Author's response to reviews

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

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Author's response to reviews: see over
Thank you for giving us the opportunity to revise our manuscript entitled ‘Reporting of euthanasia and physician-assisted suicide in the Netherlands: descriptive study’. The reviewer’s comments were very helpful and we have carefully tried to adequately address all of them as you can find below.

Response to reviewers’ manuscript on:
‘Reporting of euthanasia and physician-assisted suicide in the Netherlands: descriptive study’

The objections and comments are repeated and answered below.

Reviewer 1 – Lieve van den Block:
→ Clearly written, straightforward and easily readable
→ No major remarks only a few suggestions for the authors

Minor essential
1. ABSTRACT: Can the research questions be made explicit in the background section of the abstract?
   ➢ We now moved the research questions from the Methods section to the Background section.

2. ABSTRACT: The reference to the Oregon review system in the Conclusion is not clear for the reader who has not seen the whole manuscript. Reviewer 1 advises to reformulate the last sentence, or replace it with another element of the discussion section.
   ➢ We rephrased the last sentences in the Conclusion-section and left out the Oregon review system in the Abstract of the paper:
     “Dutch physicians substantiate their adherence to the criteria in a variable way with an emphasis on physical symptoms. The information they provide is in most cases sufficient to enable adequate review. Review committees’ control seems to focus on (unbearable) suffering and on procedural issues.”

3. RESULTS: Section about ‘Information’. Can you add (somewhere in the paragraph) that it concerns information about the prognosis?
   ➢ We have changed the heading in the Result section p7, and the Discussion section p11 in ‘The information provided to patients about their situation and prognosis’. We also mention the question as mentioned in the standard form in the text: ‘How was the patient informed about his prognosis (current situation, course, prognosis, etc)?’

4. TABLE 3: footnote 3 ‘in some cases’: how many cases exactly?
   ➢ In the footnote of Table 3 we now added the exact number of cases in which the treatment alternatives were not further specified: It concerned 3 cases.

Discretionary

5. INTRODUCTION: It is not necessary to mention the comparison with Oregon as part of the objective of this study. Paper mainly focuses on the description of cases and the evaluating of the quality of the reports. The Dutch Oregon procedure is only compared a little in the final paragraph. ➢ Suggestion to incorporate everything about the Oregon procedure in the Discussion section.
In order to make the paper more interesting for an international public, we included some information about other review procedures in the Introduction section. As suggested by reviewer 3, we now elaborate a bit more on other review procedures outside the Netherlands in the Introduction and Discussion section of our paper and for instance discuss the Washington and Luxembourg Acts as well.

6. METHODS: Some aspects of the study design might be explained in more detail e.g. were the cases not approved that were excluded, why take the last 83 cases only and how many were not studied (did you check the differences?), what do you mean with the stratification? Also, can the checklist be included?

- In this study we studied cases in which physicians had used the latest version of the standard form only; this has nothing to do of whether these cases were approved or not. We now describe the study design more clearly and explain why we only studied reported cases of euthanasia. We elaborate on the sampling procedure on p6/7, paragraph ‘Study design’.
- The checklist is written in Dutch and probably too long to include in the paper itself. However, if including the checklist is considered useful it could be added as an appendix.

7. DISCUSSION: there is a lot of information overlap with the results section. Perhaps the discussion can be shortened.

- We shortened the Results and Discussion section by deleting less relevant information that can be understood in the Tables.

8. DISCUSSION: The authors indicate there is room for improving the report form. On the basis of their experience, can some specific suggestions be incorporated?

- We have added a specific suggestion about the treatment alternatives on p 14, conclusions and suggestions for policy.
  "For treatment alternatives for instance, the question should be formulated more clearly to be able to assess whether these alternatives were considered ‘reasonable’ by the physician him- or herself."

9. DISCUSSION: It might be important for the reader to incorporate the reporting rate of euthanasia i.e. this report gives insight into how many of all cases in the Netherlands?

- We now start on p14, the first paragraph ‘Conclusions and suggestions for policy’ with the following sentence:
  “The reported cases in 2005 represent a substantial amount (80%) of all euthanasia cases in the Netherlands in that year; studying the files therefore gives important insight the actual practice of euthanasia."
Reviewer 2 – Reidun Forde

→ Interesting article, systematic, thorough and with the necessary distance
→ No major remarks only minor comments / discretionary revisions

1. METHODS: It is important to know that the sample is not representative for all euthanasia cases since half of the sample consists of cases where review committees asked for additional information. This was 6% of all the euthanasia cases which were reported. It would be useful to know the author’s assumption of how many cases which are not reported and why. That cases are not reported is puzzling since so few doctors receive critique or negative reactions. It would be useful if this had been dealt with, although this is not the focus of this paper.

➢ We clarified the methods section on p 6, Study Design.
   “We studied 75 cases where review committees had had doubts or questions and 83 cases that belonged to ‘the last’ reported cases in 2005. Weighting of the results to correct for differences in sampling fractions did not appear to affect the results; we therefore only report unweighted results. All studied cases were approved by a review committee.”

➢ On p 14, we mention the number of reported cases in the Netherlands (see also reviewer 1, point 9).

➢ On p14 we added the following sentence: “The reported cases in 2005 represent a substantial amount (80%) of all euthanasia cases in the Netherlands in that year; studying the files therefore gives important insight in the practice of euthanasia.”

2. DISCUSSION: The paper shows that Dutch doctors receive a lot of trust in the area of euthanasia and that the reporting system is not suited for a thorough and critical review of what is actually going on.

➢ This paper is a descriptive study about the reporting procedure for euthanasia and physician-assisted suicide in the Netherlands. Our main aim was to provide insight in the discourse between reporting physicians and review committees, not to review the reporting system as a whole. As mentioned in the Methods section ‘File Content’ (p 5), euthanasia files comprise more than the physician’ report only. The fact that in only 6% of cases review committees asked for additional information suggests that most files provided sufficient information to enable adequate review. In our limitation-section we added on p 14, first paragraph:
   “Our main aim was to provide insight in the discourse between reporting physicians and review committees, not to review the reporting system as a whole. ”

3. DISCUSSION. A central ethical issue for patient autonomy is information, and the authors clearly state that we do not really know what is included in this. Information very seldom consists of only objective medical facts.

➢ We agree with the reviewer that the information that was provided to the patient was unclear in some cases.

4. ABSTRACT: In the abstract they say that the patient’s request had been well-considered because the patient’s request was clear-headed OR had repeated the request. Is there an either / or here, one may both be clear-headed and repeat the request?

➢ Physicians could have mentioned more than one argument. In 15 out of 158 cases physicians had mentioned both. We have changed the wording in the abstract a bit in and/or, p 2, Results section abstract: ‘and/or’ and in the Results section, p 8, paragraph ‘the patient’s request’.

5. ABSTRACT: In the same paragraph I suggest ‘In 35%, physicians reported that there had been alternatives to relieve the patient’s suffering, but these were refused by the majority of patients.’ Or have I misunderstood?

➢ The percentage of 35% is correct.
6. INTRODUCTION. On p3 the authors state that the Dutch model is basically medically oriented. Could this be rephrased as ‘based on trust in the doctors’ assessments and actions’?

- We explain the difference between the different principles underlying the Act more clearly on p 4 and decided to remove this sentence on p 3.

7. The assumption that one or more physical symptoms is a proof of unbearable suffering could be commented on.

- In this paper we describe how physicians substantiate unbearable suffering. This does not mean that physicians only consider physical symptoms important in their assessment. We comment on this finding in the Discussion section, p11/12.

8. In Table 1. 1 patient was reported as not being fully aware of his medical situation. Does he then fill the criteria of euthanasia (only competent patient, and in competency lies the ideal of information, etc.)

- It is correct that in one case the physician had reported that the patient was not fully aware of his / her medical situation. In principle, these patients do not comply with the criterion that the patient’s request should be voluntary or well-considered. In this case, a euthanasia declaration was available. In such cases euthanasia may be allowed.

9. That the doctor knows the patient, does not guarantee that autonomy criteria are filled (also table 1).

- We agree. However, this is what some of the physicians wrote in their report when they substantiated the criteria for fulfillment of the patient’s request.
Reviewer 3 – Helene Starks

- Recommends including additional information to make the findings more accessible and relevant for audiences outside of the Netherlands.
- Recommends that 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.
- Offers specific suggestions to improve this otherwise strong paper.

Major compulsory

1. INTRODUCTION. ‘Debates often relate to concerns about whether it is possible to keep the practice of physician-assisted dying within agreed borders.’ Reviewer 3 recommends that the authors extend this idea with a 1-3 sentence summary of what these borders are meant to contain and provides some suggestions:

   ‘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.

   - The law provides criteria for due care without a description of the concerns they are aimed to address. We added a short elucidation on p 3, background, first paragraph.

     “Concerns relate to the risk that vulnerable people may be or feel coerced to request assistance in dying, that alternatives to assistance in dying are lost out of sight, or that deciding to provide assistance in dying becomes too ‘easy’ an option without careful consideration of alternatives.”

   - After describing review procedures outside the Netherlands we now explain why such external review is considered useful on p 4, Background, second paragraph.

     “The purpose of reporting and reviewing practices of euthanasia and physician-assisted suicide is to evaluate how the norms laid out in the laws and regulations are being handled in actual practice. External review enables countries to evaluate whether current regulation suffices to restrict euthanasia to cases that meet the criteria, to see where potential problems occur and to educate physicians to comply with the rules.”

2. INTRODUCTION. 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 state 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.

   - In principle the 6 criteria of due care define the norms for the practice of euthanasia and physician-assisted suicide. In the Introduction and Discussion section we describe and evaluate the content and interpretation of these due care criteria.

3. INTRODUCTION. P 3, 2nd paragraph. The Dutch model is basically medically oriented, which explains to a large extent ….’ 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?

   - We decided to leave this sentence out because we elaborate on the principles underlying the act on p.4 (see also reviewer 2, point 6)
4. INTRODUCTION. P4, ethical foundation. Include Washington as well. 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. (examples of US-studies)

- We left out the sentence that the Dutch model is basically a medical one (see also point 3). We now refer to studies that are performed in Oregon and the Netherlands in which physicians’ reasons to grant a euthanasia request are mentioned on page 4, second paragraph.

‘Various studies have been performed about how physicians perceive the patient’s suffering and in what situations patient’s requests result in euthanasia. [22-24] In the Netherlands as well as Oregon, physicians have been shown to be motivated to engage in euthanasia because of their patients’ disease-related experiences, such as severe pain, functional loss, discomfort, fatigue, and expressed loss of dignity of the patient.’

5. INTRODUCTION / DISCUSSION. I think that if you were to explore more of these arguments upfront. You might see that the differences between Oregon/Washington and the Netherlands/Belgium are not in fact that great. How might you revise your final conclusion?

- We agree with reviewer 3 that the differences are not that great. We revised our assumption in the introduction section on p 4:

  ‘Whether or not these differences in emphasis lead to differences in practice and in the review procedure is unclear.’

- We also revised the final conclusion in the discussion section on p 15:

  “Our results show that the Dutch review procedure seems to concentrate on the criterion of (unbearable) suffering and on procedural issues. US legislations do not contain criteria concerning the patients’ degree of suffering: the patient’s medical situation is addressed in the criterion concerning the patient’s life expectancy which should be six months or less. In actual medical practice, the characteristics of patients who died as a result of euthanasia are rather similar in the Netherlands and Oregon and in both countries reported cases are rarely not approved. Differences in the formulation of due care criteria concerning the patient’s medical situation apparently only have a limited impact in the practice of physician-assisted dying.”

6. METHODS. The division of the sample into two parts, confusing. P5, first paragraph. The first part…. Such additional information was asked in 6% of all reported cases. But wouldn’t that be 9% of cases? The second statement about the other 83 cases is also 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. → rewrite to make this easier to understand.

- We rephrased the sampling procedure. See also point 6 reviewer 1, point 1 reviewer 2.

7. METHODS. 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.

- We agree and deleted Figure 1 and copied the specific questions in the Tables or mentioned the specific question in the Results section (‘Information provided to the patient’ or ‘the applied method of ending life’).
8. DISCUSSION. P10. I found it awkward to read the limitations first; perhaps this is a style difference, usually these limitations come after the summary 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.

- We moved the limitation section to p 13, after the interpretations of the due care criteria.

Minor essential revisions.


- We changed ‘the’ in ‘their’

10. INTRODUCTION. p4. The authors may want to include information about the recently passed law in Washington.

- 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 patients 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’ (reference both Oregon and Washington websites)

- We appreciate and used these textual suggestions.

11. DISCUSSION. p11. Suggested edits: Line 10: ‘other reasons, such as the LACK OF PROSPECTS FOR improvement…Line 22: Include PROGNOSTIC before information.

- We changed ‘perspectives’ in ‘prospects’. We changed the sentence in: The information provided to patients about their situation and prognosis, see also reviewer 1, point 3.

Discretionary revisions.

12. RESULTS: p7. under ‘the 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.

- This patient had difficulties with speaking which might explain why the physician had problems with the assessment of the patient’s request. A written euthanasia declaration was available.

- It concerned 4 cases. We added the following sentence in the results section:

  “In 97%, a written euthanasia declaration, that is not obligatory under the Dutch legislation, was available; in one case the physician reported that the patient had not been capable to sign the declaration anymore, in one case information about whether or not there had been a written euthanasia declaration was missing in the physician’s report, in one case it concerned a declaration about general medical care instead of
euthanasia and in one case it was not clearly specified in the report why the euthanasia declaration was missing.”

13. RESULTS. 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?

- In 8 cases the reporting physicians did not substantiate the patient’s unbearable suffering.
- 27 % only noted one aspect to substantiate the unbearableness of suffering
- There was no single aspect that would suggest it has special significance with respect to suffering being unbearable. Pain, dyspnoe and fatigue were often mentioned.
- In all cases palliative treatment was offered (mostly medication (95% of cases)
- In all cases patient’s suffering was considered both unbearable and hopeless. Some physicians did not substantiate the unbearableness of the suffering (4% of all cases) or the hopelessness (8% of all cases).

14. RESULTS. p7, 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?

- As mentioned previously, we changed the wording in the heading in ‘The information provided to patients about their situation and prognosis’. We also mention the ‘information question’ in the Results Section, p8 so that it can be seen what the question exactly includes.

15. RESULTS. p8. 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. ..... 

- Unfortunately, our database gives no insight in what ‘other’ in these cases could have been.

16. RESULTS. p9. Last sentence: Further, review committees.....Similarly, it would be useful to know the full list of other topics, assuming the list isn’t too long.

- The topics of the category ‘other’ were very diverse. We now provide two examples of ‘other’ reasons why review committees asked for additional information, on p 10: ‘…..and other aspects (11%) such as whether the reporting physician was indeed the physician who had performed euthanasia and the high number of consultations for one patient.

17. DISCUSSION. p10. Under ‘patient’s request’: Possibly, this information ....A reference back to the normative values would be helpful, i.e. how is it that the story conveyed through the report provides sufficient evidence of a well-considered request?

- We agree that a reference back to the normative values is helpful. As stated in point 2, in principle the 6 criteria of due care define the norms for the practice of euthanasia and physician-assisted suicide. The law provides criteria for due care without a description of the concerns they are aimed to address. Our study did not aim to test whether the norms are interpreted in a certain way. However, in this study we aimed to show how the due care criteria are interpreted.
18. p12. Last sentence under ‘absence of reasonable alternatives’. Can you say more about why the review committees never ask the reporting physician to substantiate the 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 people were in 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?

- The health care system in the Netherlands is different from the US. Palliative, comfort and hospice care are not distinguishable from ‘regular’ care in most cases and it is therefore impossible to ask questions about palliative care/hospice care. Most written requests contain a statement that the patient is fully informed about his prognosis and feasible alternatives, but this is not obligatory. Our results are nevertheless indicative of the importance that is attached to the patient’s evaluation of alternatives, as stated on page 9, paragraph ‘Medical treatment / care’. In addition, table 3 shows that 89% of all cases received pain medication in advance and in 46% of cases other options were mentioned.

19. Are the forms, criteria, and summary statistics for the Dutch system publicly available on the web? 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.

- References 25/26 include summary reports about the Dutch act and a description of the due care criteria.