Reviewer’s report

**Title:** A qualitative study of professional and client perspectives on information flows and decision aid use.

**Version:** 1  **Date:** 9 June 2011

**Reviewer:** Jenny Theodora T van der Steen

**Reviewer’s report:**

Major compulsory comments

The authors address professional caregivers’ attitudes regarding providing of information and informal caregivers’ attitudes regarding preferences on receiving of information in dementia, using a qualitative (group) interview design in a community setting in Australia. The participants discussed a decision aid for dementia caregivers that was new to them, to assess the match between the perspectives of these groups, and how this can influence decision aid use. The authors conclude that “the paternalistic positioning of carers by some health workers suggests that they actively control and limit the provision of realistic information to carers.” The data collected are potentially useful as they may inform future work on counselling strategies.

1. Separately assessing professional and informal caregivers’ perspectives, however, is not the optimal design to address the aim. For this, observing of interaction and actual use of the decision aid is needed. The conclusion that professional caregivers’ view cause them to restrict information flows is not supported by the data. Rather, this qualitative study is hypothesis raising, and may recommend on future examining of what actually happens in practice.

2. Further, it is unclear from the data if restriction of information flows actually harms the informal caregiver. The authors seem to have taken a strong position that is not supported by the data from this study. It is still possible that informal caregivers do need some guidance, and in particular cases a paternalistic attitude might be beneficial if it results in rational and prudent dosing of information. The authors should at least discuss the alternative position.

Australian colleagues (Chang E et al., 2010; not referred to in the manuscript) found that half of families reading a booklet / decision aid agreed that it increased anxiety. Whereas it can be stated that facing the future downhill course of the dementia is beneficial, a potential harmful effect cannot be ruled out based on separate and hypothetical qualitative evaluation and discussion of a decision aid.

3. The methods lack information on the contents of the decision aid, and there was no reference. This information is crucial to a good understanding of the identified barriers in providing the information, which may be very sensitive, such as on end-of-life decision making. Selected parts of what is in the decision aid and its goals become a little clear only in the results section, with citations on information on services, a carer stress test, and dementia never going to be better, and reference to “the vignettes,” and “the Gold Book.” An overview of the
contents of the decision aid in the methods section is clearly needed.

4. If the decision aid was not the same as “Palliative Care Dementia Interface: Enhancing Community Capacity project. Dementia - information for carers, families and friends of people with severe and end stage dementia. 2nd Edition. Penrith, Australia: University of West Sydney, 2007. ISBN 0957756844, which has been tested by Chang E et al. (2010), the authors should justify their decision to develop or use a different decision aid.

5. Similarly, if so, please report on results of the literature review and consulting of the expert panel that informed development of the decision aid as stated in the methods.

6. It is unclear how the authors were able to link attitudes of specific participants to what was being said; the methods do not say that interview sessions were being audiotaped. The authors should better explain how they ensured rigour in methodology, especially since the aim as stated in the introduction was to highlight “the influence of beliefs on information control.”

7. The authors should discuss critically how their use of theory may have had implications for interpretation of the results.

8. It seems that notes have been analysed rather than full transcripts of the interviews. Please clarify and justify.

9. The authors refer to Graham C et al., 1997 and Procter R at al., 2002 to state that these studies, as well as theirs, demonstrated that knowledge of dementia resulted in a range of beneficial outcomes for informal caregivers. However, the studies referred to are cross-sectional, so interpretation of results is allowed only in terms of associations. Importantly, both Graham et al. and Procter et al. report an association between more knowledge and increased anxiety (which is the main finding of Procter et al.: “When a little knowledge is a dangerous thing…”). Anxiety is a very relevant outcome in terms of justifying or rejecting protecting attitudes of professional caregivers; lack of reference to this is a serious omission.

Minor essential revisions

10. Figure 2 is not particularly helpful. One of the four box was not supported by the data (more useful to professional caregivers, less useful to informal caregivers). Its meaning is unclear; whose view on usefulness to informal caregivers is being presented here? Moreover, it is unclear how usefulness was being assessed, and the data do not allow for a paired analyses of informal and professional views on usefulness which the figure suggests. You may consider to leave off the figure.

11. In reporting of qualitative research, terms that relate to quantification (e.g., “a less commonly asserted perspective”) may be avoided if possible.

12. The statement in the conclusion that evaluations of decision aids have not generally considered contextual factors should be backed up with references. Moreover, it may not generalize to dementia decision aids, as Graham ID et al (BMC Medical Informatics and Decision Making 2007, not referred to in the manuscript) and Arcand et al. (2011) have compared dementia decision aids with
aids evaluated in other settings (Graham et al.) or by different health care professionals (Arcand et al.). Alternative to backing up their statement with references, methods and results of the authors' literature search are provided.

Discretionary revisions

13. The authors’ conclusion (hypothesis) about protection of the family is partly consistent with recently published quantitative data of cross-national evaluation of a decision aid in palliative care in dementia by prof. Marcel Arcand. It includes an article in press which directly compares informal and professional caregivers’ views; a summary, literature and tables of which are uploaded as a pdf. In part of the cases, professional caregivers may not serve the needs of the informal caregivers as viewed after death overseeing the full trajectory, as a non-negligible minority of informal caregivers preferred to have information about palliative care early (before admission); whereas nursing home staff did not favour providing it this early. However, these groups equally (half of respondents across all groups) endorsed availability of the decision aid without interference of the professional caregiver, which is not consistent with a hypothesis of holding back information per se.

**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