On the epistemology of case studies of social phenomena in healthcare

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Winnington and MacLeod recently reported in NZMJ a case study related to voluntary assisted dying (VAD).¹ In this study, the authors used a semi-structured interview of a single participant's experience of VAD in a foreign country. This was analysed and reported in the form of a case study, with the stated intent to explore the individual's experience of VAD in this foreign country and their perception of how this may relate to the upcoming End of Life Choice Act (EoLCA) referendum, scheduled for September 2020. There are significant challenges with the study from a methodological and analytical perspective. What follows is an evaluation of these challenges and a reflection on the nature of this research.

In the introduction, the authors state, “medicine (in collaboration with law) has maintained an unwavering stance that the right-to-die produces a ‘slippery slope’ effect, whereby some patients may be obligated to terminate their lives prematurely”. Using the current state of law as support for this claim is circular logic and unhelpful for addressing the current issues of whether VAD should be legalised in New Zealand, how health and social outcomes can be maximised, nor do the authors present evidence that supports law being maintained specifically to address the ‘slippery slope’ premise. Similarly, the data cited on uptake in the Netherlands do not support the assertion of a ‘duty to die’ premise, they reflect uptake.

The ‘slippery slope’ argument has been covered extensively elsewhere, ie, the premise that legalisation of VAD will eventually lead down a slippery slope where euthanasia in all its forms is accepted.² Empirical data on experience of VAD can be interpreted to provide conflicting viewpoints of experiences in countries such as the Netherlands and Belgium.³⁴.

The authors’ suggestion that there is consensus about this within the medical profession is inaccurate, and indeed that countries have legalised VAD with the support of medical and health professionals, demonstrates that this is not correct. Unfortunately, attempts by groups in New Zealand purporting to represent the entirety of the medical profession have been misleading, as they do not represent the entire profession and indeed by their nature do not represent all health professions. That the ‘slippery slope’ premise is raised in the introduction to this study raises the question of what steps were taken to prevent and address “leakage” of the prior views of the authors, into the study—an issue linked with ascertainment that is raised later in this response.

Moving onto the study method, the authors cite the Yin case study method as the basis for their approach. The methodology section gives very little detail on this, the theoretical/epistemological basis underlying the approach, whether the interview questions were developed a priori and whether the protocol was submitted for review prior to progressing with the interview. Most notable in its absence is the process by which the individual was ascertained for study. One might wonder at this stage whether this is because the authors had strong views about VAD, one way or another; however, the absence of this information is a critical shortcoming in terms of interpretability of the findings, due to the nature of qualitative
synthesis. Related to the ascertainment is that the interview itself is semi-structured, clearly linked with prior knowledge of the individual. The relationship between the authors and the participant, prior conversation and formation of the questions, was not clearly described in the report, further raising the possibility of data leakage and of bias. Additional challenges with the method are that the authors reference thematic analysis but do not describe the method that was undertaken, nor the tools used to assist with the analysis, such as computer-assisted qualitative data analysis software (CAQDAS). Finally, although disclosure of no conflicts is made, from a meta-research perspective, the lack of financial disclosure is problematic and not consistent with many models of research quality assessment in healthcare.

In reporting the findings of the study, baseline characteristics were omitted from the report, including age category, gender, country of origin (which is an important factor in understanding the individual’s experience of said health system), prior beliefs about VAD, the quality of the relationship to the deceased family member and specific details under which that individual undertook VAD, we are unable to assess elements of external validity such as directness and generalisability. Indeed, given that this was a case study involving a single person, rather than a number of people from the family, the lack of description of the individual’s own physical and mental wellbeing leaves questions about the internal validity of the case study.

The authors describe three key themes that emerged from interviewing this individual, “expectation of [V]AD”, “stigma” and “[V]AD as contagion”. The participant disclosed what sounds like strong views and interesting beliefs around VAD relating to a perceived expectation that the individual themselves would be forced to use VAD. This seems related to the ‘slippery slope’ argument and though they perhaps may be distinct, the lack of exploration of this and tying in with prior literature about this is noteworthy.

An observation was made in the thematic reporting about the stigma that could occur on both “sides”. A point of clarification is that the critical difference is that, in the presence of legal prohibition, stigma is reflected in law. In relation to this theme of stigma, the study subject’s reflection on individuals potentially not informing their family members, it seems critical that this should have been explored with relation to this individual’s connection with their own family member and perhaps as a reflection the impact of how that disclosure or non-disclosure had affected them or their family.

 “[V]AD as contagion” appears to have been raised in the context of this individual experiencing multiple family members undergo VAD. This is mentioned twice within a short period of the discussion. That this individual has had three family members undergo VAD is a feature of the subject’s personal circumstances that is clearly critically important to this person’s narrative, the analysis and interpretation of their experience and perhaps part of their perception of contagion. This concept of ‘contagion’ is also not a new finding with there being a variety of value-laden literature and news media exploring and touting this.

In their discussion, the authors’ characterisation of the themes from the analysis of the interview suggests that generalisable phenomena were identified in this study, rather than the purpose of a case study, which was to find themes for further exploration, such as quantitation. While a single person’s experience of a major event in a foreign health system is interesting and in the presence of new findings could potentially be valuable, the authors appear to have mischaracterised the themes from this case study as evidence of the ‘slippery slope’ phenomena. As a literal “n of 1”, these observations are inductive and not generalisable to the entire population.

That the authors further assert that, “evidence from this study must be factored into the New Zealand debate before the referendum on the End of Life Choice Act in 2020” is doubtful. Reflecting on the study method, findings and synthesis, there is nothing new that this article adds to the literature, either in terms of broader themes identified globally, nor specific findings to the New Zealand healthcare nor broader community. Since these themes are not new additions, this raises the possibility that this report has been engineered as a form of social activism to leverage the NZMJ platform to legitimise poorly conducted qualitative research from a single interviewee. The authors appear
to have overreached in their assertion that “This study clearly showed how experiencing [V]AD through a relative’s lens and by partial engagement with [V]AD can impact broader family and friend networks”. At best this should be prefaced by “might” impact.

Later in their discussion the authors leave behind the premise of using the themes identified through the interview by asserting “This potential consequence of [V]AD legislation reduces our future existence to being considered only through the practical lens relating to the cost of care and reduces our life to having a dollar value, as opposed to [V]AD alleviating the fear of indignity, pain and suffering at end-of-life”, a statement not backed by the themes identified in their research, by other evidence nor citations.

In asserting “The results highlighted how [V]AD remains contentious, irrespective of legality...” the authors have further gone beyond what little is described in their methods and results. That contentiousness of an issue could be conclusively identified from thematic analysis of interviewing a single person and then omitted from the results section of a publication before being raised in the discussion of a report, raises critical quality issues about the study. At this point in the discussion, the text deteriorates into impassioned narrative and further evaluation of the discussion adds little.

Case studies are useful for exploring issues in depth in an inductive fashion, ie, developing new areas that need to be explored. VAD is far from a new issue, either in New Zealand or abroad. All of the issues that were raised in this case study have been explored in great depth elsewhere. A systematic review of these issues may be of value, particularly with respect to generalisability of the findings to the New Zealand context, but also for exploring whether these issues became a significant issue following implementation of the law (in countries where it has been implemented) or are thought experiments that go no further in practice.

It is not the purpose of case studies to identify broadly generalisable phenomena, but to identify themes or findings for further investigation. Case studies are a method used extensively in healthcare and in some ways the most fundamental form of empirical research we have. In Yin’s text on case study methodology, he describes a framework for assessing the design of case studies by addressing construct validity, internal validity, external validity and reliability. If this study’s intent was to draw out the assertions made in the discussion, the study design cannot answer these.

Finally, the past two decades has seen a steady shift to open models of publication. These include openness in terms of maximising access to articles, which the NZMJ and many other healthcare journals have engaged in. More recently, this model has extended to include an increase in the sharing of source data, inclusion of increasing supplementary items and open peer review, in which we can better understand the peer review and editorial process that led to an article being published. In this particular instance, it would be useful to understand the process that led to a journal which commonly publishes high-quality case studies, allowing one through peer review with such critical weaknesses as this.

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