Author's response to reviews

Title: Decision-making capacity and communication about care of older people during their last three months of life.

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Version: 2 Date: 14 October 2012

Author's response to reviews: see over
Dear editor,

Please find attached the revised manuscript entitled: Decision-making capacity and communication about care of older people during the last three months of life [Previous manuscript MS 7808365337836875]. Thank you for considering this manuscript for publication in BMC Palliative Care and the opportunity to revise our manuscript. Please find attached a detailed description of how we have responded to the comments of the referees and the editor. We think that the revisions have improved the manuscript substantially.

Yours faithfully,
Also on behalf of the co-authors,
Pam Kaspers

Reaction on the comments of referee 1 (Sophie Pautex):

1. Referee: ‘The study raises the important topic of the decision making capacity at the end-of-life and the topic of satisfaction of care of the proxies. The questions posed by the authors are well defined. The title and abstract accurately convey what has been found. Concerning the methods, the assessment tools are very briefly described. In particular it’s difficult to understand how care according to patient preferences was really assessed. There is only a very short description of the statistics.’

As suggested by the referee, we added an additional description of the assessment tools used in the methods section in the paragraph on measurement. In this paragraph, we also describe how care according to the patient preferences was assessed.

All data were derived from the questionnaires the proxies of deceased LASA and ADC members had filled in. The proxies completed a questionnaire that consisted of structured questions including age, gender, DMC, possession of an AD, received care, contact about and satisfaction with care, communication about and influence of ADs on care, the role of the proxy in decision-making, and cause and place of death. Decision-making capacity was asked by the question ‘Until what moment was the deceased sample member capable of making end-of-life decisions’, with the response categories ‘until the moment of death, minutes before death, hours before death, days before death, a week before death, several weeks before death, a month before death, or more than a month before death’. The proxies were asked if the
deceased sample member had formulated an AD (answered by yes, no, or do not know), and if so, which AD was formulated (one or more answers could be ticked in response categories appointed health care proxy, advance euthanasia directive, refusal of treatment document, do-not-resuscitate order, will-to-live statement). The questions about contact and satisfaction (concerning care (aim 2), the use of ADs (aim 3 and 4), role of the proxy (aim 4)) were distinguished in two types of questions: the proxies were asked to provide their perceived view of the decedents’ contact and satisfaction as well as the proxies’ own contact and satisfaction with the person’s care. With regard to the care being according to patient preferences, the proxies were asked to assess if the care received by the person, in general, was in accordance with the preferences of the person (yes, partly, no, unknown).

Furthermore, we described the analyses somewhat more extensively in the analyses paragraph.

Analyses

For describing the period of limited DMC of Dutch older people (aim 1 and 2), we used the deceased LASA sample members, since this sample is representative for the Netherlands. We included 165 of the 168 cases for which the question on limited DMC was filled in by the proxy. For describing background characteristics of deceased LASA sample members we recoded the variable on DMC in three categories: full DMC until death included ‘until a the moment of death’ and ‘minutes before death’; limited DMC before death a week or less before death, included ‘hours before death’, ‘days before death’ and ‘a week before death’; and limited DMC more than a week before death included ‘several weeks before death’, ‘a month before death’, and ‘more than a month before death’. We selected these categories as during preliminary analyses a shift of limited DMC was found especially during the last week of life (see also figure 1). Differences between groups were tested with chi-square tests, using a level of significance of p<0.05.
For the study aims that focused on (proxy) ADs, we used the cases from the LASA cohort and in addition we included people from the ADC. Purpose for this was to have a larger number of people with a (proxy) AD. For describing experiences with ADs (aim 3), we selected people with an AD who had limited DMC before death \((n=120)\). In the analyses we compared people with limited DMC for a week or less before death with people who had limited DMC more than a week before death. For studying the influence of a proxy AD (aim 4) we selected all people with limited DMC before death \((n=213)\) and compared the group with a proxy AD with the group without a proxy AD. Differences between groups were tested with chi-square tests, using a level of significance of \(p<0.05\).

2. Referee: ‘The delay between the death of the patients \((\text{sometimes} > 3\text{years})\) can make interpretation of some results difficult, even if this point is raises in the limitation. The combination of both cohorts, described as a strength make the interpretation of the tables difficult. as the number of patients is different in each table.’

We agree with the reviewer that the delay between the death of the patients and the study is a limitation. It was already described as a limitation, as the reviewer also stated. However, we rewrote the limitations paragraph to put more emphasis on it.

That data were collected through proxies of deceased people brings two types of bias. First is potential recall bias due to the retrospective reporting: the cohort members deceased between half a year and three and a half years before the proxies entered the study [12]. However, it is likely that proxies remember circumstances around the death of a relative. Second, it is known that proxies are not always accurate in assessing the patient’s own views. Yet, literature indicates that proxies are more likely to give accurate information when it concerns more factual information such as care characteristics of a deceased relative, while less factual information is more likely to be assessed less accurate by proxies [12,13]. Of course, the experiences of the relatives themselves concern an important focus of this study, and for that part the proxies are the most suitable respondents.

We agree with the reviewer that the combination of both cohorts can make the study confusing, since the number of patients differs per table. In the analyses paragraph in the methods section for each aim we describe which selection of patients we made to answer the question. In the rewriting (see also reviewer 1, point 1) we
added the number of patients in that selection. These numbers correspond with the n in the tables. We think this will help avoid the confusion.

3. Reviewer: ‘It would have been interesting to have more details about the additional value of the ADS described by the proxies.’

We agree with the reviewer that it would have been interesting to have more details about the additional value of the ADS, as described by the proxies. As the scope of our study does not provide more detailed information on this matter, we added this as a suggestion for future research in the discussion section where we discuss these results.

Over half of the relatives considered the AD of additional value, while at the same time only a small group considered that the AD determined decisions. This might indicate that relatives also see the role of an AD more as an aid in communication on end-of-life care and treatment, as some authors have suggested [21, 22]. However, it would be desirable for future research to provide more in-depth insight in the ways in which relatives experience the additional value of ADs.

4. Reviewer: ‘It would also be interesting to have more details about the circumstances of death of the patients: how many euthanasia for example? Because that could have an influence on the results.’

We agree with the reviewer that it would have been interesting to have more details about the circumstances of death of the patient, for example about euthanasia. However, we do not have data available about the numbers of euthanasia and therefore, we were unable to add this kind of information to this manuscript.

5. Reviewer: ‘In table 1: the sum of the different categories is 165?’

We thank the reviewer for her attentiveness. The number in the sample is 168, but 3 proxies did not fill in the question on limited ADC; we now explicitly mention this in the methods section, in the analysis paragraph (see point 1). In figure 1 and table 2 and 3 we changed the total n to 165.

-Reviewer: ‘The writing is acceptable.’

We edited the manuscript for language again.
Reaction on the comments of reviewer 2 (Jane Seymour):

1. Reviewer: ‘This is an interesting paper of a complex study and addressing an important area of research. I think however there is a risk of confusing the issue of relatives’ perceptions of quality of decision making and communication and their perceptions of what the decedents’ experiences might have been. There is also a risk of confusing people’s experiences of communication and their perceptions of the value of Ads (this is briefly touched on in the paper).’

As suggested by the reviewer, we revised the manuscript concerning the distinction in the perceptions of what the decedents’ experience might have been and the relatives’ own perception. Specifically, we edited the sections aims, methods and findings. Please see our more detailed reaction on the comments concerning this below.

2. Reviewer: ‘Overall, the numbers with some type of AD are so small as to make any conclusions about ADs problematic.’

We assume that the reviewer refers to the numbers of people with ADs in table 1. Table 1 describes the patient and care characteristics of the LASA sample only (aimed at an overview of the Dutch older people in general; and the ADC sample is left out). Since ADs do not occur in the Dutch population (LASA), we combined both the ADC and LASA cohort so that we could study the use of ADs with a substantial number of people with an AD. The conclusions about ADs (table 3 and 4) are not based on the small numbers that appeared in table 1. We clarified this better now in the methods section in the analyses paragraph:

For the study aims that focused on (proxy) ADs, we used the cases from the LASA cohort and in addition we included people from the ADC cohort. Purpose for this was to have a larger number of people with a (proxy) AD. For describing experiences with ADs (aim 3), we selected people with an AD who had limited DMC before death (n=120). In the analyses we compared people with limited DMC for a week or less before death with people who had limited DMC more than a week before death. For studying the influence of a proxy AD (aim 4) we selected all people with limited DMC before death (n=213) and compared the group with a proxy AD with the group without a proxy AD. Differences between groups were tested with chi-square tests, using a level of significance of p<0.05.

3. Reviewer: ‘That said, the study raises interesting questions for further research which I would like to have seen highlighted.’

As suggested by the reviewer, we added a suggestion for future research in the conclusion paragraph in the discussion section. Please see reviewer 1, point 3.
4. Reviewer: ‘My comments raise some specific areas (beyond the general points above) that need to be addressed to make the paper clearer to read:

**Major Compulsory Revisions**

**Background:** ADs usually indicate advance refusal of particular treatments in specific circumstances, while an advance statement (not discussed in the paper) can be positive or negative and address broader views about care. How these terms are used and defined of course depends on the state or country concerned. The paper would be improved if some explanation was given about the legal position in the country concerned regarding these issues.

I think a paragraph needs to be added explaining that **Ads have no relevance to the decisions about someone’s treatment until they lose capacity:** this is important in this paper. ‘

As suggested by the reviewer, we added extra information on ADs in the manuscript. In the background we added that an AD has no relevance to the decisions about someone’s treatment until they lose capacity, overall explanation of ADs and the legal status in the Netherlands. In the methods section, where we described the ADC cohort, we gave more detailed information on the most common ADs in the Netherlands,

**Background:**

People may write down their preferences in an advance directive (AD), a written statement in which they can specify preferences in end-of-life care and treatment decisions. An AD becomes of relevance when a person loses his or her capacity to make decisions. An AD can either make statements about receiving or refusing treatments in certain situations or a statement in which the person can appoint a health care proxy who will represent the individual when he or she has limited DMC. In the Netherlands, ADs that concern refusal of treatment are legally binding.

**Methods:**

In the Netherlands, two associations provide the most common types of ADs ‘Right to Die-NL’ (NVVE in Dutch) and Dutch Patient Association (NPV in Dutch). The NVVE provides four types of standard ADs. First a refusal-of-treatment document (ROTD) states in what situations a person does not want to receive life-prolonging treatment. Second, a do-not-resuscitate order (DNR). Third a document in which somebody can appoint a health care proxy (proxy AD). Finally a advance euthanasia directive (AED) in which a person can state in which situations he or she would wish life to be ended. As with oral euthanasia requests, it
does not have to be granted by the physician and a physician is only allowed to grant when the criteria for due care are met. The NPV is a Christian oriented patient organization and provides a ‘will-to-live statement’ in which a person declares that he or she prefers to receive proper care, meaning no excessive, medically useless treatments at the end of life. In addition, it states that the person in question does not want active ending of life.

5. Reviewer: ‘Aims: The second aim of the paper is to ‘describe the potential differences in background characteristics and satisfaction with the communication about care between older people with full DMC until death and older people with limited DMC and their relatives’. This wording implies that the views / experiences of people with and without capacity will be compared, whereas it later becomes clear that it is relative’s views that are explored. This needs to be explained more clearly. Later on we learn that the proxies are asked to provide their perceived view of the decedents’ satisfaction with care as well as their own satisfaction with the person’s care: this needs further clarification and the limitations of this exercise need to be highlighted.’

We rewrote the second aim more precise now:

Second, we aim to describe the potential differences in background characteristics, the patient’s satisfaction with communication about care (according to their relative), and relatives’ satisfaction with communication about care between older people with full DMC until death and older people with limited DMC.

In the limitation paragraph we more clearly describe the limitations of proxies as respondents (please see reviewer 1, point 2).

6. Reviewer: ‘Methods
I think there is potential confusion between the use of the term questionnaire to refer to those completed by the people now deceased in the cohort studies and those completed by their proxies in the study reported in this paper. Perhaps this confusion can be reduced by giving a little more information about the questionnaires administered in the cohort studies.’

As suggested by the reviewer, we changed the method section by giving more information about the questionnaire administered in the study. We start with explaining that all data in this study are derived from the proxy questionnaire (see reviewer 1, point 1).

7. Reviewer: ‘Methods: This sentence on page 7 is particularly confusing:
A total of 184 proxies completed the questionnaire (72%), 52 proxies (20%) did not respond, and 20 proxies (8%) were not willing to participate. Most deceased were NVVE members (238, of whom 167 filled out a questionnaire).’

As suggested by the reviewer, we changed the sentence into the following.

‘ Of the ADC participants, 263 died between 2006-2009 and had given permission to contact a proxy. Of them, 256 proxies were approached (NVVE n=232, NPV n=24), as 7 proxies
could not be reached (NVVE n=6, NPV n=1). A total of 184 proxies (NVVE n=167, NPV n=17) completed the questionnaire (72%), 52 proxies (20%) did not respond, and 20 proxies (8%) were not willing to participate.

8. Reviewer: Methods ‘As noted above, the limitations of the exercise need to be discussed.’

We did revise the limitation section substantively (please see reviewer 1, point 2).

9. Reviewer: ‘Findings’
The text is quite difficult to follow and I am not always clear when the percentages given refer to a range or differences between groups.

In the text about communication, it is not clear whether the authors are talking about perceptions of the decedent’s satisfaction with communication or the relative’s satisfaction. For example, this wording is problematic in this regard:

...compared to people with limited DMC more than a week before death (‘good’ 48%); communication was considered bad in 32% of people with limited DMC for more than a week

As suggested by the reviewer, we made changes throughout the findings section concerning clarifying 1. if percentages refer to a range or difference and 2. if the results are the perceptions of the decedent as perceived by the relatives, or the satisfaction of the relatives themselves. The sentence given as example by the reviewer, we changed as follows:

‘Significantly more relatives of people experiencing limited DMC a week or less before death said they perceived communication with physicians was ‘good’ by themselves (63%), compared to the relatives of people with limited DMC more than a week before death (‘good’ 48%); communication was considered bad in 32% by the relatives of people with limited DMC for more than a week (limited DMC ≤ week 11%).’

10. Reviewer: ‘Minor Essential Revisions - Sentences not clear:

Therefore, we aim to explore how many older people develop limited DMC’

We rephrased the sentence as follows.

‘Therefore, we aim to explore how many older people develop limited DMC and how long before death these older people develop limited DMC.’

11. Reviewer: Sentence not clear: ‘since it is not very well possible to let proxies distinguish between sudden- and non-sudden deaths in a uniform way’.

We omitted this part of the sentence from the manuscript.
12. **Reviewer:** ‘**Sentences not clear**

As shown in table 2, according to the relatives of the deceased, in more than half of the cases, care received was in accordance with the preferences of both people with full and limited DMC, regardless of the duration of limited DMC (60-81%). However, people with limited DMC for more than a week significantly less often received care according to their preferences than people with limited DMC for a week (60% versus 81%) (Figures here need checking).’

*The sentence was indeed not clear; we rephrased it into the following.*

As shown in table 2, according to the relatives of the deceased, in more than half of the cases, care received was in accordance with the patient’s preferences both for people with full and people with limited DMC (both 71%). Looking within the group of people within limited DMC, people with limited DMC for more than a week significantly less often received care according to their preferences (60%) than people with limited DMC for a week (81%).

13 **Reviewer:** ‘**Sentences not clear** - While about a quarter of older people has limited DMC for more than a month before that, there is especially an increase in limited DMC in the last week of life when two third of older people have limited DMC; about a quarter remains lucid until death.’

*As suggested by reviewer 2, we rephrased the following sentence.*

While about a quarter of older people has limited DMC for more than a month before death, there is especially an increase in limited DMC in the last week of life. In the last week, two thirds of older people have limited DMC; about a quarter remains lucid until death.

14. **Reviewer:** ‘Needs some language corrections before being published’

*We edited the manuscript for language again.*
Reaction on the comments of the editor Gunn Grande:

Editorial Requirements:

1. Formatting
Can you please revise your manuscript so that the 'Competing Interests', 'Authors' Contributions' and 'Acknowledgements', appear as three separate sections. These should appear in the following order after the Conclusions section.

Done.

2. Figure Legends
Please remove Figure Legends from the images and include these in a separate section within the main manuscript, after the References.

Done.

3. Tables
Can you please remove all tables from the additional files and include these in the main manuscript, after the Figure Legends.

Done