Reviewer's report

Title: Patient, caregiver, health professional and researcher views and experiences of participating in research at the end of life: a critical interpretive synthesis of the literature

Version: 1 Date: 10 November 2011

Reviewer: Johan Bilsen

Reviewer's report:

This manuscript is a valuable contribution to the scientific knowledge about a topic of great importance in EOL-research. It is well-written, the aim is clear, and the research questions are well defined. The methods are appropriate although they could be more extensively described. The data are sound and clearly reported. The discussion and conclusions are adequately supported by the data, mostly well balanced. Limitations are clearly stated, but could be a bit more elaborated. Others work is correctly referenced.

I have only one major compulsory revision point and some minor comments:

Major Compulsory Revisions

*Results, Flow chart of search results. I did not found the flow chart in the manuscript or supplementary file sent to me.

Minor Essential Revisions

1) Title of the manuscript. What do the authors mean with ‘professional’? Why mentioning “professionals” separately? Caregivers and researchers are not professionals? Perhaps: ‘other health professionals’?

2) Abstract, Conclusion. The conclusion goes too far in my opinion. It is not clear what is meant by ‘Ethical’ concerns regarding patient participation in EOL care research. A lot of ethical concerns are possible in this context. The aim of this study is not to give evidence about ethical concerns but to investigate evidence (from published articles) regarding views on and experience with participation in research (mainly addressing the assumption that patients at the EOL are too vulnerable to participate in research), as stated in the Aim of the Abstract.

3) Introduction, Par. 1. The outlined demographic and morbidity evolution is not typical for the global population, but mainly for developed countries.

4) Research questions. Perhaps a question can be added about possible relationships between factors and the outcome “willing to participate” / “experienced distress”.

5) Methods, Design. Because it is crucial for the reader to well understand the followed methods, it would be helpful to give here already some more information about what is meant by “CIS”, besides referring to the literature.

6) Methods, Inclusion criteria. In the abstract, also systematic reviews were
included. Why not including these articles (e.g. ref. 12 and 13, mentioned earlier in the introduction), especially because “papers already included in previous reviews were also excluded”.

7) Methods, Synthesis, par. 1. The three major categories seems to me more belonging to the result section than to the methods section.

8) Results, throughout the text and table 1. To facilitate the reader in connecting the text to the table, I suggest to number all the papers in table 1 (with between brackets the number of the references at the end of the manuscript), and to refer throughout the text of the results only to the numbers in the table. It would also be helpful for the reader to have all individual numbers of the mentioned papers in the text instead of –sometimes- the amount of papers (e.g. not “most studie(9)” , but “most studies (1,2,3,4,....)”). Table 1 has no title in the version I received.

9) Results, Participation in research using surveys,...par.3, Philipps et al. How to interpret the (p_0.001)?

10) Discussion/Conclusion. Sometimes the authors talk about ‘ethical concern about patients at the EOL as too vulnerable’, sometimes just about ‘ethical concerns about participation in EOL’. I think it is important to clarify about what ‘ethical issues’ regarding participation this study gives evidence, and about what issues it doesn’t.

11) Limitations. The different gaps in the evidence base are perhaps not neutral with regard to the aim of this study. It is possible that it is no coincidence, but that they represent in some sense an indication for undetected problems in EOL-research. Also possible publication bias should be considered.

12) References. Sometimes information is missing, e.g. about the reports.

**Level of interest:** An article whose findings are important to those with closely related research interests

**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