Author's response to reviews

Title: End-of-life care in Germany: First results of the cross-sectional EPACS study.

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Author's response to reviews: see over
Dear Miss Hewitt,

Please find enclosed the revised manuscript of the article „End-of-life care in Germany: First results of the cross-sectional EPACS study (Establishment of Hospice and Palliative Care Services in Germany)“.

We would like to respond the reviewer’s comments as follows:

**Reviewer Christoph Ostgathe**

1) It stays rather unclear whether the focus of the data is end-of-life home care or end of life care in general. The focus seems to be on home care as the new legislation is a central issue and the data is meant to be a baseline for the evaluation “... the impact of structural changes implemented in outpatient palliative care in Germany”. But only 25% of the population is home based. Overall there is no information on place of death. The focus should be made more clear.

**Answer:** the focus of the data is „end-of-life-care“. Since only first results are presented in this article, we did not go into detail concerning clinical care. Further differentiated analyses are intended.
2) More detailed information on the ethics committee decision (#?) should be provided

Answer: Concerning information on the ethics committee, the following was supplemented: “the ethical committee of the medical association of the Germany State Rhineland-Palatine and the data protection officer of Rhineland-Palatinate approved the EPACS-study. It is conform to the actual Declaration of Helsinki on Ethical Principles for Medical Research”.

3) The standard documentation tool HOPE is mentioned, but this tool is a team documentation tool mainly on basic data. The presumably used questionnaire is a module for relatives after the patient has died – offered within the HOPE system. This particular module was developed by the German Hospice Organisation (now DHPV formerly BAG) and it has not been tested for its psychometric properties yet, so the results may be of limited quality. This has to be discussed in the limitations section. Interestingly the authors even state that there is validity for “the method of data collection .... “. This should be revised and clarified.

Answer: For our study, a specific questionnaire was developed and used for the first time. In order to ensure a later comparability, questions of the HOPE-questionnaire were included. This information has been specified in the methods section. The problem concerning validity was discussed in the limitations section.

4) The population of deceased patients is not sufficiently described. There is no information on the type of diseases for the whole group (– only for the group that had professional home care). Type of disease may have a mayor impact on the perceived quality of end of life care. Is there any information on the type of death (suddenly, accident, predictable …) for the whole group. Where was the place of death? (see above)

Answer: The data mentioned by the reviewer is very important. Yet the author’s opinion is that enough data has been presented, since the article is a matter of “first results”. The questions raised by Mr. Ostgathe will be covered specifically and extensively in a following article.

5) The data presented would benefit from a clear concentration on what is said in the title. There is too much data about not participation, which does not inform sufficiently about quality of end-of-life home care. This part should be taken out completely. Except for a short information on reason for not participating
**Answer:** One of the article’s main goals is to present and discuss the executed methods. The authors consider it absolutely necessary to maintain data about “not participating”. This is to further encourage the discussion about epidemiological methodical research in palliative medicine.

6) Overall the results section is very hard to read; too much data is presented, doubling data from the tables and figures. Here it would be helpful to refer to the major findings and format it in a way that it can be read more easily.

**Answer:** The authors examined the „results section” with regard to doubling data. They consider a demonstration of the data in text and partly tables necessary.

7) The discussion section has to be revised thoroughly. Again here the concentration on the non-participation is of lower importance for the major question. Additionally the authors narrow the discussion mainly on repetition of the data, trying to explain, rather than bringing the data found into the context of the very lively discussion in the literature for example on quality and quality indicators in end-of-life care

**Answer:** the discussion has been revised. The focus on “non participation” yet has been kept (see answer point 5).

8) Page 4 first line an approach

**Answer:** done

**Minor revisions:**

9) Page 5” .... services are made possible nationwide”, this very unspecific. With the new law every patient in need has the right to receive specialised palliative home care. Out of this an obligation to reimburse this service arises for the health insurances. Actually this reimbursement is negotiated in many regions in Germany.

**Answer:** the information was added.

10) Page 11 what does that mean: ... “the reaction .... was lower(?)”

**Answer:** the information was specified.
Discretionary Revisions

11) Interestingly the overall satisfaction seems to be quite high so it should be discussed whether the structural changes are really necessary. The authors may comment on that “dangerous” question. Or is satisfaction a insufficient indicator because relatives tend to answer socially expected?

Answer: the discussion was enlarged by the aspect of satisfaction with care. Global satisfaction is generally high, but massive dissatisfaction with one aspect of care may occur, which does not appear in the global assessment (satisfaction paradox). In future research, several aspects of care will have to be judged separately.

Reviewer: Mitsunori Miyashita

Comments:

1) In the title, the full spelling of EPACS should be described

Answer: done

2) The full text of HOPE questionnaire should be described in appendix

Answer: Since a separate questionnaire has been developed which only contains some questions of the HOPE-questionnaire, the authors did not describe this one in detail.

3) The figure 2 should be by pie chart or band chart. In this type of data, the total percentage of bar should be 100%.

Answer: done.

4) From figure 4 to 7, also, figures should be by band chart

Answer: done
5) The related factors to the satisfaction and HOPE questionnaire should be explored.

**Answer:** see commentary point 3 (Mr. Ostgathe) and point 2 (Mr. Miyashita).

6) The information about cause of death should be described. This is most important variable. If you could not get this data, you should estimate from census, etc.

**Answer:** Information about the cause of death is certainly very interesting. Our study did not request this information because of two reasons:

- Main goal was to document “end-of-life-care” in Germany immediately before death. Illnesses before death are therefore of much more importance than the actual cause of death. Our study contains data about illnesses immediately before death.
- It is well known in Germany that the procedure to declare the cause of death does not provide correct data.

The authors thank the editorial team and the reviewers very much for the constructive commentaries and hope to have considered them adequately. For any further information please feel free to contact us.

Sincerely,

Dr. Luis Carlos Escobar Pinzón