general information from their personal experience described by the participant: ‘I did a lot of Instagramming around when it happened just to explain what VAD was.’<sup>48</sup> Related to Theme 2 (participants’ *motivations* when taking these actions), this sharing of their story or information was not aimed at directing attention to an issue within the VAD system but was more about other factors: explaining the patient was accessing VAD; processing grief; and continuing the patient’s legacy or honouring their memory.

Other times, sharing the patient’s story (via the means described above) went beyond simply placing information in the public domain and was best characterised as advocacy. This reflects a motivation to alter the VAD system (linked to Theme 2). For example, the story had either a focus on drawing attention to a specific issue or problem faced with the VAD system, or on shifting cultural conversations, destigmatising VAD, or creating awareness and educating that VAD was a legal option: ‘[T]hat’s probably why I participated in some of those media opportunities, [it] was to try to get the people to be aware, to be thinking of it, to start those conversations.’<sup>49</sup>

Participation in this research was another way that participants shared their stories or advocated for change. Many of our participants explicitly commented that their motivation for being involved in the research was to improve the system by sharing their story (linked to Theme 2): ‘[I]t’s research and the literature that actually helps to improve the system.’<sup>50</sup>

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46 Family caregiver interview 13.

47 Family caregiver interview 17.

48 Family caregiver interview 24.

49 Family caregiver interview 21.

50 Ibid.



#### 4 *Complaints and Feedback*

Many participants provided feedback about their experience to a range of entities including institutions (hospitals and health services), the Department of Health, the Premier of Victoria, the Federal Government, and the VAD Review Board. The contact with the VAD Review Board occurred both within and outside the usual course of contact between it and the nominated contact person. This engagement with these entities occurred via emails, letters, telephone calls, and formal written submissions.

For example, one participant who had an early experience with an institution that had not developed policies about VAD telephoned the institution and said: 'Look, this was our experience. Can you have a think about this?'<sup>51</sup> One participant wrote to the Federal Government to draw attention to the impact of the telehealth prohibition in Victoria, which had impacted her family member's VAD access due to having to travel for appointments when very unwell.

One participant wrote a formal submission to a government body, including detailed research and arguments, to change its approach to a particular issue. This went beyond providing feedback about one's own experience to seeking change (linked to Theme 3) based on a more comprehensive analysis of the relevant issues and a concrete policy proposal to address the identified harm.

No participants reported initiating a complaint to an ombudsman, tribunal, or formal litigation, although one participant 'followed up a few times with a friend who's a solicitor and we went and met [representatives of the institution] a few times'.<sup>52</sup>

#### 5 *Taking on a System Role*

Several participants described undertaking a role in the VAD system, external to their role as a family caregiver supporting a patient, due to their experience with VAD. For one participant who was a doctor, this included becoming a VAD provider to assist others in accessing this option. Other participants described wanting to assist others in accessing VAD by volunteering to witness the written declaration required by the *VAD Act*. Two participants took on roles with an advocacy organisation: one as peer support for others going through the VAD experience; and another in a senior, formal role with the organisation.

#### 6 *Law Reform Efforts*

Participants also added their perspectives to parliamentary inquiries and law reform processes in other Australian states and international jurisdictions as they considered passing VAD legislation: 'At that point I had been speaking to [MP] as well in [another state] ... About all the things we'd found difficult and what I hope would never have to happen, you know, in other states ... we spoke quite a few times'.<sup>53</sup>

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51 Ibid.

52 Family caregiver interview 11.

53 Family caregiver interview 6.

## 7 Future Activity Planned

Some of the participants we interviewed had only been through the VAD process very recently, so had expressed that they planned or were in the process of preparing to undertake actions outlined here but had not yet had the opportunity to do so. One participant, for example, stated: ‘I’m very determined that this is the direction I’m going to take myself in. Something to do with VAD ... I definitely want to be an agent of change’.<sup>54</sup>

Table 4: Illustrative Quotes (Theme 1)

Sub-theme	Quote
Exercising Consumer Choice	‘It was interesting because dad had previously been in a faith-based private hospital. It was a lovely private hospital, beautiful facilities, and the doctors were great and stuff. He talked about going back there and I said, “But, dad, please be aware that they” – because they’d put out a statement that they were conscientious objectors, they would not support, they would not facilitate VAD at all in their facilities. So I said to dad, “Please be aware, dad, that if you choose go back to [objecting institution] you won’t be able to access the VAD system. They will not facilitate it. That’s been their public statement.” So then from there, he decided to go to another one ...’ <sup>55</sup>
Advocating for the Patient	‘You know, there’s just so many blooming things required to qualify for VAD – hoops to jump through – and I’m realising lately how hard I had to work to get [patient name] through the VAD process. Not only the paperwork and the proof, you know, your residency for two years, and of course you can’t find the rates forms and all sorts of things, and passports and everything.’ <sup>56</sup>
Storytelling	‘[W]e’re honoured to think that people still want to hear his story ... If one little thing that we’ve said today can help one other family, well ... that’s [patient’s] legacy still moving on.’ <sup>57</sup>  ‘And I’m about to embark upon a series of talks with rotary clubs about it. I want to demystify it and I want people to know that if they’re thinking about it, they should think about it earlier and get things in motion, and it doesn’t mean you ever have to use it. But if you think you might want to use it, then get things in motion early.’ <sup>58</sup>  ‘I just think it’s so good to have evidence-based research and people’s stories to help sway public opinion.’ <sup>59</sup>

54 Family caregiver interview 26.

55 Family caregiver interview 21.

56 Family caregiver interview 11.

57 Family caregiver interview 19.

58 Family caregiver interview 25.

59 Family caregiver interview 1.

Sub-theme	Quote
Complaints and Feedback	<p>'But yeah, I got really frustrated sort of through the week. By Friday I was really angry, and I express-posted a letter to the Premier, seeing as it was his legislation. So that should have been there Monday morning ... I emailed the – I sent an email to DHHS on the Friday, the 6th, through the navigators because I didn't have a direct thing at that stage. I'd spoken to our local MP, and she'd called DHHS trying to find out what was going on.'<sup>60</sup></p> <p>'So that's my main bugbear and I've written to a couple of federal MPs about this and the relevance of this law in today's society. You know, it's not really – and my understanding is it came about, this law, around Philip Nitschke's times when people were potentially trying to access this all illegally.'<sup>61</sup></p>
Taking on a System Role	<p>'I've joined Dying With Dignity Victoria ... and I'm going to offer my services as a volunteer peer support or a volunteer – just a person who may have five family members that were all there but they can't talk about it anymore, who else are they going to talk to?'<sup>62</sup></p>
Law Reform Efforts	<p>'At that point like I had been speaking to [MP name] as well in [state]. I ended up speaking to him at length that Friday because that's when things were really starting to move for [state] as well. About all the things that we'd found difficult and what I hope would never have to happen, you know, in other states. So we spoke quite a few times.'<sup>63</sup></p>
Future Activity Planned	<p>'I think [co-participant] and I each feel very strongly about [the prohibition on registered health practitioners raising VAD with patients]. In fact, I'm intending to write a letter to the Review Board on our experience and what have you, and that's going to be one of the things I mention as a bit of a learning experience. Maybe not directly relevant to mum, but for the benefit of others.'<sup>64</sup></p>

## B Theme 2: Motivation for Performing Actions

Participants reported a range of motivations for engaging in actions outlined in Theme 1. Some explicitly stated their motivations but in other instances, motivation was inferred from the nature of the act. Motivations aligned with three broad categories: patient-oriented motivations; personal motivations; and system improvement motivations.

### 1 Patient-Oriented Motivations

There were two patient-oriented motivations: (1) supporting the patient's choice, and (2) honouring the patient's legacy.

The primary patient-oriented motivation was to try and ensure the patient was able to access their choice for VAD. This motivation was primarily linked to the actions of exercising consumer choice and advocating for the patient outlined in

60 Family caregiver interview 5.

61 Family caregiver interview 6.

62 Family caregiver interview 2.

63 Family caregiver interview 6.

64 Family caregiver interview 17.

Theme 1. As an example of the relationship between advocating for the patient (Theme 1) and ensuring the patient's choice was supported (Theme 2), one participant commented: 'Had she not had [co-participant] and all the rest of the family supporting, it would have stopped at that first conversation.'<sup>65</sup> This is also linked to Theme 3 because the outcome was to help the patient access their choice for VAD. Some participants reported undertaking other kinds of actions in order to support the patient's choice. For example, one participant described advocating publicly via radio interviews and contacting the Department of Health. The participant appeared to be primarily motivated by a desire to support the patient's choice when undertaking these actions, by publicly outlining the problems faced by the patient in accessing VAD to prompt the government and others into action to address them for the particular patient this participant was supporting.

A second patient-oriented motivation was honouring the patient's legacy. Participants described performing actions such as sharing their story because 'a big part of what dad's thing was, was that he wanted people to know about it'.<sup>66</sup> By storytelling or advocating in their loved one's 'honour', the participant was able to fulfil the patient's wishes and keep them 'alive' and their 'legacy still moving'. In one instance, where the patient faced multiple roadblocks in the VAD process, the participant explained that the patient had explicitly encouraged her to speak publicly about their VAD experience, to 'go and stick it up 'em'.<sup>67</sup> In another interview, participants reported the patient wrote a letter detailing their story before death and sent it to a patient advocacy organisation, explaining this was part of that patient 'providing a legacy ... through a few different avenues ... he did want it to reach someone and somewhere'.<sup>68</sup>

## 2 *Personal Motivations*

There were two personal motivations: (1) processing grief, and (2) feeling a moral obligation.

Several participants explained their motivation included processing grief. One participant expressed this as wanting to 'get this monkey off my back'.<sup>69</sup> This participant advocated for changing an aspect of the law that had resulted in a patient missing out on VAD due to a perceived technicality. Some participants reported participating in research itself was therapeutic, as it provided an opportunity to talk about the complexities of the VAD process, which they felt unable to speak about publicly.

Interestingly, one participant did not experience the intensity of grief their partner and co-participant did. This participant had supported a parent-in-law to access VAD. The participant indicated that the patient being an in-law rather than their own parent allowed them to undertake actions they otherwise might not have

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65 Ibid.

66 Family caregiver interview 16.

67 Family caregiver interview 6.

68 Family caregiver interview 24.

69 Family caregiver interview 5.

if they were 'crippled' by grief. This participant reported: 'I don't have that, so I can act and so, therefore, I feel kind of compelled to do so.'<sup>70</sup>

Linked to this notion of feeling 'compelled' to act was the feeling of a moral obligation to act. A participant who became a provider after their family member's experience described feeling they had a moral obligation to do so. If their family member was using VAD, they felt as though were bound to be involved in supporting access for others.

### 3 System Improvement Motivations

There were two system improvement motivations: (1) encouraging a change in behaviour, and (2) making the system better.

One participant who had a negative VAD experience appeared to primarily be motivated to encourage a doctor to change their behaviour. This participant made a complaint because the doctor acted in a way that they perceived was inappropriate, by obstructing a referral. By making the complaint, the participant hoped 'to make him think about his behaviour'.<sup>71</sup>

A key system improvement motivation cited by many participants was making the system better for others. This was separate from improving a patient's experience; they recognised that it was too late for them to benefit from their efforts to improve the system. This motivation was expressed in different ways, such as wanting to 'make the system better', 'be an agent of change', 'advance the cause', or 'give back'.

Some participants expressed this desire in general terms, as wanting to help or make the process easier. For example: 'That's definitely my motivations [sic], [it] is to just help to improve the service system.'<sup>72</sup> One participant who had a positive experience shared that experience to highlight what made the process positive, rather than advocating for any particular system improvement. Other participants were focused on raising awareness about VAD. Many felt privileged that they knew VAD was an option and were concerned others did not. Participants explained they wanted others to be aware of the option because it helped their loved ones and wanted to demystify VAD by making information more accessible. Other participants perceived stigma regarding VAD and the need to facilitate 'courageous conversations' to normalise VAD as an end-of-life choice.

Others had specific issues they were motivated to address, such as fixing a particular barrier they experienced or perceived in the system. For one participant, whose family member accessed VAD early on, the motivation was to provide feedback to provoke an institution to implement a clear position statement on VAD, so 'no one else has to go through that'.<sup>73</sup> Others advocated for issues such as removing the ban on telehealth or changing eligibility criteria, so others did not

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70 Family caregiver interview 17.

71 Family caregiver interview 11.

72 Family caregiver interview 21.

73 Ibid.

have to experience the same roadblock: ‘[I]t’s not for [patient] anymore, it won’t help her.’<sup>74</sup>

Notably, no participants expressed a motivation to make the system better by increasing safety or the number of safeguards. Participants’ perceptions about making the system better centred around making the process easier, raising awareness and helping to destigmatise VAD, and addressing specific barriers to access.

Table 5: Illustrative Quotes (Theme 2)

Sub-theme	Quote
Patient-Oriented Motivations	
Supporting the Patient’s Choice	‘That place was chosen because they would allow it. But it also had to be selective about the staff who would be working at the particular time he decided to take the medication. So there was, yeah, a bit of navigating and a lot of privacy – or, you know, it was very – it was harshly spoken about within the staff because, you know, some people don’t agree with it.’ <sup>75</sup>
Honouring the Patient’s Legacy	‘It’s interesting. We kind of object, I think, when we hear people say, “Oh, it only matters to me because I know someone who’s affected by it.” You know, we probably hear that coming out of the mouths of politicians and we think, well, why can’t you just care because it’s important? But I think there is a real human tendency for us to focus on what’s most in front of us at any particular moment in time. And what has made an emotional impact on us. So I guess that the honest truth is it is something that made a deep emotional impact, and in some ways, I feel like it’s a way for me to honour [patient’s] – my mother-in-law’s – courage in pursuing VAD despite the fact that obviously she wouldn’t have chosen that end for herself had she had other options on the table that were more palatable. And so I guess I often think about her, and I think about what would she hope might come out of her own experience. And I guess I feel a sense of responsibility in a really positive way to try and make a contribution in her memory.’ <sup>76</sup>
Personal Motivations	
Processing Grief	‘I think the other selfish part of is that [sic] to share the story helps me with my grief. So when I did that story about dad for the [patient advocacy organisation] that was for me – it was part of my grief journey, too, was to actually capture dad’s story, to capture our experience of his death and to share that was actually part of that grieving process.’ <sup>77</sup>

74 Family caregiver interview 5.

75 Family caregiver interview 4.

76 Family caregiver interview 17.

77 Family caregiver interview 21.



Sub-theme	Quote
Feeling a Moral Obligation	<p>Participant: 'Because I had no intention of doing the training ... it was that's good. Someone else can do it. That's fine. I don't need to get involved. But just morally if my [family member] was using it, I was morally bound to do it, to provide it. Because I had no problems with it. I just thought it wasn't something I wanted to mess my soul with ... I was one of the early ones to do the training. I did the training as soon as the thing opened up.'</p> <p>Interviewer: 'Got it. And, that was, as you said, prompted by –'</p> <p>Participant: '[Patient name].'<sup>78</sup></p>
System Improvement Motivations	
Encouraging a Change in Behaviour	<p>'I actually made a formal complaint about my partner's GP and the registration body, another acronym, they were very concerned, but they said all they could do was counsel the GP – and he's semi-retired – and advise him to change his practice. But that's fine. Again it was just a bit of a nuisance for him, but I managed to make him think about his behaviour.'<sup>79</sup></p>
Making the System Better	<p>'My thoughts were that, well, you know, and it was all new and all that, if I could do anything that might get things changed, either a bit simpler or that at least others had more of a feeling about what it might be like and what they've got to do, and if I could help support changes to the legislation in other states, then if what I did was useful then I'd be prepared to do it, and I did. So it's as simple as that, really.'<sup>80</sup></p> <p>'I guess, having walked through the process alongside [patient], you can see the things that did, worked well, and the things that didn't work so well. And I think you're conscious of having an ability to illuminate that for policymakers and for people who've got the ability to actually change the system. Obviously, they have their own perspective, I guess, on what's working and what's not working, but it is, I think, a different perspective from that consumer/carer perspective as well.'<sup>81</sup></p>

### C Theme 3: Perceived Outcomes of Actions

Participants perceived their actions had two overarching outcomes: patient-facing outcomes and system-facing outcomes. This theme intersects with Themes 1 and 2 as some acts are inherently linked to particular motivations and directed towards particular outcomes.

#### 1 Patient-Facing Outcomes: Improved Individual Patient's Experience and Access

A key outcome was improving the patient's VAD access or assisting them to progress further through the VAD process (noting some patients initiated the process but did not access VAD). This outcome was linked to the actions of exercising

78 Family caregiver interview 25.

79 Family caregiver interview 11.

80 Family caregiver interview 23.

81 Family caregiver interview 17.

consumer choice and advocating for the patient (Theme 1). One example of this outcome was finding a doctor to assist with the VAD process. This improved access for the patient because they were connected with a willing provider or improved the experience because they could pursue VAD with a doctor with whom they had an existing therapeutic relationship. In one instance, family caregivers explained to a doctor that VAD was a lawful option, with the outcome being the doctor assisted the patient to access VAD as one of the two required doctors in the process. Other participants described telling a doctor who had not participated in VAD before ‘to just go away, think about it, get back to [them]’.<sup>82</sup> The outcome was that the doctor did the training and assisted the patient with VAD.

Patients, supported by family caregivers, also navigated conscientious objections of individual doctors: ‘Had she not had ... the rest of the family supporting, it would have stopped at that first conversation when the doctor – you know, she spoke to that conscientious objector I reckon, and he would have gone “No, she didn’t raise it properly”’.<sup>83</sup> The participants thought the patient raised VAD sufficiently, but due to the doctor’s conscientious objection it was not interpreted as a sufficient request for information, so the doctor did not discuss VAD. By advocating for the patient’s choice and assisting the patient to locate a willing doctor (Theme 1), participants ensured the outcome (Theme 3) was that the patient’s access was not precluded due to a conscientious objection.

Participants also reported patients (supported by family caregivers) selectively choosing health services willing to allow VAD and described navigating around institutional objections to facilitate access (Theme 1). The outcome of this action was to ensure patients were not prohibited from accessing VAD due to institutional positions of health services. This outcome was achieved by reviewing policies published on institutional websites, directly asking staff, and being aware of public statements regarding the institution’s position.

Another outcome was reducing inefficiencies in the process for individual patients. This included calling the Statewide Pharmacy Service to advocate for earlier delivery of the VAD substance, and persistence in advocating for patients to ensure their wishes were heard by healthcare teams and that appointments occurred in a timely manner: ‘[The consultation with the neurologist] was booked for the 2<sup>nd</sup> of June and through my heckling I managed to get that pulled back maybe a week.’<sup>84</sup>

## 2 System-Facing Outcomes

Participants also perceived their actions had a range of broader system-facing outcomes, such as increased community awareness about VAD, increasing the number of health professionals (particularly doctors) participating in the VAD system, and increasing the efficiency of other participants (or ‘actors’) in the VAD system.

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82 Family caregiver interview 26.

83 Family caregiver interview 17.

84 Family caregiver interview 6.

Participants reported that sharing information with others led to increased community awareness. One participant discussed VAD with a friend who did not know it was available and thought this information had enabled that person's family member to access VAD. Another discussed VAD with a friend who was previously opposed, which led their friend to become an advocate for VAD. Some participants, who work as health professionals, shared information to raise awareness and explain the importance of VAD, based on their personal experience. They perceived outcomes from this including that 'a couple more people know about it' or 'have actually expressed an interest in me talking about my journey now'.<sup>85</sup>

Another system-facing outcome was the changed professional practice of other actors in the VAD system. This manifested in two ways. The first was more health professionals, particularly doctors, willing to take on formal roles within the VAD system (eg, as VAD providers). As described in Theme 1, one participant who was a doctor became a VAD provider. Patients also raised VAD with their treating doctors who, in several instances, went on to do the training and provide VAD, thereby creating more trained VAD providers who could potentially assist other patients with VAD.

The second was that by participating in VAD or providing feedback, this provided an opportunity for those already within the VAD system to become more experienced actors in the system. By this we mean that other individuals within the system became more efficient or proficient in their VAD role as a result of interactions with patients and family caregivers. As an example, one participant reported: 'The pharmacist ... told me, you know, like he learnt from that day, you know, not to assume people like things to be worded in certain ways'.<sup>86</sup>

Table 6: Illustrative Quotes (Theme 3)

Sub-theme	Quote
Patient-Facing Outcomes: Improved Individual Patient's Experience and Access	<p>'I had to persuade a GP we didn't know to get involved in [patient name]'s VAD and he was very reluctant. In the end, it was the oncologist who again said, "I can't help you." The oncologist said, "I don't approve and I can't help you." But it was the oncologist's receptionist who gave me the name of a specialist who would help. She said, "Just get the GP to refer you to them." So I just said to the GP, "I'm not saying anything or asking. Just put this name on a referral and send it over please," and that's how it happened. So it was a real uphill battle here to get the VAD process started for [patient name].'<sup>87</sup></p> <p>'[Y]ou've got a [family caregiver who is a doctor] here pulling all the – banging on doors and making phone calls that's happy to do that, but otherwise this wouldn't have happened in time, you know.'<sup>88</sup></p>

85 Family caregiver interview 16.

86 Family caregiver interview 6.

87 Family caregiver interview 11.

88 Family caregiver interview 6.

Sub-theme	Quote
	<p>'On this particular day, it was the 8<sup>th</sup>, that [the pharmacy] rang and they said, "When would you like us to come in?" I said, "I'd like you to come in today." "Oh, right. Well, we've got a few other things," and this and that. I said, "I know there's only two of you in the whole of the state," at that time. I don't know how many there are now. I was really quite firm and fair, and I said ... "You see everything to do with dad. He has been vehement, straight, on it, has told you this is what he wants and he wants it's [sic] done ... He needs – he wants you to come today ... " and that's how I said it. They rang back and they said, "We can come at 12 o'clock today" ...'<sup>89</sup></p>
System-Level Outcomes	<p>'In terms of seeing the impact, I think not yet, but informally, yes, like, I think it is really interesting that once you start to talk about your experiences which I have done quite openly with, in different settings, everywhere from my book club to in class ... People kind of know, then, that you're someone who's open to talking about these things. I've certainly had one in the last couple of weeks where someone who – that is from my book group, has a dear friend who has MND [motor neurone disease] and we talked about resources that she might be able to share with her, and the possibility of having a conversation. And I said I was very happy to do that if that's something she wanted. So I guess it's those, what I see as those little tiny human-to-human impacts at this point, rather than the big system changes, yeah.'<sup>90</sup></p> <p>'I've actually had an experience of somebody whom I know and their father was very, very ill and I told them about our VAD process. She had no idea about it. I still haven't – it's second-hand at this present moment, I haven't seen her since her father passed away which was a day before mum did actually, but from what I've gathered they actually used the VAD process. I think me sharing that information has either introduced it to them as a family or, you know, at least allowed this woman to kind of – like the fact that somebody else was going through the same and navigating the same system.'<sup>91</sup></p> <p>'I took the information book that they gave us at the start of our journey to my tearoom at work, which is at a vaccination centre, because so many nurses didn't realise it was a thing. It was like, oh is that legal? I was amazed. So to just have it on the tearoom table there and people can flick through, and people have flicked through it, and I just think, yay, a couple more people know about it.'<sup>92</sup></p>

#### **D Theme 4: Factors Impacting Action, Motivation, and/or Outcome**

Factors both extrinsic and intrinsic to the individual participant or patient impacted whether they took action (Theme 1), were motivated to do so (Theme 2), and could achieve the desired outcome (Theme 3). This theme is an overarching theme, as it impacts the other three themes. For example, a family caregiver who supports VAD is more likely to take action to support the patient's choice (Theme 1), be motivated to take action to help ensure the patient's access to their choice (Theme 2), and consequently, it may be more likely that the outcome is the patient

89 Family caregiver interview 2.

90 Family caregiver interview 17.

91 Family caregiver interview 13.

92 Family caregiver interview 16.

accessing their choice for VAD (Theme 3). See Figure 2 for an example of how Theme 4 impacts the other three themes.

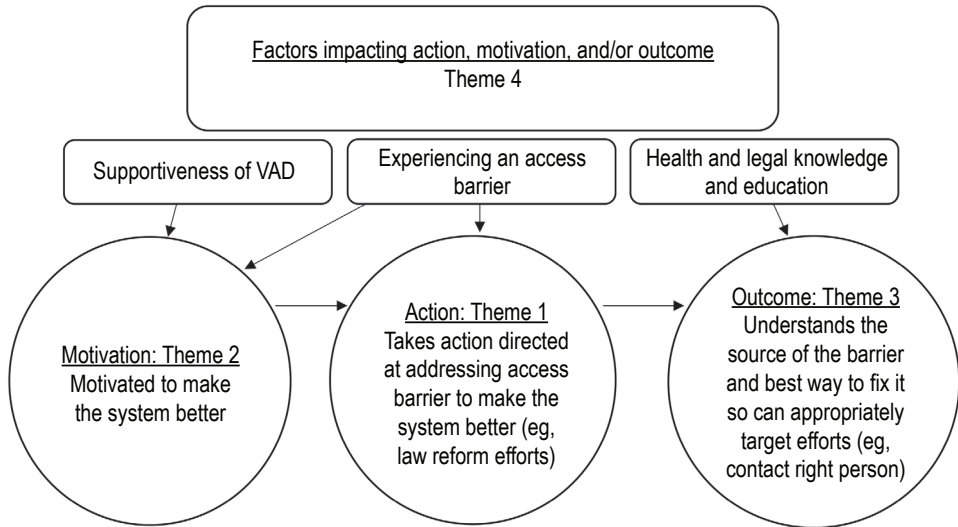


Figure 2: An example of how Theme 4 impacts the other three themes

### 1 Extrinsic Impacting Factors

There were two extrinsic impacting factors: (1) the nature of the VAD experience, and (2) connection to an advocacy group.

The nature of the VAD experience *facilitated* actions being undertaken (Theme 1) and the motivation behind these actions (Theme 2). For example, if there were barriers (such as inability to use telehealth, difficulty connecting to a willing doctor, individual conscientious objection, institutional objection, or technical eligibility criteria prohibiting access) experienced during the VAD process, this facilitated an opportunity or triggered a motivation for participants or patients to engage in actions described in Theme 1. For some patients or participants, encountering barriers was linked to the timing of their VAD experience and relative system immaturity. Early on, some institutions had not developed policies on responding to VAD, VAD services were new, and there was a limited pool of willing and trained doctors, especially neurologists. System immaturity seemingly increased the burden on the family caregiver to advocate or utilise their knowledge to ensure access for the patient and prompted them to provide feedback or engage in other actions described in Theme 1 to make the system better (Theme 2).

Many participants were connected to patient advocacy organisations, such as Dying With Dignity or Go Gentle Australia. Often, the patient or family caregiver was already a member of the organisation, suggesting pre-existing interest in and support for VAD. In other instances, the connection was made after the patient accessed VAD and facilitated an opportunity to engage in action (Theme 1). Connection to an advocacy group ostensibly *facilitated* patients and family caregivers to take action to make the system better (Theme 2).

## 2 *Intrinsic Impacting Factors*

There were three intrinsic impacting factors: (1) whether the participant or patient was supportive of VAD, (2) health and legal knowledge and education, and (3) personality characteristics.

One factor that *facilitated* participants' actions was supportiveness of VAD. All participants interviewed were supportive of the patient's choice. This is not to say they did not experience any reservations, but they did not hold a moral opposition to VAD or the patient's choice. This meant participants were willing to act (Theme 1) and were motivated to do so (Theme 2). For example, family caregivers expressed motivations such as honouring legacy or making the VAD system better and took actions such as sharing information about the patient's choice and experience. Implicit here is in-principle support of VAD, as it is unlikely that participants would be motivated to raise awareness about VAD if they objected to it.

Many participants worked in the healthcare sector or described another family member with health expertise being involved in supporting the patient. Regarding legal knowledge, many participants expressed they, or the patient, were well-informed about the law (and in some instances, had read the *VAD Act* or were lawyers themselves). These characteristics – health and legal knowledge – were shared by many of our participants and appeared to *facilitate* them undertaking actions (Theme 1), and impacted why they did so (Theme 2) and the outcomes of actions (Theme 3).

Many participants explicitly commented that this health or legal expertise improved their ability to navigate through the VAD process and facilitate access to VAD. The recognition of this position of privilege in terms of their health and legal knowledge, which many felt enabled or facilitated their loved one to access VAD, was a factor motivating (Theme 2) participants to engage in actions (Theme 1). For example, one participant reported: 'For mum and myself it was always thinking, well, how do others get onto the pathway? So we've been able to navigate it, but we might be exceptions.'<sup>93</sup>

Linked to this was education generally: participants described that they were well educated, which impacted on their ability to navigate VAD:

We were both what you would call – in terms of the general population of our age group we were well educated. Which I think possibly may have played a contributing factor in, one, knowing how to go about research, two, being able to understand how to use the technology.<sup>94</sup>

However, some participants reported that despite high levels of education, the VAD process was still difficult to navigate: 'So for someone as educated as her, it was, you know, a bit difficult to navigate. So we reflected on how difficult it must be for people who don't have PhDs and don't have first language as English and also just have other challenges like – as we also did.'<sup>95</sup>

Several participants explicitly attributed their personality as a reason for acting in particular ways. For example, participants described themselves as

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93 Family caregiver interview 7.

94 Family caregiver interview 1.

95 Family caregiver interview 8.



being 'assertive', 'bossy', 'capable', and being the 'doer' in the family. These characteristics *facilitated* participants to take action because it was inherent in their personality to do so (Theme 1) and could make their action more effective as they could identify the right recipient for their requests, storytelling, feedback, or complaints (Theme 3).

Table 7: Illustrative Quotes (Theme 4)

Sub-theme	Quote
Extrinsic Impacting Factors	
Nature of the VAD Experience	'So I'm hoping that people's experiences now will be nothing like what ours were, but it was purely and simply because of the maturity of the system that we were working within at that time. And I'm confident that there would be – and that's probably why I participated in some of those media opportunities, was to try to get the people to be aware, to be thinking of it, to start those conversations so that it wasn't – you know, they didn't have to be like dad and trying to sort through this murky system of "but I've asked three doctors", "Oh, I've got to go home to get the medication. I'm not ready yet." You know, that sort of all these little things I think was around the maturity of the VAD.' <sup>96</sup>
Connection to Advocacy Group	'Because the eligibility was not just my concern ... seeing you have read the article that was printed in the [newspaper], that came about by [VAD advocate] in talking to me knew that a journalist was coming that wanted to interview him ... to write an article because of the impending possible legislation in [another state] from VAD. He understood she wanted to write articles, which would help them make the right sort of legislation and obviously particularly in relation to prognosis. It was through her coming down from [another state] to meet him that he got her to come out and meet me as what he saw as a typical case that would fall through the cracks because of the Victorian legislation with the prognosis problem.' <sup>97</sup>  'And she was also asked to speak to the [state] Parliament, which she did ... How did that come about? Through [VAD advocate] I think.' <sup>98</sup>
Intrinsic Impacting Factors	
Support of VAD	'I look back and I think, you know, of all the things that we have done, perhaps this is our greatest gift to her. You know, to support her decision to go through the process with all those appointments and to sit with her at the end is perhaps our greatest gift.' <sup>99</sup>  'I joined a voluntary euthanasia group, known down here as DWD, Dying With Dignity ... So I joined that and attended meetings and what have you for some years before I knew I even had cancer.' <sup>100</sup>

96 Family caregiver interview 21.

97 Patient interview 1.

98 Family caregiver interview 27.

99 Family caregiver interview 3.

100 Patient interview 1.

Sub-theme	Quote
Health and Legal Knowledge and Education	<p>‘But caveats here, and I think the number one being that we were coming from an almost insider perspective given mum’s role [as a doctor]. So I think what that meant was that they were able to see ahead and advocate in advance. Were we not kind of upper-middle class, well-educated people with a foot in the health sector, we probably might have a different experience.’<sup>101</sup></p> <p>‘I think if it was someone who didn’t have the legal knowledge or the science – to be honest, more broadly in terms of palliative care, without people like my uncle, who was a doctor, and my aunts and the [region’s healthcare service], I’m not sure that other people would have had the overwhelmingly good and positive experience that we did.’<sup>102</sup></p> <p>‘Well, mind you, I’d read the 87 pages of VAD legislation, so I was pretty up with what the process was going to be.’<sup>103</sup></p> <p>‘So she immediately rang [family member] and said to him, “We need your help,” because he’s got a lot of clinical associates, “Please can you follow this up for us? You know who the people to ask are to get this moving quickly because it clearly needs to be as quickly as possible.” So he was fantastic. He was the one who contacted care navigators and did all the preliminary talking on [patient]’s behalf.’<sup>104</sup></p>
Personality Characteristics	<p>‘I am a very bossy, assertive person.’<sup>105</sup></p> <p>‘I was familiar with everything. I am confident, I’m assertive.’<sup>106</sup></p> <p>‘So we just had that in place because of ... me being a bulldog a little bit ...’<sup>107</sup></p> <p>‘I’m a solver and a doer, and so I had a bit of a role within the family – “Give it to [participant], she’ll sort that out.”’<sup>108</sup></p>

## IV DISCUSSION

### A Overview of Findings

The key finding of this research is that patients and family caregivers were able to alter the behaviour of key participants in Victoria’s VAD system to influence their experience of the VAD process and bring about change in the system as a whole. The nature of their experience, including any barriers faced, was a key impacting factor that facilitated patients and family caregivers to act to influence their experience or alter the behaviour of others. Patients and family caregivers performed various actions to overcome barriers to access that they experienced in the VAD process. These actions included exercising consumer choice by selecting particular doctors

101 Family caregiver interview 20.

102 Family caregiver interview 12.

103 Family caregiver interview 3.

104 Family caregiver interview 22.

105 Family caregiver interview 11.

106 Family caregiver interview 26.

107 Family caregiver interview 2.

108 Family caregiver interview 15.

and institutions, storytelling, and making complaints and providing feedback. While the primary motivation for most participants was improving the individual patient's experience by navigating barriers to access, many participants also reported being motivated to make Victoria's VAD system better for others *beyond* their own experience. Participants' conceptions of making the system better centred on reducing barriers to access and not adding unnecessary safeguards.

Participants perceived their actions to overcome barriers to access as having two broad impacts. The first was the impacts on the individual, such as improving the individual patient's experience of VAD and facilitating access to their choice. The second was the impacts on other participants in the system, including increasing public awareness about VAD, creating more willing providers, and altering the behaviour and efficiency of other participants in the VAD system. Figure 3 represents how actions, motivations, and impacts reported in Themes 1–3 relate to either individual or system-wide altering of behaviour (or both) and how Theme 4 applied across all categories. We do note the ways in which participants affected others' behaviour were complex and multi-faceted and could result in influencing both the individual's experience and the system more widely. For example, very effective individual influencing of behaviour could have unintended or unexpected system-level impacts.

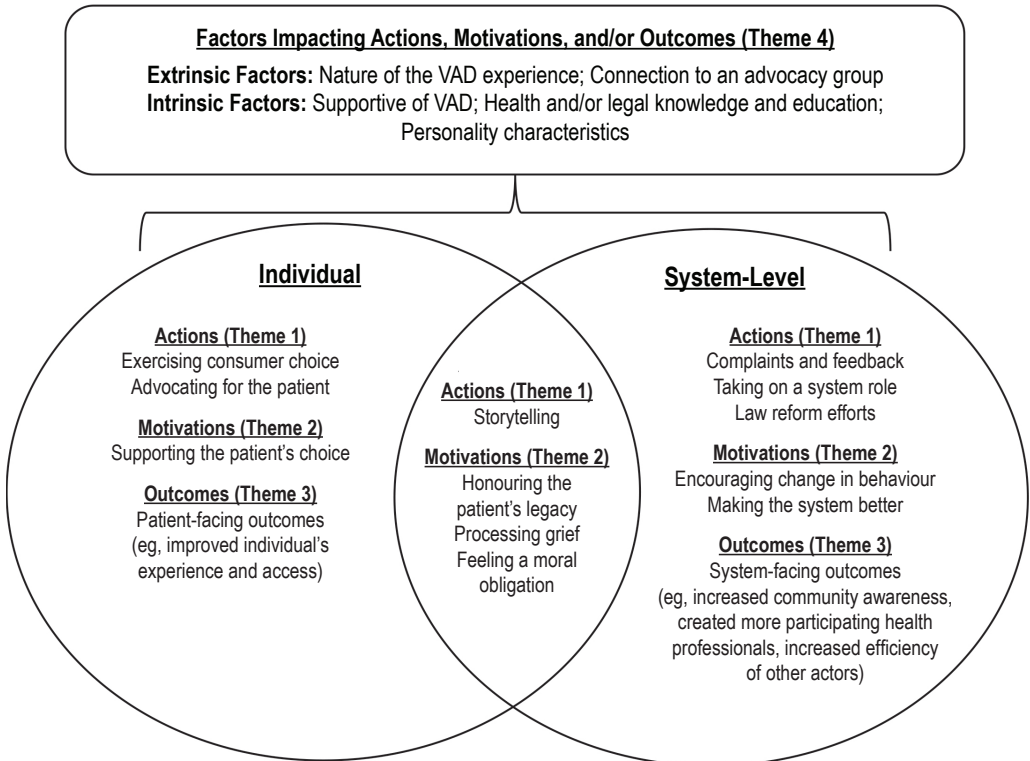


Figure 3: Relationship between individual and system-level influencing or altering of behaviour

## B Meaning of ‘Regulation’

The actions of patients and family caregivers reported in our study may potentially be considered ‘regulatory’. As noted in the introduction, we adopt Black’s definition of regulation which has three elements: (1) sustained and focused action, as opposed to one-off or incidental action; (2) directed at altering the behaviour of others; and (3) with an intention to produce a particular, albeit broadly identified, outcome.<sup>109</sup> We first consider whether actions that influence the *individual* experience of healthcare may be considered ‘regulatory’, and then consider this in relation to actions altering behaviour at a *system* level.

## C Influencing Behaviour within the Individual Healthcare Relationship

Most patients and family caregivers in our sample took actions that influenced behaviour within the individual healthcare relationship. The nature of the VAD process, including experiencing barriers to access as reported elsewhere in the literature,<sup>110</sup> facilitated and motivated patients and family caregivers to influence the individual healthcare relationship and to ensure the patient’s choice for access to VAD was supported. To overcome barriers to access, participants and patients took actions like exercising consumer choice or advocating for the patient. The reported impact of these actions was that patients and, particularly, family caregivers improved the individual patient’s experience of or access to VAD. This is consistent with findings of a systematic review by Claudia Gamondi et al which included studies from Canada, the United States, the Netherlands, and Switzerland, and found that family members had an important role in advocating for patients to support them to access their choice for assisted dying.<sup>111</sup> A Dutch systematic review,<sup>112</sup> and a body of Canadian scholarship,<sup>113</sup> also highlight the essential role of family caregivers in supporting patients through the VAD process.

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109 Black (n 27) 26.

110 White et al, ‘The Impact on Patients’ (n 11); White et al, ‘Access to Voluntary Assisted Dying’ (n 11); Willmott et al, ‘Participating Doctors’ Perspectives’ (n 21); White et al, ‘Prospective Oversight and Approval’ (n 21); Rutherford (n 21).

111 Claudia Gamondi et al, ‘Family Members’ Experiences of Assisted Dying: A Systematic Literature Review with Thematic Synthesis’ (2019) 33(8) *Palliative Medicine* 1091 <<https://doi.org/10.1177/0269216319857630>>.

112 Bernadette Roest, Margo Trappenburg and Carlo Leget, ‘The Involvement of Family in the Dutch Practice of Euthanasia and Physician Assisted Suicide: A Systematic Mixed Studies Review’ (2019) 20(1) *BMC Medical Ethics* 23:1–21 <<https://doi.org/10.1186/s12910-019-0361-2>>.

113 Brigitte M Hales et al, ‘Improving the Medical Assistance in Dying (MAID) Process: A Qualitative Study of Family Caregiver Perspectives’ (2019) 17(5) *Palliative and Supportive Care* 590 <<https://doi.org/10.1017/S147895151900004X>>; Simon JW Oczkowski et al, ‘How We Can Improve the Quality of Care for Patients Requesting Medical Assistance in Dying: A Qualitative Study of Health Care Providers’ (2021) 61(3) *Journal of Pain and Symptom Management* 513 <<https://doi.org/10.1016/j.jpainsymman.2020.08.018>>; Janine Brown et al, ‘Medical Assistance in Dying: Patients’, Families’, and Health Care Providers’ Perspectives on Access and Care Delivery’ (2020) 23(11) *Journal of Palliative Medicine* 1468 <<https://doi.org/10.1089/jpm.2019.0509>> (‘Medical Assistance in Dying’); Janine Brown et al, ‘Care Considerations in a Patient- and Family-Centered Medical Assistance in Dying Program’ (2022) 37(3) *Journal of Palliative Care* 341 <<https://doi.org/10.1177/0825859720951661>> (‘Care Considerations’); Simon JW Oczkowski et al, ‘How Can We Improve the Experiences of Patients and Families Who Request Medical Assistance in Dying? A Multi-centre Qualitative Study’ (2021) 20(1)

Our results show that by taking actions that influenced the individual healthcare relationship, patients and family caregivers have performed various actions on Healy's pyramid.<sup>114</sup> A clear example is that they were '[i]nformed patients' and '[s]elective consumers' by being aware of and educated about VAD as an option, asserting their choice for access to VAD, selecting individual doctors to assist with VAD, and institutions in which to receive care.<sup>115</sup> A key benefit of patients and family caregivers being informed patients was that they knew about VAD as a legal option and could initiate discussions with doctors, as required under the *VAD Act*. The benefits of being selective consumers included locating doctors who were willing to access VAD, and being able to navigate around objecting institutions, in order to improve the patient's access (Theme 3). Another example of how action to influence behaviour in the individual healthcare relationship may relate to an aspect of Healy's pyramid is that patients and family caregivers were 'active participants' in their healthcare. Healy describes that patients are often reticent to question or challenge health professionals, so active participation can be difficult.<sup>116</sup> Our results demonstrate, however, that patients (supported by family caregivers) were assertive and confident in their choice for access to VAD and were active participants in the VAD process, including by ascertaining doctors' and institutions' views on VAD. While no one in this sample would fall within the highest level of Healy's pyramid – 'aggrieved litigants'<sup>117</sup> – one participant did engage solicitors and meet with an institution to raise issues with the institution's handling of the VAD process.

Black might argue that actions focussed on influencing the individual experience of healthcare, rather than altering the behaviour of others in the system or the system more broadly, may not constitute 'regulation'.<sup>118</sup> This is because the scope is limited to the individual healthcare relationship and the action may fall short of being sustained and focused or directed at altering the behaviour of others; rather, it is more about making choices and taking steps to support one's own access. Regardless of whether it is conceived of as 'regulation', engaging individuals in influencing their own care is now well recognised as an important goal in healthcare.<sup>119</sup> To illustrate the importance of this goal in the Australian context, this is reflected in the Australian Charter of Healthcare Rights, which affirms patients' rights to information, partnership, respect, and access.<sup>120</sup> It is also reflected in the *VAD Act* itself, namely in the goals described in the introduction

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*BMC Palliative Care* 185 <<https://doi.org/10.1186/s12904-021-00882-4>> ('How Can We Improve the Experiences').

114 Healy, 'Patients as Regulatory Actors' (n 25) 593–4.

115 Ibid.

116 Ibid 602.

117 Ibid 594, 603.

118 Black (n 27).

119 Alex H Krist et al, 'Engaging Patients in Decision-Making and Behavior Change to Promote Prevention' (2017) 37(2) *Information Services and Use* 105 <<https://doi.org/10.3233/ISU-170826>>.

120 Australian Commission on Safety and Quality in Healthcare, 'Australian Charter of Healthcare Rights' (Charter, 2020) <<https://www.safetyandquality.gov.au/publications-and-resources/resource-library/australian-charter-healthcare-rights-second-edition-a4-accessible>>.

relating to promoting autonomy and high-quality care which supports a person's choices and preferences. Studies in other contexts have found that patients and family caregivers can influence their own care, which resonates with our findings. For example, Yves Longtin et al draw together evidence from several studies to argue that patients 'can be persuasive and substantially modify behavior of health care workers'<sup>121</sup> and note that patients who made requests of healthcare providers, such as requesting particular medication or a specialty referral, were more likely to have their requests granted.<sup>122</sup> When individuals participate in influencing their own healthcare, patients have better outcomes.<sup>123</sup>

#### D Altering Behaviour at a System Level

Many participants took actions that altered behaviour beyond the individual healthcare relationship and, in some instances, had an impact at a system level. For example, patients and family caregivers made complaints and provided feedback (Healy's 'vocal complainants').<sup>124</sup> There were numerous examples of family caregivers in particular providing feedback about aspects of the VAD experience that they perceived could be improved. An obvious example is the participant who telephoned an institution and asked them to address their lack of institutional policies on VAD. This action was often inherently associated with a desire to alter behaviour at a system level because their individual experience of the VAD process had already occurred. Family caregivers also took on formal roles within the VAD system with advocacy groups and as providers themselves (Healy's 'active partners').<sup>125</sup> Healy notes that consumer representation on boards and councils is now often a priority for health systems,<sup>126</sup> and our results demonstrate that participants were engaged in formal roles within the system which provided an opportunity for them to alter the system from 'inside'.

In addition to falling within categories on Healy's pyramid, some actions described by our participants would also seemingly meet Black's definition of regulation. For example, one participant described providing feedback to the Victorian Government, participating in radio interviews, *and* preparing a research paper directed at altering the Victorian Government's policy position on a particular aspect of the *VAD Act*. These actions continued after their personal experience supporting a person to access VAD was completed and were motivated, among other reasons, by a desire to make the system better. This is a clear example of sustained and focused attempts to alter the behaviour of others to produce a

121 Yves Longtin et al, 'Patient Participation: Current Knowledge and Applicability to Patient Safety' (2010) 85(1) *Mayo Clinic Proceedings* 53, 55 <<https://doi.org/10.4065/mcp.2009.0248>>.

122 Ibid.

123 Healy, 'Patients as Regulatory Actors' (n 25); Krist et al (n 119); Longtin et al (n 121); Angela Coulter and Jo Ellins, 'Effectiveness of Strategies for Informing, Educating, and Involving Patients' (2007) 335(7609) *British Medical Journal* 24 <<https://doi.org/10.1136/bmj.39246.581169.80>>; Judith Healy, *Improving Health Care Safety and Quality: Reluctant Regulators* (Routledge, 1<sup>st</sup> ed, 2011) ch 9 <<https://doi.org/10.4324/9781315588049>>.

124 Healy, 'Patients as Regulatory Actors' (n 25) 594, 598–9.

125 Ibid 601–3.

126 Ibid.

particular outcome, in line with Black's definition of regulation,<sup>127</sup> that transcends action to support one's own access. The impacts of actions described by our participants included increased community awareness about VAD, more health professionals (particularly doctors) participating in roles within the VAD system, and increased efficiency of other actors.

The finding that patients and family caregivers intentionally alter behaviour to overcome barriers in the VAD system, and therefore potentially engage in 'regulatory' action, is novel in the VAD context. However, the finding that patients were motivated to alter behaviour and improve healthcare systems beyond their own experience is consistent with findings from studies in other contexts.<sup>128</sup> For example, a study by Renée Bouwman et al investigating why individuals complained about adverse events found that personal considerations were less important than system level considerations: participants sought to improve the quality of healthcare by making complaints for several reasons, including to prevent others from experiencing the same kind of event and highlighting learning opportunities for institutions.<sup>129</sup>

In general, literature on patient and family involvement in 'regulation' is in its 'infancy',<sup>130</sup> and more research is needed including on the impacts and benefits of patient and family involvement in 'regulation'. In a study of patient and family involvement in 'regulation' in four countries (including Australia), the authors reported that the benefits of involvement by patients and family caregivers in 'regulation' included enhancing the quality of regulation and consequently quality of care, legitimising decision-making by other regulators, and empowering patients and family caregivers.<sup>131</sup> Other studies have reported that only a small portion of patients and family caregivers felt that their action, such as making a complaint, had actually led to an improvement in healthcare quality and there was a gap between what they expected to achieve through making a complaint and what they perceived was achieved.<sup>132</sup> Our findings resonate with both perspectives: on one hand, participants reported substantive impacts on the system as described above, but there are also examples in our study of instances where participants' actions did not have the intended effect. One example of the latter is the participant whose

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127 Black (n 27) 26.

128 Renée Bouwman et al, 'Patients' Perspectives on the Role of Their Complaints in the Regulatory Process' (2016) 19(2) *Health Expectations* 483 <<https://doi.org/10.1111/hex.12373>>; Siri Wiig et al, 'Next of Kin Involvement in Regulatory Investigations of Adverse Events that Caused Patient Death: A Process Evaluation (Part I – The Next of Kin's Perspective)' (2021) 17(8) *Journal of Patient Safety* e1713 <<https://doi.org/10.1097/PTS.0000000000000630>> ('Next of Kin Involvement'); MM Bismark et al, 'Remedies Sought and Obtained in Healthcare Complaints' (2011) 20(9) *BMJ Quality and Safety* 806 <<https://doi.org/10.1136/bmjqs-2011-000109>>; Roland D Friele, Emmy M Sluijs and Johan Legemaate, 'Complaints Handling in Hospitals: An Empirical Study of Discrepancies between Patients' Expectations and Their Experiences' (2008) 8(1) *BMC Health Services Research* 199:1–11 <<https://doi.org/10.1186/1472-6963-8-199>>.

129 Bouwman et al (n 128) 491, 493.

130 Wiig et al, 'What Methods Are Used?' (n 28) 2.

131 Ibid.

132 Bouwman et al (n 128) 493; Bismark et al (n 128) 809; Friele, Sluijs and Legemaate (n 128) 2.



advocacy regarding the interpretation of an eligibility criterion has not yet resulted in a change to the interpretation of that criterion.

We do note that VAD is different from other contexts where the role of patients and family caregivers in altering healthcare delivery has been considered.<sup>133</sup> VAD in Victoria (and elsewhere in Australia) is a new and (for some) controversial health service, which is highly regulated by law via a prescribed process set out in the *VAD Act*, overseen by the VAD Review Board. The key ‘regulatory’ activities that arise as reported in this sample are therefore not focussed on reporting adverse events, like other regulatory literature, but rather on ensuring that the *VAD Act* is fulfilling its stated policy goals (which, as outlined above, include ensuring the system is safe, but also that it supports autonomy, accessibility, and high-quality care). This includes, for example, ensuring there are sufficient providers and pathways to access for eligible persons who make this choice.

### E Importance of Family Caregivers

Family caregivers played a particularly important role in assisting patients to influence their own healthcare, and also in altering the behaviour of other VAD participants and the system as a whole. This may be explained by a couple of factors. While in many healthcare contexts a patient may have limited ability to alter behaviour because they are unwell, this is likely to be even more pronounced in the VAD context where patients are terminally ill, necessitating a more active role for family caregivers in supporting them. Further, the result of choosing to access VAD, unlike many other aspects of healthcare is the patient dies (though we note the role of family caregiver involvement in ‘regulatory’ processes has also been considered in the context of adverse events leading to a patient’s death).<sup>134</sup> Consequently, family caregivers take on a particularly important role in taking action to alter behaviour because the patient is not able to do so. This also often meant that family caregivers’ motivations were to alter the system to make it better for others because it was too late for the individual patient they were supporting to benefit from any change.

Literature from Canada, the Netherlands, Switzerland, and the United States highlights the critical role of family caregivers in supporting patients to obtain VAD.<sup>135</sup> It also highlights that family opposition to VAD can result in the person not accessing it, demonstrating the power of family support (and conversely, of family opposition).<sup>136</sup> Although this literature does not take a ‘regulatory’ lens, as this article does, and focuses instead on their role in supporting patient access rather than altering behaviour as ‘regulators’, these findings nonetheless highlight the importance of family caregivers in taking action to support patients to overcome

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133 Bouwman et al (n 128); Bismark et al (n 128); Friele, Sluijs and Legemaate (n 128).

134 Siri Wiig, Peter D Hibbert and Jeffrey Braithwaite, ‘The Patient Died: What about Involvement in the Investigation Process?’ (2020) 32(5) *International Journal for Quality in Health Care* 342 <<https://doi.org/10.1093/intqhc/mzaa034>>.

135 Gamondi et al (n 111); Hales et al (n 113); Oczkowski et al, ‘How Can We Improve the Experiences’ (n 113); Brown et al, ‘Medical Assistance in Dying’ (n 113); Brown et al, ‘Care Considerations’ (n 113).

136 Gamondi et al (n 111) 2.

the effects of illness and shape their experience of VAD.<sup>137</sup> Given the complexity of their experiences,<sup>138</sup> support for family caregivers assisting a person through the VAD process and afterwards is critical. There have also been calls for assisted dying clinical guidelines to explicitly consider the important role of family caregivers,<sup>139</sup> and our findings echo the importance of this.

## F Implications of Finding That Patients and Family Caregivers May Potentially 'Regulate'

In some respects, the finding that patients and family caregivers are engaged in attempting to improve the functioning of the wider VAD system is a positive one. As the individuals who are most affected by poor quality regulation, they have the keenest interest in influencing regulation to make it better,<sup>140</sup> and should have the opportunity to influence decision-making and behaviour.<sup>141</sup> It also suggests that patients and family caregivers in our sample were able to overcome the barriers outlined in the literature to acting as 'regulators'. Key barriers identified in the literature include information asymmetry and knowledge barriers, and power imbalances.<sup>142</sup>

The first barrier of information asymmetry between health professionals and patients and family caregivers was not pronounced in this study. As noted in Theme 4, it was striking how many of our participants and patients had health and/or legal expertise, including many being health professionals or lawyers. Participants reported (Theme 4) that their knowledge of the VAD process and education helped them to take potentially 'regulatory' actions reported in Theme 1. The sixth VAD Review Board Report highlights that VAD applicants in Victoria 'are considerably more highly educated than the general public of the same age'.<sup>143</sup> This report also describes that, of individuals aged over 55, 59% of VAD applicants had completed year 12 or equivalent, compared to 39% of the general population.<sup>144</sup> This resonates with our findings: patients in our sample were well educated with 9 out of 28 patients (approximately 32.1%) having completed high school, and 12 out of 28 (approximately 42.9%) having a university diploma, bachelor's degree, or postgraduate degree (ie, approximately 75% have completed high school or higher).<sup>145</sup> High levels of education, health knowledge, and legal knowledge may help to partially explain why patients and family caregivers were successfully able to

137 Hales et al (n 113); Oczkowski et al, 'How Can We Improve the Experiences' (n 113); Brown et al, 'Medical Assistance in Dying' (n 113); Brown et al, 'Care Considerations' (n 113).

138 Andrea N Frolic et al, 'Double-Edged MAiD Death Family Legacy: A Qualitative Descriptive Study' (2024) 14(e1) *BMJ Supportive and Palliative Care* e845 <<https://doi.org/10.1136/bmjspcare-2020-002648>>.

139 Gamondi et al (n 111) 13.

140 Healy, 'Patients as Regulatory Actors' (n 25) 592.

141 Wiig et al, 'Next of Kin Involvement' (n 128).

142 Healy, 'Patients as Regulatory Actors' (n 25) 595.

143 *2022 Annual Report* (n 18) 14.

144 *Ibid.*

145 We do not suggest that this figure is generalisable, given our qualitative methodology. However, information about levels of education of patients in this sample is provided as evidence supporting our interpretation of the data within our sample. See, eg, Joseph A Maxwell, 'Using Numbers in Qualitative Research' (2010) 16(6) *Qualitative Inquiry* 475 <<https://doi.org/10.1177/1077800410364740>>.

navigate potential barriers to access, such as the legal prohibition on doctors raising VAD with patients (doctors have voiced concerns that a lack of health literacy may result in this prohibition being a barrier to access in Victoria's VAD system).<sup>146</sup>

Linked to education is socio-economic status.<sup>147</sup> Literature from Canada,<sup>148</sup> the United States and the Netherlands,<sup>149</sup> and Switzerland,<sup>150</sup> has also reported that patients from a higher socio-economic background are more likely to access VAD.<sup>151</sup> A systematic review by Sara Willems et al found that patients from higher socio-economic backgrounds with higher education levels 'communicate more actively (they ask more questions, are more opinionated) and show more affective expressiveness, eliciting more information from their physician'.<sup>152</sup> Conversely, patients from lower socio-economic and education backgrounds were subject to 'a more directive and a less participatory consulting style characterised by e.g. less involvement in treatment decisions; a higher percentage of biomedical talk and physicians' question asking; lower patient control over communication; less diagnostic and treatment information, more physical examination'.<sup>153</sup> While this does not entirely explain how patients and family caregivers in this sample were able to overcome the barrier of information asymmetry in order to act in ways that were potentially 'regulatory', it may at least partially explain why they were able to do so.

A second reported barrier is power imbalances. The relative imbalance between patients and physicians may be lessened for patients who are more highly educated,<sup>154</sup> as many patients and participants in this sample were. However, the power of an individual patient or family member is still likely to be more limited than other regulators,<sup>155</sup> such as a health institution or government decision-maker. One way that patients and family caregivers overcame power imbalances in this study was by enlisting others with greater power to support their actions.<sup>156</sup> For patients, a family member with particular knowledge may be a more powerful

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146 Rutherford (n 21) 962.

147 Kenneth Chambaere et al, 'Is Educational Attainment Related to End-of-Life Decision-Making? A Large Post-mortem Survey in Belgium' (2013) 13(1) *BMC Public Health* 1055:1–9, 1 <<https://doi.org/10.1186/1471-2458-13-1055>>.

148 James Downar et al, 'Early Experience with Medical Assistance in Dying in Ontario, Canada: A Cohort Study' (2020) 192(8) *Canadian Medical Association Journal* <<https://doi.org/10.1503/cmaj.200016>>; Donald A Redelmeier et al, 'Association of Socioeconomic Status with Medical Assistance in Dying: A Case-Control Analysis' (2021) 11(5) *BMJ Open* e043547:1–10 <<https://doi.org/10.1136/bmjopen-2020-043547>>.

149 Margaret P Battin et al, 'Legal Physician-Assisted Dying in Oregon and the Netherlands: Evidence concerning the Impact on Patients in "Vulnerable" Groups' (2007) 33(10) *Journal of Medical Ethics* 591 <<https://doi.org/10.1136/jme.2007.022335>>.

150 Nicole Steck et al, 'Suicide Assisted by Right-to-Die Associations: A Population Based Cohort Study' (2014) 43(2) *International Journal of Epidemiology* 614 <<https://doi.org/10.1093/ije/dyu010>>.

151 Chambaere et al (n 147) 3–5.

152 S Willems et al, 'Socio-economic Status of the Patient and Doctor–Patient Communication: Does It Make a Difference?' (2005) 56(2) *Patient Education and Counseling* 139, 143 <<https://doi.org/10.1016/j.pec.2004.02.011>>.

153 Ibid.

154 Ibid 145; Chambaere et al (n 147) 7.

155 Healy, 'Patients as Regulatory Actors' (n 25) 592.

156 Ibid 602–3; Braithwaite (n 25) 29–31.

actor, and the patient may draw on the family member as part of their 'regulatory' 'network'.<sup>157</sup> As noted above, family caregivers were key supports for patients in this study. Networks extended beyond family members, though, and included advocacy groups, decision-makers within organisations, and parliamentarians. The 'regulatory' relationship between patients and family caregivers, and others (such as advocacy groups and parliamentarians) was symbiotic. Patients and family caregivers have the unique power of lived experience and their ability to tell stories is powerful and influential on policymakers.<sup>158</sup> This meant that patients and family caregivers were also enlisted by advocacy groups and parliamentarians to achieve their objectives (including law reform and drawing attention to aspects of VAD regulation perceived as barriers to access). This is illustrated by some participants in this study who explained that they did not go out of their way to seek opportunities, but that they just responded to opportunities or requests for assistance. The power of patients and family caregivers as part of networks could also be used inversely to argue *against* changes to VAD regulations (though this is outside the scope of this article).

Despite patients and family caregivers in this study overcoming barriers to acting as 'regulators', 'regulation' is still not an easy role for patients and family caregivers to undertake,<sup>159</sup> particularly when the action is prompted by a negative experience such as encountering a barrier to accessing VAD. While patients and family caregivers should have the opportunity to 'regulate' if they wish,<sup>160</sup> and their perspectives may make a tangible difference, it 'does not mean that all patients choose to be involved or indeed should have to be responsible for monitoring care'.<sup>161</sup> This is consistent with Australian research by David J Carter, James Brown, and Carla Saunders, which suggests the public does not perceive individual patients as being responsible for ensuring quality healthcare.<sup>162</sup> This also raises a criticism of movements towards increasing participation. As Andrea Cornwall writes, initiatives to increase participation by patients 'tend to be premised on the idea that everyone would want to participate if only they could',<sup>163</sup> which is a flawed assumption. While Victoria's VAD system should engage with patients and family caregivers who want to 'regulate' and capitalise on these participation opportunities, it should equally recognise that not all patients and family caregivers wish to do so. It should also acknowledge the middle ground that participation is not all or nothing: some individuals may wish to participate but only to a certain extent, in ways they feel comfortable. The current approach of the VAD Review

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157 Healy, 'Patients as Regulatory Actors' (n 25) 602–3.

158 Ibid 599.

159 Ibid 591.

160 Wiig et al, 'Next of Kin Involvement' (n 128).

161 Josephine Ocloo and Rachel Matthews, 'From Tokenism to Empowerment: Progressing Patient and Public Involvement in Healthcare Improvement' (2016) 25(8) *BMJ Quality and Safety* 626, 626 <<https://doi.org/10.1136/bmjqs-2015-004839>>.

162 David J Carter, James Brown and Carla Saunders, 'The Patient's Voice: Australian Health Care Quality and Safety Regulation from the Perspective of the Public' (2018) 25(2) *Journal of Law and Medicine* 408.

163 Andrea Cornwall, 'Unpacking "Participation": Models, Meanings and Practices' (2008) 43(3) *Community Development Journal* 269, 279 <<https://doi.org/10.1093/cdj/bsn010>>.

Board in seeking optional feedback, as reported by participants in this study, is a good example of such a middle-ground approach. As noted above, the nature of the VAD experience including experiencing barriers to access was a key facilitator of 'regulatory action'. Victoria's VAD system is still relatively new, and these barriers to access may decrease naturally as the system matures, resulting in less 'regulatory' activity being undertaken by patients and family caregivers. In the meantime, acknowledging the important role of patients and family caregivers in supporting patients to access their choice for VAD, and potentially acting as 'regulators' in Victoria's VAD system more broadly, is important. Supports for family members in particular are needed, taking into account their important role in Victoria's VAD system.

### G Strengths and Limitations

This article is the first internationally to consider the ways in which patients and family caregivers may act as 'regulatory actors' in VAD systems. It is also one of the first studies in Australia to report on patient and family caregiver perspectives and experiences of the Victorian VAD system.

In terms of limitations, despite recruiting both patients and family caregivers, only one of our participants was a patient, which may be a function of how unwell patients seeking VAD are. Family caregiver perspectives are valuable in understanding patients' experiences,<sup>164</sup> particularly in relation to the quality of service provision,<sup>165</sup> although we note that patients may have perceived their experiences differently. Family caregiver perspectives are also valuable as they allow perspectives to be obtained after the patient's death. Therefore, many of our participants had an opportunity to reflect on their perspectives and the impact of the VAD death, and the time and opportunity to engage in further 'regulatory' behaviour, which was central to answering the research explored in this article. Family caregiver perspectives were therefore critical in answering our research question.

Further research with patients who missed out on VAD, and their family caregivers, is also needed to understand those experiences in more detail and how this prompted behaviour to alter the VAD system. Research with other stakeholders such as health professionals or regulators would also be beneficial in triangulating some of the data and perceptions of patients and family caregivers of their own role in altering the VAD system.

Because of our qualitative methodology, we do not suggest that our findings are generalisable but are nonetheless valuable as the qualitative approach allowed for in-depth exploration of participants' experiences and perceptions of their role (and patients' experiences).

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164 Beverly R Williams et al, 'Identifying and Responding to Ethical and Methodological Issues in After-death Interviews with Next-of-Kin' (2008) 32(3) *Death Studies* 197 <<https://doi.org/10.1080/07481180701881297>>.

165 CJ McPherson and JM Addington-Hall, 'Judging the Quality of Care at the End of Life: Can Proxies Provide Reliable Information?' (2003) 56(1) *Social Science and Medicine* 95 <[https://doi.org/10.1016/S0277-9536\(02\)00011-4](https://doi.org/10.1016/S0277-9536(02)00011-4)>.

Finally, because our method included recruitment via patient advocacy organisations, the participants we recruited were supportive of VAD and might have been more likely to alter the VAD system (as it is reported in Theme 4 that connection to an advocacy group was an impacting factor across the other three themes). Further research with individuals who are opposed to VAD is needed (and might provide more insights about how individuals opposed to VAD may seek to alter behaviour or impact the system in different ways).

## V CONCLUSION

Patients and family caregivers are at the heart of Victoria's VAD system and are more than just passive recipients of healthcare in the VAD context. This research found that patients and family caregivers alter behaviour in Victoria's VAD system at an individual and system-wide level. Participants described overcoming barriers such as illness, information asymmetry, and power imbalances in order to influence their own healthcare, as well as to alter the behaviour of other participants in the VAD system and influence the system more broadly. However, 'regulatory activity' (and particularly activity directed at system-level altering of behaviour) can be challenging for patients and family caregivers to undertake, especially given that in this sample it appears to largely be driven by experiences of barriers to access. Supports for patients and family caregivers are needed, given their important role in influencing the operation of Victoria's VAD system. Consideration of how these barriers to access can be reduced by other regulatory means is also critical to reduce the 'regulatory' burden on patients and family caregivers.