Reviewer's report

Title: Quality of Life in Dementia: a Study on Proxy Bias

Version: 2 Date: 9 May 2013

Reviewer: Hilde Verbeek

Reviewer's report:

The authors have prepared a well written and highly relevant manuscript on the assessment of quality of life in people with dementia, focusing on the influence of proxy bias. Especially in people with dementia this is an important research area, as both in research and practice we rely on proxy assessment of quality of life ratings, mainly due to the severe cognitive problems patients experience. This manuscript provides some insights on factors influencing this proxy bias. I have the following comments and suggestions for improvement of the manuscript.

Major revisions

Methods.

Why did the authors not include the stage of dementia in the linear mixed models, as it is known that this has an important impact on the ratings of QoL for people with dementia? It could be that for people with dementia who experienced more severe cognitive impairments, it is more difficult for proxies to assess their quality of life compared with people with less cognitive impairments. In my opinion, the authors should take this into account.

Results.

Please add the number of people included in the analyses. Were QoL AD socres and EQ5D scores available for all 175 dyads of people with dementia and their proxy? How many dyads were included in the linear mixed model analyses? Usually, the completion rate of QoL-AD is lower for people with dementia compared with proxy ratings.

Minor revisions

Methods, respondents. Please add the country of data collection and time period

Methods, quality of life measures

QoL-AD The authors use the QoL-AD to assess both patient and proxy quality of life. To assess proxy quality of life, this is an uncommon procedure. It would be helpful for readers if the authors included a reference of a study in which this procedure has been validated or used, as the original reference the authors mention (39), does not address this issue.

EQ 5D. Please specify in the method section whether the EQ5D was used to measure proxy QoL or also the patient perspective. This is currently unclear for readers.
Analyses. It would be interesting to also analyse the data using the patient QoL-AD score as a dependent variable and the proxy QoL AD score as an independent variable. Why did the authors choose only to analyse models using the EQD as a dependent variable?

Could the authors please add the time points for the statistical models data? I.e. please specify at which time points the EQ5D and QoL-AD scores were assessed for use in the model (e.g. only baseline data?) Furthermore, it would be helpful if the authors added how they dealt with missing data.

Results
The authors should state in the results section that the overall explained variance of the model is relatively low (R²=0.095)

Discussion
Why do the authors use a numbering for the variables related to proxy bias and start with age, the least strong characteristics? It appears a bit odd to read that first and least strong predictor was age. On what is this numbering then based on? I would suggest to start with the most important one.

The authors’ explanation for how ‘money’ has an influence is highly speculative in my opinion and not supported by any literature. The authors should compare this with other known literature or delete this from the manuscript, in my opinion, as it appears a too arbitrary judgement. This also accounts for the reasoning why ‘ability to do things for fun’ was related. Please delete or compare it with other known literature. For example, an alternative explanation for the relation could be that proxies who do more things for fun experience less burden and people who experience less burden may rate QoL of their relative in a more positive way than people who feel burdened.

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

**Quality of written English:** Acceptable

**Statistical review:** Yes, and I have assessed the statistics in my report.

**Declaration of competing interests:**
'I declare that I have no competing interests'