Reviewer's report

Title: Choosing care homes as the least preferred place to die: a cross-national survey of public preferences in seven European countries

Version: 2  Date: 9 August 2014

Reviewer: Saskia Juenger

Reviewer's report:

Overall comment
The manuscript Choosing care homes as the least preferred place to die: a cross-national survey of public preferences in seven European countries is an important paper about a highly relevant topic of care- and health services provision in Europe. The manuscript is very well written and it was a pleasure to read it. The background section is very clear and concise, and the relevance and purpose of this paper are clearly described. The authors have chosen a sound methodological strategy to address their research questions; supplementary files provide a high level of transparency regarding the research methodology. The limitations of the work are clearly stated. The questionnaire is thoroughly developed, building its rationale on a theoretical model, and its wording is very thoughtful.

The discussion appropriately addresses the statistical findings of the telephone survey. In my personal view, the discussion would benefit from a look beyond the variables researched in this study and a more in-depth consideration of the broader (national) context of living and dying in nursing homes (see details under “discretionary revisions”). The conclusions are informative; they draw attention to an important challenge of future health care provision and provide meaningful implications for further research.

Discretionary revisions
1. Abstract – p. 3, lines 55-57: When first reading these lines, the aim of the research appears a little confusing since it sounds extremely narrow and negative. Only when the reader understands that this research question was addressed as part of a broader project or as a closer investigation of findings from the study on preferences regarding the place of death, it becomes logical. I would therefore suggest adding something like “As part of a broader study on preferences on the place of death...” or “To examine more closely / gain a deeper insight into the findings from a larger project on preferences regarding the place of death, we investigated...”.

2. Abstract – p. 3, lines 70-71: The direction of “negatively associated” and “positively associated” is not very clear here due to the double negation of “least preferred place of death”. Would it be possible to express this more directly, e.g. “Respondents doing household were less likely to...”?
3. Background, p. 5, lines 130-133: I would suggest slightly rephrasing this passage as follows: “Cross-national comparisons show different availability of care home beds and proportions of care home deaths [6, 16, 17]. The service provision in care homes (including palliative care provision and ability) and source of funding are also diverse [3, 4, 13, 18]. Therefore, this study aimed at a cross-national investigation of the general population’s views since this was expected to provide important insights into / understanding of preferences regarding nursing homes as the place of death.”

4. With regard to the differences between care home service provision in different European countries, I wondered whether it might be helpful to provide a little bit more background information about nursing homes in the countries addressed by this survey, e.g. a few key characteristics listed in a table; or a very short sketch of nursing home service provision in these countries as a supplementary file; or reference to an information source where the reader can get more information on how nursing homes work in these seven European countries.

5. Results, p. 10, line 242 (Table 2): I noted quite some differences between participants’ socio-demographic characteristics in the different countries (e.g. education level, perceived health status, etc.). I wondered whether it would be appropriate to refer to these differences in the discussion since they may have affected the participants’ responses, or the generalisability of the results (i.e. in how far the sample was representative for the different countries’ population).

6. Results, p. 11, lines 266-269: These findings for Italy and Portugal are not picked up in the discussion while the situation in the Netherlands and Germany is particularly addressed. In my view these results would also deserve attention since it will be important for the reader to make some sense of these statistical outcomes - or otherwise it would be helpful to address the lack of a plausible explanation based on the available data or considering of the broader context of these findings. Similarly, this is true for the finding that Italy had the highest number of associated factors associated with the preference (p. 12, lines 276-277).

7. Discussion, p. 13, lines 316-318: I am not sure whether I find the logic of this argument convincing. The authors say that they did not find an influence of experience of serious illness on the preference for care homes, while continuing to say that those permanently sick or disabled in Belgium were actually more likely to choose care homes as the least preferred place to die. So first of all, there appeared to be a relationship between health status and preference. Moreover, in my view a possible interpretation could be that this group of respondents has a higher level of awareness or a greater perceived vulnerability regarding issues of autonomy, anticipated loss of control, and stronger negative associations with being cared for in a nursing home. Likewise, this is true for the argument on p. 14, lines 339-340: I would not assume that older people would be more optimistic about care homes – on the contrary, I would expect them to consider this option more realistically and therefore potentially have a stronger negative affect towards this place than younger people who might feel themselves “further away” from this option.
8. Discussion, p. 14, lines 348-350: In my view the discussion would benefit from a more in-depth reflection of possible reasons for the choice of nursing homes as the least preferred place to die. While in the conclusions section the authors recommend qualitative studies to explore in depth the reasons why people do not wish to die in care homes – which in my view is brilliant – this could also be more clearly emphasised in the discussion section. For example, the authors refer to personal knowledge and having relatives in care homes as possible influencing factors they did not cover. It would be helpful and interesting for the reader to suggest how qualitative research might help to provide explanations for the statistical findings and provide insights into people’s particular ideas, images, expectations, and motivations for their answers. Also, reference to characteristics of care home provision in the countries involved in this survey might add to the depth and meaningfulness of the discussion, as well as public awareness / perceptions and attitudes in the general population. Next to personal knowledge and having relatives in care homes, reporting in the media will have an important impact on people’s associations and connotations with the term “care home”. For example, nursing homes are currently quite frequently addressed in the German media – often highlighting the lack of quality of care, staff shortage, or even scandalous incidents such as abuse, violence, or neglect of residents. I found a quite recent article (from the USA, though) on the adverse impact of media coverage on the reputation of care homes that might be informative in this regard: http://www.ncbi.nlm.nih.gov/pubmed/23032355 - and a related link providing a summary of this paper:

In 2009, a report on the population’s perspectives on the quality and status of long-term care in Germany was published, based on a representative survey by the German “Institut für Demoskopie Allensbach”. One chapter specifically addresses the image of care homes in the German population. I attached the report to this review (unfortunately only in German language – but maybe it will somehow be helpful, though?).

Level of interest: An article of importance in its field

Quality of written English: Acceptable

Statistical review: Yes, but I do not feel adequately qualified to assess the statistics.

Declaration of competing interests:

I declare that I have no competing interests.