Author’s response to reviews

Title: The involvement of family in the Dutch practice of euthanasia and physician assisted suicide: a systematic mixed studies review

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Author’s response to reviews:

Dear editor and reviewers of BMC Medical ethics,

Thank you very much for your review of our manuscript “Euthanasia and the Family in the Netherlands; a systematic mixed studies review” and your valuable comments. Hereby we send you our revised manuscript, now entitled “The involvement of family in the Dutch practice of euthanasia and physician assisted suicide; a systematic mixed studies review”. In this letter we address the points you raised in your review. In the manuscript, the changed sentences and paragraphs have been highlighted.

Comment 1: punctuation and grammar

We thank the reviewer for his feedback on language use in our manuscript. We have sent our manuscript to a language editing service and have processed their comments. Hopefully this will contribute to the readability and the quality of our manuscript. Since this applies to the whole manuscript, we did not highlight those changes in the text.

Comment 2: clarification of concepts

Euthanasia: The outsiders’ perspective of the reviewer helped us take a critical second look at the concepts used in our manuscript. Being immersed in the Dutch context/practice of EAS ourselves, we had unwittingly narrowed down physician assisted dying to euthanasia only, since euthanasia is practiced and discussed much more often in the Netherlands compared to physician
assisted suicide. We have changed the title and clarified the definitions of euthanasia and physician assisted suicide in the introduction.

Family: The lack of clarity about the concept of ‘family’ in the Dutch practice of EAS as described by the reviewer, is exactly one the most problematic issues we encountered while carrying out our review. We now realize that we had not sufficiently addressed this point in our manuscript. Therefore, we have clarified the concepts of ‘family’ and ‘family members’ as they are used in the context of Dutch healthcare in the introduction (see page 4). Furthermore, we address this point extensively in the results-section (see page 7) and the discussion (see page 20-21). However, we decided to keep the term ‘family’ for the title of our manuscript and we continue to use it in the manuscript instead of ‘the patient’s significant others’ or ‘beloved people’, as the notion of ‘family’ remains the most suitable concept in the Dutch context presented in our review.

Comment 3: missing pieces of literature

We thank the reviewer for his valuable suggestions on missing pieces of literature. We read the suggested pieces with great interest and have integrated the majority in our review, mainly in the discussion. In addition, we searched for and included some other papers containing ethical arguments about family involvement, empirical data on caregivers’ burden and the cultural situatedness of EAS as well.

Comment 4: limited analysis of findings

We agree with the reviewer that more explanation and analysis would enhance the quality of our manuscript. Therefore we have made major revisions in the results section and in the discussion. In the results section, findings are now explained at more length where possible, although more explanation was not always found in the original studies (for instance, on the question why Dutch physicians invest more in talking to families compared to colleagues from elsewhere). In the discussion, we deepened the analysis of the empirical findings and elaborated on the consequences of the empirical findings for the ethical debate on EAS in the Netherlands.

Specific comments:

- p. 3, line 46: provide percentages of rates of acceptance over time: we returned to the source of this empirical information, and discovered that in the Dutch standardized assessment of public opinions, a stable high percentage of public acceptance of EAS is described. We include this in the introduction.
- Box 1 is not visible, Box 2 is not visible: This was most likely due to problems with layout and file output. We have changed this.

- p. 7, line 153: Explain ADL: we removed this abbreviation and replaced it with a full-text explanation of the concept.

Thank you for again considering our manuscript for publication, we hope that it meets your expectations and will of course be happy to improve it further if necessary. We look forward to your reply.

Yours sincerely,

Bernadette Roest