Reviewer's report

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

Version: 1 Date: 29 August 2012

Reviewer: Jane Seymour

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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). Overall, the numbers with some type of AD are so small as to make any conclusions about ADs problematic. That said, the study raises interesting questions for further research which I would like to have seen highlighted.

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.

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.
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. 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 noted above, the limitations of the exercise need to be discussed.

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

Minor Essential Revisions

Sentences not clear:
Therefore, we aim to explore how many older people and how long before death develop limited DMC

since it is not very well possible to let proxies distinguish between sudden- and non-sudden deaths in a uniform way

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)

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
Level of interest: An article of importance in its field

Quality of written English: Needs some language corrections before being published

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