Reviewer’s report

Title: Reporting of euthanasia and physician-assisted suicide in the Netherlands: descriptive study

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Reviewer: Helene Starks

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This descriptive study is a content analysis of 158 physician reports filed in 2005 to 5 regional euthanasia oversight committees in the Netherlands. These committees are tasked with assuring that the processes involved with implementing euthanasia and assisted dying comply with the criteria for due care. This paper is interesting and worthy of publication. However, I would recommend including additional information as noted below to make the findings more accessible and relevant for audiences outside of the Netherlands. In addition, I believe the authors should enhance their analysis with a bit more conceptual work so that these empirical data can enhance reflection on the normative claims that are inherent in the Dutch and US regulations. I offer specific suggestions below for where and how I think the authors can improve this otherwise strong paper.

Major compulsory revisions:

Introduction:

1. p. 3, end of 1st paragraph:

“Debates about legalization often relate to concerns about whether it is possible to keep the practice of physician-assisted dying within agreed borders.” I recommend that the authors extend this idea with a 1-3 sentence summary of what these borders are meant to contain. The purpose of these oversight committee reviews is to report on the practices of euthanasia and assisted suicide and decide how the norms laid out in the laws and regulations are being performed. It is worth describing the range of concerns here and what the regulations are trying to balance, i.e., worries about coercion, unnecessary foreshortening of life, what elements of suffering — including physical, psychosocial, and existential factors — are or should be considered to be meet the criteria of “unbearable” or “hopeless” and other arguments in the literature the authors feel relate to their analysis. It would help to have more normative claims up front regarding what is at stake with respect to the practice and oversight of euthanasia and assisted dying, especially since the stated purpose of the article is to assess the “arguments Dutch physicians use to substantiate that they have adhered to the requirements of due care and which aspects attract review committees’ attention.”

Part of my rationale for wanting these normative claims up front is because of the way the authors describe what the different regulatory processes in the
Netherlands and the US are meant to do, especially in relation to ethical principles. For example, on p. 3, end of 2nd paragraph they write: “The Dutch model is basically medically oriented, which explains to a large extent the support it has always received from the social and political arena.” This sentence needs a bit more elaboration: why does having something in the medical arena receive support from the social and political arena? Is it because medicine is inherently trusted by society or is it that this is the case in the Netherlands? The authors point to this at the end of this section on p. 4, end of first paragraph: “The ethical foundation of those three [FOUR, if you include Washington as noted below] Acts is a combination of respect for autonomy and obligations of beneficence. However, for the Dutch and Belgian Acts, addressing the patient’s suffering is the most important principle underlying the Act. The Oregon Act, on the other hand, puts emphasis on patients’ rights and on helping patients to maintain control and independence. Such an emphasis can be expected to lead to a review procedure which focuses on societal and procedural aspects, whereas the Belgian and the Dutch focus on addressing suffering may lead to an emphasis on medical aspects, such as patient’s symptoms and function loss.” From my point of view, the Oregon (and Washington) Death with Dignity Acts also are medical models, but the authors couch this in terms patients’ rights about maintaining control and independence. The criteria for Oregon implement the medical model by requiring a prognosis of 6 months or less, which is typically determined by using many/most of the same criteria that the Dutch physicians reported defining their arguments of patients’ unbearable suffering and hopelessness. The authors may want to read and reference studies from the US about what how these patients and physicians perceive suffering and how it relates to their requests for aid-in-dying, e.g.,:


I think that if you were to explore more of these theoretical arguments up front, you might see that the differences between Oregon/Washington and the
Netherlands/Belgium are not in fact that great. If you agree, how might you revise your final conclusion (p. 14)?

Study design
2. The division of the sample into two parts confused me. On p.5, first paragraph, it seems this is contradictory information: “The first part included all 75 cases in 2005 where review committees had had doubts or questions and asked the reporting physician to provide additional information. Such additional information was asked in 6% of all reported cases.” But wouldn’t that be 9.5 cases? The second statement about the other 83 cases also is confusing: why should these be representative of all the cases? Then they conclude with the sample restricted to 68% of cases in 2005, which would be about 107 people. From the tables, it looks like all 158 were included in analyses, with the subsample of 75 included in the additional analyses reported in Table 5. This part of the narrative should be rewritten to make this easier to understand.

Checklist
3. I would recommend deleting Figure 1 and simply summarizing the main themes/headers in the text, then reference that the specific questions are included in the data tables.

Discussion
4. p. 10: I found it awkward to read the limitations first; perhaps this is a style difference, usually these limitations come after the summary discussion ideas, not before. I would suggest moving this to the conclusions section and integrating how these limitations should temper our interpretation of the suggestions for policy.

Minor essential revisions:
5. p. 3, 2nd para, line 19. Typo in the middle of the sentence [my suggested edits are IN CAPS]: “To demonstrate their compliance with these criteria, physicians have to submit a detailed report, which describes THEIR way of acting and its circumstances.

6. p. 4, suggested edits: The authors may want to include information about the recently passed law in Washington. I have edited their paragraph to clarify both the Washington and Oregon process: “The patient’s primary physician and a consultant are required to confirm the diagnosis of a terminal condition and the prognosis, determine that the patient is capable, and refer the patient TO A PSYCHIATRIST OR CLINICAL PSYCHOLOGIST for [counseling] FURTHER EVALUATION, if either BELIEVES that the patient’s judgment is impaired by depression or other psychiatric / psychological disorder. The primary physician should also inform the patient of all feasible alternatives. [19] If the patient MEETS THE ELIGIBILITY CRITERIA and the physician WRITES A PRESCRIPTION [adhere to the prescribed criteria], physicians have to report to the Oregon Health Division which lethal medications were prescribed. They further have to indicate that they FULFILLED [complied with] the requirements by
checking the boxes in the attending physician’s compliance form.[20] After receiving the report of the death of the patient, the Health Division asks the reporting physician whether the patient indeed had died from the medication. THE WASHINGTON DEATH WITH DIGNITY ACT WAS PASSED IN 2008 AND IMPLEMENTED IN MARCH 2009. THE LAW AND REQUIREMENTS ARE VIRTUALLY IDENTICAL TO THE OREGON ACT.” [You could reference both Oregon and Washington websites if people want to go and see the forms/questions directly.]

7. p. 11, suggested edits: Line 10: “Other reasons, such as the LACK OF PROSPECTS FOR improvement...”. Line 22: Include PROGNOSTIC before information (if you agree with my recommendation below; see #10).

Discretionary revisions:

Results

8. p. 7, under “Patient’s request”: With respect to the 1 case, was there anything interesting or that we should know in relation to what explains why the physician granted the request in spite of the patient not having awareness of his situation? In addition, was there anything to inform/explain why 3% (n=4 or 5?) of the cases were missing a written euthanasia declaration? For qualitative work, it’s especially useful to include the full range of experiences as we can often learn quite a lot from the outliers in the sample.

9. Similarly, under “Patient’s suffering”, particularly with respect to the “one or more physical symptoms”: Other literature suggests that it is a combination of many factors that lead people to define the threshold for their intolerance of suffering. How many people only noted one symptom? Was there any pattern in that single symptom that would suggest it has special significance with respect to being “unbearable”? Was there any mention of treatments attempted/offered to try to alleviate these symptoms? Finally, was it possible to determine what percent of patients were deemed to be both hopeless and have unbearable suffering?

10. p. 7, under “The information provided to the patient”: Should the word “prognostic” be included here before “information”? What type of information is included in the one question?

11. p. 8, under “The consultation”: At the end of the paragraph, an example would be useful: “In 10% of cases physicians reported in other terms about the relationship,” i.e., XXXX.

12. p. 9, last sentence: “Further, review committees relatively often asked about the type of medication (13%) and about topics not directly related to the criteria of due care, such as the quality of the physician’s report (13%).” Similarly, it would be useful to know the full list of other topics, assuming the list isn’t too long.

13. p. 10, under “Patient’s request”: “Possibly, this information was convincing enough for review committees if the file did not contain information suggesting otherwise.” A reference back to the normative values here would be helpful, i.e.,
how is it that the story conveyed through the report provides sufficient evidence of a well-considered request?

14. p. 12, last sentence under “absence of reasonable alternatives”: Can you san more about why the review committees never ask the reporting physician to substantiate lack of alternatives? This is important information to surface because it is a test of the norms and these details help us see exactly what assumptions are in play, i.e., they don’t ask because they expect it was done? Or because patients refused? This is a somewhat grey zone in the US reporting system as well -- it is addressed by a statement on the patient’s written request “I have been fully informed of my diagnosis, prognosis, the nature of medication to be prescribed and potential associated risks, the expected result, and feasible alternatives, including comfort care, hospice care, and pain control.” With this language included in a form, the assumption is that the patient has actually been told about alternatives. It is not clear from Table 3 whether most of these patients were on hospice or receiving palliative care. In Oregon, about 88% are on hospice and this IS something that is asked on the physician after-death reporting forms. Would being on hospice suffice as a reasonable alternative under the Dutch system?

15. A final question: Are the forms, criteria, and summary statistics for the Dutch system publically available on the web (as they are in the US)? If so, you might want to put in a reference to where a reader would find them. I find it very useful to look at the exact questions asked on the forms when thinking about what assumptions are driving the questions.

**Level of interest:** An article of importance in its field

**Quality of written English:** Acceptable

**Statistical review:** No, the manuscript does not need to be seen by a statistician.

**Declaration of competing interests:**

I declare that I have no competing interests.