Author’s response to reviews

Title: Too much safety? Safeguards and equal access in the context of voluntary assisted dying legislation

Authors:
Rosalind McDougall (rmcdo@unimelb.edu.au)
Bridget Pratt (bridget.pratt@unimelb.edu.au)

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Author’s response to reviews:

We are grateful to the reviewers for their feedback and the opportunity to improve the manuscript. Reviewer 3 was the only reviewer to suggest revisions, so we indicate below the ways in which we have revised the manuscript in response to her insights.

1. "I do have one recommendation that might strengthen the argument. As the paper is currently written, there seems to be some confusion about the different roles of law and healthcare. In other words, there is a tension between the function of law (e.g., safeguards) and the function of healthcare (e.g., promoting equitable access in the context of safeguards). This means that the argument is less convincing than it could be. It seems to me that with something as ethically contentious as VAD, the role of the law is to safeguard the rights of all citizens and the role of healthcare it to put in place as many systems as possible to ensure equal access (e.g., navigators and dedicated teams). But when these are conflated the argument is less convincing."

We thank the reviewer for stimulating us to think further about this aspect of our paper. In contrast to her view, we see health law and healthcare as two parts of the one health system. This is in line with Ruger’s view that health policy, health law and health practice are unified in important ways (Ruger, reference 23 in the manuscript, p.44). In our view, laws about healthcare are part of the overall healthcare system and ought to be concerned with equal access. We see promoting equitable access as part of the role of health law, rather than exclusively the role of the health sector (understood as healthcare organisations and workers). We see the legislation, the government-issued guidance, and the government’s provision of VAD care navigators as a set of government mechanisms within the health system, for which equal access should be an aim.

We have made this position clearer in the revised version of the manuscript, by explicitly stating our view that laws about healthcare ought to be concerned with equal access in the introduction of the paper: “Our view is that legislation about healthcare – as one element of an overall health system – ought to be concerned with equal access” (p.4)

We have also clarified the 3 specific points in the paper where the reviewer highlighted that this issue was problematic, listed below:
A. "One example is in the section on high quality care. The law and the healthcare responses to that law are conflated here. It would be much more useful to discuss the role of healthcare in determining quality in the context of these safeguards."

We have addressed this conflation by adding the following sentences in this section, on p.18: “Detailed specification of high quality VAD care may not be appropriate in legislation, and better placed in other contexts. However, this specification has not yet been achieved or communicated.”

B. "I was also interested that you did not discuss the role of VAD navigators in the section on patient agency? It seemed that this was a healthcare response to promote equal access when the safeguards potentially compromised equal access?"

We have added the following sentence on navigators in this section, on p.15: “The state government’s provision of VAD care navigators is an attempt to address this issue, particularly in relation to finding willing doctors.”

C. "A further example is the issue of conscientious objection. Without addressing the roles of law and healthcare it is difficult to understand why it is important to guard the rights of conscientious objectors."

Rather than entering the debate about the role of the law in protecting conscientious objectors, we have pointed the reader to this issue and the existing bioethical and legal scholarship. We have added the following sentence: “There is an extensive literature in ethics and health law about the justifiability of legal protections for conscientious objectors in medicine [eg. 35.36]” (page 13).

2. "As an aside, you may also want to think about how access in the context of VAD parallels other healthcare interventions where safety must be balanced with risk and quality. For example, not all institutions do all procedures for safety and quality reasons. We further often transfer patients to other institutions that can provide better care, even at end of life (e.g., medical units to hospice). My question is, is there something unique about VAD that takes it outside of these realms of consideration?"

This important point has been added on p.20 with the following sentence: “The reasons motivating a health service’s choice of pathway B or C may include quality of care; not all procedures can be provided in all health services when specific staff skills or facilities are required.”