Author’s response to reviews

Title: Euthanasia requests in Dementia Cases; what are experiences and needs of Dutch physicians? A qualitative interview Study

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Title : Euthanasia requests in Dementia Cases; what are experiences and needs of Dutch physicians?

A qualitative interview Study
Nijmegen, 1th of August 2019

Dear Ralf J. Jox, MD, PhD

We appreciate your and the reviewers’ time and efforts for carefully reading this manuscript and providing constructive feedback. They were most helpful to improve our manuscript. We have addressed the comments from reviewers 1 and 2 as indicated in the review letter. We hope that the revision has improved the paper reviewer comments.

On behalf of all the authors,

Jaap Schuurmans

Respons to review comments

Chris A. Gastmans (Reviewer 1):

Thank you for giving me the opportunity to review this manuscript. Although the topic of this paper is very interesting, I do have some critical comments I will explain below.

I have the impression that the paper is mostly focusing on euthanasia in persons with advanced dementia. However, the authors write about ‘person with dementia’. Does this mean that the paper covers also euthanasia requests of persons with dementia who are still competent enough to formulate an actual request? This point should be clarified.
Yes, the paper concerns euthanasia requests in all stages of dementia. Mostly, a euthanasia request and an AED are made when the person with dementia is in an early stage of the disease, when the person with dementia’s mental capacity is still good, and when the general practitioner is the primary caregiver. As the request and AED always concern the future, part of these persons with dementia will be admitted to a nursing home, where the elderly care physician will be the primary caregiver. In such cases, cognitive capacity is much lower than of PWD living at home. We clarified this point on page 3 lines 94 and 95:

“We hypothesized that dealing with euthanasia requests from PWD, whether or not they are still competent, impacts physicians.”

Design: Can you give more details about the design that is used in this study? What kind of qualitative approach was used?

As we mentioned in the analysis section, we applied direct content analysis. We added this information also to the design paragraph. We clarified this point on page 4 line 104:

“We performed a qualitative interview study with a direct content analysis approach.”

Participants and recruitment: The two sources of recruitment are very specific: 1) Group of physicians opposing euthanasia in PWD and 2) Physicians working for End of Life Clinic, who are extremely tolerant to euthanasia requests. How is possible recruitment bias avoided? How could physicians without an explicit pro/contra profile towards euthanasia in PWD be included in the sample?

We were not clear enough about group 1. What the physicians in group 1 have in common, is that they all are worried about euthanasia in persons with advanced dementia, who are not capable anymore. Within this group, the opinions about euthanasia in general and in PWD who are still capable and AEDs however varied widely. We made this more clear on page 4 lines 113 to 117

“We used two different sources for recruitment. One was a list of doctors that signed a critical statement published in Dutch national newspapers about euthanasia procedures for persons with advanced dementia and who had provided their email addresses. {Chabot, 2017; Miller, 2019} This critical statement opposed euthanasia in non-competent persons with advanced dementia,
who are not able to confirm the actual euthanasia wish. Taking account of the above-mentioned criteria, physicians from this list were invited by e-mail to take part.”

And regarding group 2, physicians working for the End of Life Clinic, We gave more clarification and added information and literature on page 4 lines 118 to 123:

“The other source was the End of Life clinic. This clinic deals with euthanasia requests, and when due care criteria are met, offers euthanasia or assisted suicide to people of whom the own physicians are not able or do not want to perform it. The physicians of the End of Life clinic are less reticent to perform euthanasia in case of PWD. (Snijdewind, 2015) Via the director, two physicians employed at the End of Life clinic agreed to participate. We also used snowballing. After we reached saturation, we stopped inviting physicians to take part.”

Purposeful sampling: The authors argue that they used purposive sampling. Why is purposive sampling not followed by theoretical sampling?

Although it would have been interesting to follow grounded theory and to develop a theory, this was not our research aim.

Saturation: The number of participants (11) is quite small. There is a serious risk that you reached only saturation for the two specific groups of physicians you included in the study. I have serious doubts you obtained the perceptions of physicians who have not such a clear pro/contra attitude. It is also reported that 10 of 11 participating physicians signed the critical statement about euthanasia in PWD. Again, this increases the risk for serious bias in the sample and for having not reached saturation.

See our answer on your previous remark regarding the diversity of opinions within group 1. However, we agree that, although we reached saturation, 11 is quite a small number. Therefore we added to the limitations section: page 12 lines 383 to 388:

“However, this study also has limitations. Although we included physicians with a wide variety of opinions and experience on this topic and tried to provide a broad perspective, the majority of participants signed the critical statement about euthanasia in persons with advanced dementia.
Although saturation was reached, by interviewing just a small number of physicians on such a sensitive issue, we might have missed essential information.”

It is unclear how many general practitioners and how many elderly care physicians participated. These two groups of physicians are explicitly mentioned, but no information about the number of physicians of these two groups is reported in Table 2. Also, the religious background of the participants is not reported in Table 2.

We added the profession to Table 2. Five general practitioners and six elderly care physicians participated. We did not ask their religious background.

P. 6: Pressure by relatives: It is not specified whether the patient has an AED. Is the family requesting euthanasia for an incompetent patient without AED?

This pressure, mentioned by several participants, concerned euthanasia requests with or without AED.

P. 9: Doctors' emotions: According Table 2, most participating doctors have no experience with conducting euthanasia in PWD. On how many participants is this paragraph based?

Although most participating physicians had no experience with conducting euthanasia in PWD, nearly all of them had experience with euthanasia requests, and with emotions when such requests are discussed with the patient and family (table 2)

I would strongly advice to add the number or code of the physicians linked to the quotes reported in the manuscripts.

We added a letter to each quote, referring to a certain physician (A to K) throughout the results section.
The discussion section needs a major revision as it is quite superfluous in its current state. The main results are mentioned and a general comparative link is made with previous research. However, the PhD study of Marieke de Boer that focused on the same topic as this paper if fully neglected. There is even no reference to this important research in the reference list.

We did a major revision of the discussion session. And although the papers of Marieke de Boer et al of a decade ago focused on AED in nursing homes, we added references to their important research. Page 3 line 71 to 75; “More than a decade ago, several studies focused on the debate on euthanasia and on advance euthanasia directives (AEDs) for patients with dementia (PWD), {Hertogh, 2007;de Boer, 2010} and on experiences of physicians in nursing homes with this topic.{de Boer, 2011} At that time, elderly care physicians and relatives appeared to be reluctant to adhere to AEDs. However, since then a lot has changed in the public debate, opinion of physicians and daily practice.”

And on page 10 lines 326 to 328; “The physicians we interviewed showed a larger variety of opinions than twelve years ago. {de Boer, 2011} The adaptation of the KNMG guideline on this topic in 2015 might have contributed to these obvious changes.”

A more in-depth ethical reflection based on the results should be developed.

We gave the discussion session a major revision, including a more in-depth ethical reflection. Please see pages 10 to 12 lines 319 to 388.

It is mentioned that this study is the first study focusing on experiences of physicians regarding euthanasia in patients with dementia. I do not agree with this statement. According to me, the study of Marieke de Boer was the first one. Moreover, the study of de Boer used a much more robust methodology. I refer to the following two studies that at least need to be integrated in this paper:


Indeed, we were not first, as Marieke de Boer ten years ago did her PhD on AED in nursing homes, and published very relevant studies. We skipped the sentence of being the first.

Claudia Gamondi (Reviewer 2):

I thank the editor for having given me the opportunity to review this piece of research. This paper outlines a qualitative research investigating Dutch physicians' views about euthanasia conducted upon advanced directives. Authors conclude that the majority of participants were asking for more clarification of their professional guidelines and that euthanasia in dementia can be ethically and emotionally challenging for many of them. The topic is of relevance for national and international discussion, given the raising number of countries legalizing forms of assisted dying.

The Introduction is well structured and offers a good overview of the area. Authors should consider the following points:

- Lines 68 the statement: "Dutch society expects euthanasia requests to be granted" needs a stronger reference readable in English.

We added a reference to a recent paper on this topic. Page 3 lines 70 to 71;

“This is related to the changed view in Dutch society in the direction of being in control of your own life and a right to die. {Kouwenhoven, 2019}”

- Lines 73-74: To allow a better understanding of epidemiology, total numbers should be presented with percentages of the overall cases of euthanasia each year.

We added these numbers. Page 3 lines 77 to 79;

“Moreover, in 2010, euthanasia for PWD took place in 25 cases (of 3136 cases in total), in 2014 in 81 cases (of 5306 in total), and in 2018 in 146 cases (of 6126 in total), mostly in competent PWD.

Lines 77-78: "And although the percentage of Advance Euthanasia Directives (AEDs) did not increase between 1998 and 2011, in the past decade a growing number of people does": it is not clear what authors mean by this. Please rephrase it.
We rephrased this sentence to make it clearer. Page 3 lines 79 to 81;

“The number of AEDs and euthanasia requests from PWD are larger, as not every request or AED ends up in euthanasia. {Evenblij, 2019;Evans, 2015;Harnas S, 20187}”

For international readers, please briefly describe if other countries allow euthanasia on advance directives and in dementia.

We added information about this. Page 3 lines 86 to 88;

“Although the number of countries where euthanasia and physicians-assisted suicide is legalized is increasing, {Emanuel, 2016} legally replacing verbal communication by an AED if a patient can no longer express his own wishes is only possible in the Netherlands.”

The methodology of the study follows from the research aims. There are some points that need clarification and more work.

- line 104: how researchers had a list of emails?

We added this information to the text. Page 4 lines 113 to 115;

“One was a list of doctors that signed a critical statement published in Dutch national newspapers about euthanasia procedures for persons with advanced dementia and who had provided their email addresses. {Chabot, 2017;Miller, 2019}”

And on page 4 lines 121 to 122;

“Via the director, two physicians employed at the End of Life clinic agreed to participate.”

- line 105: do authors mean purposeful sampling?

We changed this paragraph to make it clearer. Page 4 lines 110 to 113;
"In order to find physicians with different attitudes towards euthanasia for PWD, we purposively recruited physicians with a variety of experience in granting euthanasia for this patient group, male and female doctors, GPs and elderly care physicians."

- line 108: authors should provide more information to international readers about the "critical statement published in Dutch national newspapers" and what was the interpretation of the researchers of the attitudes of the physicians that signed this critical statement.

We added more details and a reference to this sentence. Page 3 lines 90 to 91;

“This led to several campaigns by physicians who, because of ethical concerns, opposed AED authorisation of euthanasia in case of advanced dementia due to their ethical concerns. {Chabot, 2017; Miller, 2018}“

As we also explained to reviewer 1, signing this statement only meant that they are against granting euthanasia to a person with advanced dementia who is not capable anymore and therefore cannot confirm an actual euthanasia wish. They had a variety of views on euthanasia requests and granting euthanasia in earlier stages. Our study did not focus on granting euthanasia in persons with advanced dementia but on euthanasia requests which are mainly first posed in an early stage of dementia. Signing this statement will have hardly influenced our results.

- line 117: which literature guided the preparation of the interview grid? How the two pilot interviews were handled? Were they included in the analysis?

The two pilot interviews were not included, which information new added to the text We rephrased this sentence. Page 4, line 127 to 128;

“Based on scientific and grey literature, the public debate and two pilot interviews which were not included in the analysis, a topic guide with four open questions was developed. (Table 1)”

- line 122: Authors should better motivate the choice of using multiple interviewers and discuss implications for data collection and analysis.
We clarified this on page 4 to 5, line 129 to 131;

“There were two core interviewers (LC and LW); one of them was always leading the interview. During each interview, an additional researcher was present (RB, TR, LC, LW), who took notes and could ask additional questions.”

- line 128: which differences emerged? how differences in interpretation were handled?

- How quotes were selected? How the translation in English of the quotes was performed? Quotes need to be related to a participant; please give a number or a pseudonymous. Some quotes are very long and do not apparently give reason of the codes created (example lines 292-296).

The quotes were translated in English by a certified translator. We added to the methods section additional information. Page 5 line 139 to 143

‘If no consensus was reached, the codes were discussed with the project leaders (YE and JS)’

Finally, during a meeting with all researchers, codes were merged into categories and themes, and an affinity diagram was made (24,25) during the coding process and merging processes, quotes that best reflected the codes within a category were selected. Each quote received a letter (A-K), representing the physician who mentioned it.”

- The section on data analysis needs to be more explicit in how the coding was done and how the codes generated.

We adapted the text accordingly. Page 5, line 136 to 140;

“After two interviews, we applied conventional thematic content analysis of the transcripts to develop a codebook. {Hsieh, 2005} Two researchers independently coded each interview line-by-line, after which they discussed differences until consensus was reached. If no consensus was reached, the codes were discussed with the project leaders (YE and JS).”

Results: The results section presents interesting findings, whereas the text is more a presentation of single quotes than descriptive of the codes. in some points, it becomes verbose and arduous to read. I would suggest the authors to be more descriptive in the results section, providing more
information about each code. If the word count would be too high, quotes could be presented in boxes or figures.

We revised the results section, and deleted text where possible. We prefer not to put the quotes etc in a box, as this is, to our opinion, less comfortable to read. However, we added a new table with all the codes, categories and themes. Table 3

- Line 132: how were these 11 participants selected out of how many that showed interest? If maximum variation sampling was chosen, how researchers tested participants attitudes before choosing participants?

We added more information about this in the methods section. Page 4 line 110 to 123;

“Between December 2017 and February 2018 participants were recruited. In order to find physicians with different attitudes towards euthanasia for PWD, we purposively recruited physicians with a variety of experience in granting euthanasia for this patient group, male and female doctors, GPs and elderly care physicians. We used two different sources for recruitment. One was a list of doctors that signed a critical statement published in Dutch national newspapers about euthanasia procedures for persons with advanced dementia and who had provided their email addresses. {Chabot, 2017; Miller, 2019} This critical statement opposed euthanasia in non-competent persons with advanced dementia. Taking account of the above-mentioned criteria, physicians from this list were invited by e-mail to take part.

The other source was the End of Life clinic. This clinic deals with euthanasia requests, and when due care criteria are met, offers euthanasia or assisted suicide to people of whom the own physicians are not able to or do not want to perform it. The physicians of the End of Life clinic are less reticent to perform euthanasia in case of PWD. {Snijdewind, 2015} Via the director, two physicians employed at the End of Life clinic agreed to participate. We also used snowballing. After we reached saturation, we stopped inviting physicians to take part.”

- Lines 132- 133: was this 10-2 participants' ratio reflecting the maximum variation sampling chosen by researchers?

The number of physicians who work for the End-of-Life clinic and deal with euthanasia requests of persons with dementia is limited, and including a higher of group 2 therefore was not possible.
However, the eleven physicians had a wide variety of attitudes towards dealing with euthanasia requests in persons with dementia.

- Line 193: is the word "dementia friendly" a direct quote? if yes should be written appropriately.

We changed the wording, and left ‘dementia friendly’ only within a quote. Page 7 line 223;

“In my opinion we should not just be a dementia-friendly society”

- Line 268: is this an affirmation of participants or the view of authors?

This was the view of participants.

The discussion:

To sharpen the discussion, it will be of help to discuss the clinical and policy implication of their findings in a separate paragraph.

We thoroughly revised the discussion section and added clinical and policy implications. Page 10 to 12, lines 319 to 379,

The strengths and limitations paragraphs should be reflected more in depth. Reflexivity of researchers should be explored and discussed. Authors should also discuss how the personal views of most of participants could have influenced their apparent low rate of euthanasia requests and how this low rate could have impacted the results of this research.

We adapted this section. Page 12, line 382 to 388. However, the rate of euthanasia requests was not low, but the rate of granted euthanasia, which is something different. This is not strange, as in the Netherlands this number per year still is quite low, as also mentioned in the text page 3 line 77 to 79.
The overall English of the paper should be extensively reworked.

A native English speaking general practitioner corrected the entire document.

Yours Sincerely,

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