

Access to voluntary assisted dying in Victoria: a qualitative study of family caregivers' perceptions of barriers and facilitators

Ben P White , Ruthie Jeanneret, Eliana Close , Lindy Willmott 

The known: Australian doctors involved in voluntary assisted dying have identified access barriers, including legal prohibition of telehealth consultations and raising the topic with their patients, and procedural complexity.

The new: The experiences of family caregivers of people seeking voluntary assisted dying in Victoria confirmed barriers previously identified by doctors, but also identified new problems, including institutional objection. People can nevertheless navigate the process, partly shielded from system complexity by key facilitators, including care navigators, coordinating doctors, and the Statewide Pharmacy Service.

The implications: Adequate support for doctors, navigators, and other facilitators of access is vital for the efficient functioning of the voluntary assisted dying application process.

Legislation permitting voluntary assisted dying has been enacted in all Australian states; the territories may follow suit now the Australian government no longer prohibits them doing so.¹ The application process for voluntary assisted dying must be sufficiently rigorous to exclude people who are ineligible, but provide choice for those who are eligible.²

There is a growing body of literature on doctors' early experience in Victoria, the first Australian state to enact voluntary assisted dying legislation. They reported procedural difficulties, including complex and bureaucratic approval processes³⁻⁶ and legal challenges, such as the prohibition of initiating conversations with patients about voluntary assisted dying³ and federal criminal law restrictions on telehealth consultations for this purpose.^{3,7-8} However, the experience of people seeking assistance to die has not been reported. Their perspectives, central to improving health care and person-centred care,⁹ are critical when evaluating how voluntary assisted dying is managed.

Overseas investigations of the personal experience of voluntary assisted dying have examined communication during eligibility assessments¹⁰⁻¹¹ and the factors underlying applications for assisted dying.¹²⁻¹⁶ Procedural barriers to and facilitators of access, as reported by people seeking assistance and their caregivers, have also been reported.^{10,17-21}

Given the lack of research in Australia, we investigated the early experiences of people seeking an assisted death under the *Voluntary Assisted Dying Act 2017* (Vic),²² focusing on barriers to and facilitators of access.

Methods

We report our study according to the Consolidated Criteria for Reporting Qualitative Research (COREQ).²³ Eligible for

Abstract

Objectives: To investigate barriers to and facilitators of access to voluntary assisted dying in Victoria under the *Voluntary Assisted Dying Act 2017* (Vic).

Design, setting, participants: Qualitative study; semi-structured interviews with people who had applied for voluntary assisted dying or their family caregivers, recruited via social media and interested advocacy groups; interviews conducted 17 August – 26 November 2021.

Main outcome measures: Barriers to and facilitators of access to voluntary assisted dying.

Results: We interviewed 33 participants about 28 people who had applied for voluntary assisted dying; all but one of the interviews were with family caregivers after their relatives' deaths, and all but three were conducted via Zoom. The major barriers to access identified by participants were finding trained and willing doctors to assess eligibility for voluntary assisted dying; the time required for the application process (especially given how ill the applicants were); the prohibition of telehealth consultations; institutional objections to voluntary assisted dying; and the prohibition of health practitioners raising voluntary assisted dying with their patients. The major facilitators mentioned were care navigators (both the Statewide service and local navigators); finding a supportive coordinating practitioner; the Statewide Pharmacy Service; and system flow once the process had been initiated (although not during the early days of voluntary assisted dying in Victoria). Access was particularly difficult for people in regional areas or with neurodegenerative conditions.

Conclusions: Access to voluntary assisted dying has improved in Victoria, and people generally felt supported while navigating the application process once they found a coordinating practitioner or a navigator. But this step, and other barriers, often still made patient access difficult. Adequate support for doctors, navigators and other facilitators of access is vital for the effective functioning of the overall process.

participation were people seeking voluntary assisted dying in Victoria and family caregivers who had supported a person during this process. We recruited participants via Twitter (@HealthLawQUT; 11 August, 12 and 19 October 2021) and through the advocacy groups Go Gentle Australia (<https://www.gogentleaustralia.org.au>) and Dying with Dignity Victoria (<https://www.dwdv.org.au>), who circulated study details via social media and in their newsletters and emails (recruitment requests to these organisations: 4 August 2021). We initially employed convenience sampling, but later (from 19 October 2021) used purposive sampling to obtain a broad representation of voluntary assisted dying applicants²⁴ with respect to age, gender, illness, location (metropolitan or regional), date of application for assistance, and their experience of voluntary assisted dying (died using self- or practitioner-administered medication, sought voluntary assisted dying but had not proceeded, or were not approved). Later recruitment communications included

the specific participant characteristics sought, including direct emails from the two advocacy groups to potentially matching participants (recruitment request to the organisations: 22 October 2021).

Our interview guide ([Supporting Information](#)) was based on our analysis of the Victorian legislation,² interviews with doctors,³⁻⁵ and discussions within the research team. The questions explored were the process of seeking access to voluntary assisted dying, including obtaining information, eligibility assessment, and obtaining and taking the medication used; navigating the voluntary assisted dying application process; and overall perceptions of the process. Interviews explored the applicants' experiences of seeking voluntary assisted dying; family caregivers were therefore asked to focus on their relatives' experiences.

All semi-structured interviews were conducted by authors BPW and RJ (with one a designated lead) during 17 August – 26 November 2021 as Zoom video conferences, except for two undertaken by telephone and one in person. Recruitment ceased once data saturation had been reached (information redundancy).²⁵ Interviews were digitally audio-recorded and transcribed verbatim. Participants could amend their transcript (member checking),²⁶ and some provided supplementary information at this point (eg, chronology or narrative of their experience).

We used NVivo 1.6.1 (QSR International) to store, code, and search transcripts and supplementary information. Thematic analysis was applied line by line, using codes developed deductively (based on relevant publications and iterative discussion of emerging themes) and inductively.²⁷ Seventeen interviews were coded by BPW and RJ (codes discussed and refined periodically), eleven by BPW alone. Authors BPW and RJ discussed each interview after its completion, and regularly conferred during the data collection and analysis phases of the study (iterative analysis). Themes were discussed and tested by all authors.

Ethics approval

Our study was approved by the Queensland University of Technology Human Research Ethics Committee (200000270). Each participant provided informed consent in advance.

Results

We interviewed a total of 33 participants ([Box 1](#)) about 28 people who had applied for voluntary assisted dying ([Box 2](#)). All but one of the interviews were with family caregivers after their family members' deaths; one of the two applicants for voluntary assisted dying who had consented to participation died before they could be interviewed. Eight participants were recruited during the purposive sampling period. The median length of the interviews was 90 minutes (range, 56–130 minutes).

Barriers to access to voluntary assisted dying ([Box 3](#))

Difficulty finding doctors

The main barrier to access was finding doctors willing to assist people seeking voluntary assisted dying. Identifying a coordinating practitioner (the first doctor in the process) was particularly difficult. This was especially the case when the process was new in Victoria; it was all "secret squirrel business", and no list of doctors who might be willing to assist was available.

Participants said that the difficulty in finding doctors was related to the need for one doctor to be a specialist in the illness of the applicant; conscientious objection; apprehension with regard to involvement or a lack of interest in voluntary assisted dying; and doctors not having completed or wanting to undertake the legally required training. People with neurological conditions or living outside metropolitan areas often mentioned these problems.

The time required for the voluntary assisted dying application process

Procedural delays were particularly frequent during the early days of voluntary assisted dying in Victoria, and were often linked with the difficulty of finding doctors willing to assist. Delays were greater for people living in regional areas. Participants recognised that a rigorous assessment process was needed, but many felt it took "too long" and was "overdone", and was "a complicated and drawn-out undertaking".

The time involved was particularly problematic given the physical condition of applicants for voluntary assisted dying; to be eligible, clinical expectation of death within six months (twelve months for people with neurodegenerative conditions) is required. This prerequisite was identified by many participants as needing revision. Concerns were expressed about "missing the boat", and many participants referred to the "race" to gain access to voluntary assisted dying before the applicant died, became too unwell to navigate the system, or lost the capacity or ability to communicate. For some people, late awareness of the short time remaining to them compounded their access problems.

However, some participants described the process as proceeding "really quickly". Perceptions of time could be influenced by expectations of the time required for the application process, the urgency of the need for access to voluntary assisted dying, and levels of suffering: "every day felt like a month".

Telehealth prohibition

The prohibition of using telehealth consultations during the voluntary assisted dying process was an "absolute pain", causing delays and suffering, leaving people "in tears and distressed and [in] hysterics". Although this problem was often raised by people in regional areas, metropolitan participants were also concerned about requiring very unwell people to travel. The widespread use of telehealth during the coronavirus disease 2019 (COVID-19) pandemic compounded participants' sense of its prohibition being unjustified. They did, however, acknowledge the limits of telehealth care and that its use in voluntary assisted dying should be cautious. Some thought it appropriate after a first in-person consultation, while others noted challenges for conducting some neurological assessments and for people with communication difficulties.

Institutional objection

Institutional objections were identified as access barriers for seventeen applicants for voluntary assisted dying, including institutions prohibiting eligibility assessments and barring entry to assessing doctors. Some institutions prohibited receiving or using the voluntary assisted dying medication provided by the Statewide Pharmacy Service²⁸ on their premises.

These objections led to delays and reduced choice. Some participants described relatives having to choose between pursuing voluntary assisted dying and being admitted to a

1 Characteristics of the 33 interviewees

Characteristic	Number
Age (years), mean (SD)	56.6 (15.1)
20–29	1
30–39	4
40–49	7
50–59	3
60–69	13
70–79	4
80–89	1
Gender	
Women	26
Men	7
Relationship to person seeking voluntary assisted dying*	
Child (including stepchild, child in-law)	17
Spouse (including de facto partner)	10
Parent	3
Sibling	2
Close friend	1
Self	1

SD = standard deviation. * One participant spoke about two people and is included here in two categories. In five interviews, two family caregivers were interviewed together (eg, a son and daughter-in-law about the son's parent's experience). Two interviews were conducted with different family members separately about the same person. ♦

hospital that did not support this aim to have their pain and symptoms managed. Some had to leave their current place of care (their "so-called 'home'" in the case of people in residential aged care facilities) to gain access, but this depended on alternatives being available.

Participants also described emotional and relationship costs of institutional objections. Some people were "terrified" about missing out, and delays and reduced choice caused "distress" and "great sadness". Some felt distrust for the institution and staff in terms of clinical recommendations, and one participant described pursuing the voluntary assisted dying process in secret.

Prohibition of health practitioners initiating discussion of voluntary assisted dying

Participants generally found problematic the prohibition of health practitioners raising the option of voluntary assisted dying with their patients. Although they understood that the intent was to ensure free choice, most were concerned that doctors were "muzzled" or "silenced". Some people found it difficult to raise the subject with their doctors, and others described conversations that were "awkward and a bit contorted" as they tried to find "the right words". Concerns were repeatedly expressed about the prohibition particularly reducing access for people from culturally and linguistically diverse backgrounds, and people with lower levels of education or poorer technology and information literacy: "If you're not exposed to it, you don't know to ask."

2 Characteristics of the 28 people whose experiences of seeking voluntary assisted dying were discussed in the interviews

Characteristic	Number
Age (years), mean (SD)	70.8 (15.4)
20–29	1
30–39	1
40–49	0
50–59	3
60–69	7
70–79	8
80–89	6
90–99	2
Gender	
Women	13
Men	15
Location	
Metropolitan	16
Regional*	12
Highest level of education	
Some high school	7
High school	9
University (diploma)	1
University (undergraduate degree)	7
University (postgraduate degree, including graduate diploma)	4
Primary disease, illness, medical condition	
Cancer	18
Neurological	9
Other	1
Time 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
Outcome of assessment	
Assessed as eligible for voluntary assisted dying	24
Death by self-administered medication	19
Death by practitioner administered medication	3
Natural death	1
Person waiting to take medication	1
Assessed as ineligible; died	1
Death prior to completing eligibility assessment	3

SD = standard deviation. * One person classified as regional moved to a metropolitan area during the voluntary assisted dying process. ♦

3 Sample comments by participating family caregivers about barriers to access to voluntary assisted dying

Difficulty finding doctors

- [The doctor] was just matter of fact about it and said “Look, I can’t do it.” ... when I asked him, “Well, do you know if there’s any other doctors at the hospital?” ... he said he would try to help, and he did try to help. Unfortunately, he then encountered the same hurdles that we encountered of no knowledge, no public registers, and there wasn’t necessarily another person for him to refer us to.
- [The doctor] took up the issue [and] must have written to several dozen neurologists over several weeks outlining and requesting the need for assistance. Many never answered, others responded to say that they were objectors and others just said they were unavailable. One made an appointment ... without realising the purpose and this was later quickly withdrawn. There was no data provided by anyone as to a list, for example, of specialists who might be available.

The time required for the voluntary assisted dying application process

- Like the whole process, every day just seemed like a month and every other appointment just seemed like another hurdle to jump over and another hoop to go through and another boulder to climb to get to the top of the mountain. So retrospectively, you know, if you’re going to tell people they can’t access this medication until they’re within zero to six months of dying ... they’re potentially ruling out all their travel time to be able to make these interviews ... if we’re not allowed to use telehealth.

Telehealth prohibition

- Certainly for mobility-related neurological degenerative diseases, and anything else really, the inability to telehealth is just horrendous. I mean I am supportive of a face-to-face consultation, and potentially the first one, but we were restricted in all those other times of not being able to use telehealth. Growing up in [Town], that’s six and a half hours from Melbourne. You know, if you’re going to tell people they can’t access this medication until they’re within zero to six months of dying ... they’re potentially ruling out all their travel time to be able to make these interviews ... if we’re not allowed to use telehealth.

Institutional objection

- [That] was a significant challenge and just created a whole lot of stress on what was her last day. You know, it was this frantic rush and ... then having to wheel her out and she couldn’t say goodbye to people. Yeah, it just was just [laughs] ... you get to the top of the mountain and then you’ve got that last big, huge boulder to climb over. It will always be a great sadness for me that the last few precious hours on Mum’s last day were mostly filled with stress and distress, having to scurry around moving her out of her so-called “home”.
- She was a doctor from [another hospital], she was there to see a patient on the patient’s request, she should have been allowed in and they actively stopped her.

Prohibition of health practitioners initiating discussion of voluntary assisted dying

- I think it’s the rigidity of the Victorian legislation with the person having to raise the matter ... it takes a fairly determined person to raise it with their health care team. I think for a whole raft of reasons, including health literacy and communication ... it’s a real problem with the Victorian legislation.
- I personally think it’s ridiculous that the doctors can’t proactively mention this. I actually think it’s borderline negligent. Not on their fault, but it’s the equivalent of you’re withholding an important medical and lifestyle option from a patient when they’re facing into this difficult scenario. To kind of withhold it from them just to me seems ridiculous and negligent, and I can come up with all sorts of other adjectives.
- [This] is just something that I feel strongly about ... It should never be someone else’s suggestion. It really has to come from the individual, the person ... It shouldn’t come from [my spouse] or my children. It needs to come from me. But equally if I don’t know that it’s an option for me, then I’m disempowered.

Facilitators of access to voluntary assisted dying (Box 4)

Care navigators

Participants identified the Statewide care navigators²⁸ as the most significant facilitators of access, “the jewel in the crown”. This was particularly the case at the beginning of the process,

4 Sample comments by participating family caregivers about facilitators of access to voluntary assisted dying

Care navigators

- Then obviously the care navigator, which is the first port of call, they were fantastic ... I keep going on about that word compassion and care ... They made a very difficult situation more manageable.
- [All] the way through I’ve been in contact with the navigators. Without them this could not happen. It could not happen, it is not possible. I knew the whole process. I was familiar with everything. I am confident, I’m assertive. I could not have done it without them.
- [The best thing] ... It would be [name of local care navigator], the liaison ... there was never a time that I was unsure of the next process. We were so well informed we knew what was going on at all times.

Finding a supportive coordinating practitioner

- [If] we hadn’t had a doctor of that commitment ... and skill I’m not sure what would have happened. Well, the best [thing about the system] ... is the support and help that we got from the doctor [who] guided us through the whole process.
- The next step was we went to his oncologist and said “Look, I have been investigating dying with dignity and I think this is the path that I would like to go down.” And that changed everything with the oncologist. It made a huge difference because he was extremely supportive. We were just so, so lucky. That was fortuitous.
- I think once Mum raised it with the oncologist, the doctor that we dealt with was amazing. He made then the next steps just all come together. He was the coordinator and he was very compassionate and available ... [If] in the first meeting about it, we thought, oh my God, there’s this to do and that to do and we’re going to have to provide this and provide that, that might have felt overwhelming ... [Mum] wasn’t good with paperwork ... [and] I think she would have thought, oh God, this is going to be a lot of work. But I think we both felt, when we had that first meeting about it, that we were going to be well managed through it.

Statewide Pharmacy Service

- The two pharmacists that came down were just beautiful humans. They were friendly, they were kind, they were – went through everything, any questions that anyone had answered freely. They were amazing, I have nothing but absolute praise for them.
- [With] the medication the pharmacists were great. They were very comprehensive. The manual was lovely and simple. You know, it was literally do this, turn the page, do this, turn the page, do this, turn the page. It was set out from a timing perspective. They did suggest that we mix the medication before so that ... was all organised and we didn’t have to think about it.
- I called the [Statewide] pharmacy and they said “We can get it to you.” So this was, I think on the Tuesday or Wednesday, “We can get it to you on the Monday.” I just burst into tears and I said “I can’t do that, because things are going quickly” ... Then they said “Leave it with us, we will absolutely do our best.” They called me back, and they said “We can do it on Friday.”

System flow after initiation of access

- [The voluntary assisted dying] coordinator did a lot of the organisation stuff. She’d work with the oncologist, but then she’d do the running around and ... the admin organisation side of it and contact the people and say “Okay, can you come in? I need another witness. Can you come in? We’ll set up the date at this time.” So it was like a coordinated team working together and we just were, I guess, the participants. We didn’t have to go and do that. We could just sit back and it happened all around us.
- I think as I mentioned before, the biggest challenge for us was that Dad was an early adopter. So he was very, very early on in the system. So I think that many of the challenges or the barriers that we experienced were because of the lack of maturity in the broader system.

when people and their families often struggled to locate doctors for assistance and to understand the initial procedural steps. Also important were local voluntary assisted dying navigators; for example, dedicated staff appointed by a hospital or health care service.

Participants highlighted the impact of the navigators’ compassion and personal commitment to the people seeking voluntary

assisted dying and their families. Their facilitating function seems to have increased with time, perhaps reflecting additional staff appointments to the service, broader improvements to procedural arrangements for voluntary assisted dying, and a growing pool of trained and willing doctors.

Finding a supportive coordinating practitioner

Finding a supportive coordinating practitioner was a key facilitator. Many participants described this happening by luck; for example, the applicant's usual doctor agreed to assess their eligibility or referred them to a willing colleague. Some participants described being at a loss about what to do next if their doctor was not willing to assist. For some, the coordinating doctor actively provided guidance throughout the process, fulfilling a role similar to navigators, and many participants spoke in glowing terms of their doctors' compassion and personal commitment.

Statewide Pharmacy Service

Although their interaction with people seeking voluntary assisted dying is focused on providing education and supplying the required medication, the Statewide Pharmacy Service was identified as a key facilitator. Participants described empathetic pharmacists who provided comprehensive medication administration training, tailored to people and their families, as well as a user-friendly booklet. Applicants for voluntary assisted dying and family caregivers found this "very reassuring", understood and had confidence in the process, and appreciated the offer of further advice if needed. Nevertheless, the capacity of a single state-wide pharmacy service was sometimes mentioned as a problem. Some participants reported delays in medication access, particularly in regional areas, although pharmacists tried to expedite supply in urgent cases.

System flow after initiation of access

Participants generally described the process, once a coordinating practitioner or a navigator had been found, as well supported and flowing "seamlessly". Although it was time-consuming and complicated, many participants reported that once the applicant "got through that door", the next steps "just flowed" without needing to be organised by the applicant or their caregivers. This was often linked to proactive process management by the coordinating practitioner, the Statewide or local navigators, as well as family caregiver support.

These positive experiences were generally reported by people engaged with voluntary assisted dying after the application processes had become established in Victoria. Early users did not report effective system flow, and some explicitly identified early operation problems as contributing to negative experiences.

Discussion

The application process for voluntary assisted dying in Victoria, from the perspective of applicants and their families, is generally working acceptably now that the process has become established. The more recent experience is that initial access can be difficult, but once achieved, the further steps proceed smoothly. In contrast to the procedural difficulties reported by doctors (especially during the early years of voluntary assisted dying in Victoria),³⁻⁵ calls that applicants and family caregivers be shielded from system complexity appear to have been heard.²⁹

However, participants also described barriers to access. Some reflect the experience of Victorian doctors who have reported challenges associated with not being permitted to raise voluntary assisted dying with their patients or to use telehealth services during the process, as well as difficulties for very ill people with little time available to them navigating a complex process.³⁻⁴ Some barriers are new, such as the impact of institutional objection on access.³⁰ These barriers are broadly similar to those reported overseas, including the urgency imposed by the progression of a person's illness,¹⁸ difficulties in locating a coordinating practitioner,¹⁹ and the impact of institutional objections.^{19,21,31}

The experiences of caregivers were generally consistent with those of doctors, and suggest that more needs to be done to ease access for eligible people, including efforts to further mitigate system complexity. Voluntary assisted dying care navigators (both Statewide and local), coordinating doctors, and the Statewide pharmacists are critical in this regard. As also reported overseas, participants emphasised that all three are pivotal to making a complex system functional,¹⁷ so that its viability depends on supporting them adequately.¹⁹ Participant reports of some navigator and pharmacist capacity limitations may indicate the need for greater support. Doctors, particularly the relatively small number who assist people seeking voluntary assisted dying,^{3,32} also need support by increasing both the pool of doctors trained in this area and their remuneration.^{6,33}

Our findings suggest strategies for improving access to voluntary assisted dying are needed. As people in regional areas and those with neurodegenerative conditions, in particular, reported access difficulties, attention to assisting these two groups is necessary. Some access problems are difficult because they are embedded in the Victorian legislation, such as the cumulative impact of a time-consuming application process on people for whom only limited time remains. Others could be more readily solved; for example, federal law could be amended to remove the telehealth prohibition,⁷⁻⁸ and state government policy could be amended to direct objecting institutions to not impede access to voluntary assisted dying.

Limitations

We have reported the first study of the experiences of people seeking voluntary assisted dying in Victoria, albeit largely as described by their family caregivers. Purposive sampling later in our study increased the diversity of our sample, but a broader range of experiences should be explored, including those of people who requested voluntary assisted dying but were deemed ineligible or who did not seek access but may have done so had they been aware of it. The nature of our sample may mean there are barriers to voluntary assisted dying not raised by our participants. Further, as we recruited some participants via advocacy groups, they may have viewed voluntary assisted dying more favourably than the general public in Victoria. The experiences of people seeking voluntary assisted dying may differ from those reported by their family members, but the accounts of relatives can nonetheless provide insights into experiences otherwise difficult to access, given that people seeking voluntary assisted dying in Victoria are by definition terminally ill. The perspectives of applicants for voluntary assisted dying should nevertheless be directly explored. Finally, as a qualitative study based on a non-representative sample of self-selected participants in one state, our findings may not be more broadly generalisable.

Conclusion

Access to voluntary assisted dying in Victoria appears to have improved over time as the application process has become more established. Family caregivers reported generally positive experiences once they had gained access to the voluntary assisted dying application process, but legal and practice barriers remain. Crucial to ensuring access is finding a doctor willing to assist, and navigators play a critical role supporting people to make this connection. Adequate support for doctors, navigators, and other facilitators is vital for the effective functioning of voluntary assisted dying processes.

Acknowledgements: This investigation was supported by an Australian Research Council Future Fellowship (FT190100410: Enhancing End-of-Life Decision-Making: Optimal Regulation of Voluntary Assisted Dying). We acknowledge the research assistance provided by Katie Cain (Australian Centre for Health Law Research, Queensland University of Technology), and gratefully acknowledge the participants in our study.

Open access: Open access publishing facilitated by Queensland University of Technology, as part of the Wiley – Queensland University of Technology agreement via the Council of Australian University Librarians.

Competing interests: Ben P White and Lindy Willmott were engaged by the Victorian, Western Australian, and Queensland governments to provide the legislatively required training for doctors involved in voluntary assisted dying. Ruthie Jeanneret and Eliana Close were employed in the Victorian, Western Australian, and Queensland training projects.

If you or anyone you know is experiencing distress, please call Lifeline on 13 11 14 (www.lifeline.org.au) or Beyond Blue (www.beyondblue.org.au) on 1300 22 46 36. ■

Received 23 August 2022, accepted 10 May 2023

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Supporting Information

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