Reviewer’s report

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

Version: 2 Date: 9 January 2013

Reviewer: A. Simon Pickard

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This paper aims to examine the agreement between patients and proxy ratings of HRQL in Alzheimer’s in the context of substituted judgment when the proxy assessed HRQL from the patient’s perspective, and also examines projection bias based on the extent to which proxy characteristics, including their self-reported HRQL, correlates with their assessment of the patient. It is a generally thoughtful and well-written paper.

Major

1. Given the condition of the patients, it seems inconceivable that every single dyad was retained over a one year timeframe. Can you report how many patients dropped out over time? How many caregivers/dyads? Compare characteristics of dropouts after T0 to those retained until T12.

Minor compulsory

2. In the paper, some confusion may arise over terminology as the caregiver self-assessment of HRQL is called proxy-proxy in the paper. This can be confusing, particularly because the framework describing perspectives in ref 38 (Pickard and Knight) use proxy only when a surrogate assessment is made, with “proxy-proxy” describing a proxy assessment of the patient from the proxy’s perspective). Thus, as there is no surrogate assessment, it would be clearer to change the assessment described as “proxy-proxy” to “caregiver self-assessment”.

3. Methods: is there further detail available on patient and caregiver assessments, e.g. how long did each assessment take (mean, range etc – list in Table 1); what happened if the patient did not understand the question?

4. Provide guidance for interpreting ICC levels in the methods.

Discretionary

5. The background notes that very limited research has been done to identify proxy-related factors that explain differences between patient and proxy assessments in dementia. A number of factors have been identified in the broader literature. These are described in reference 38, and would help to inform the discussion section regarding sources of systematic differences/bias.

6. It would be interesting to know if level of cognition is a mediator – was this considered in the analyses?

7. There is nuance to the issue of the validity of proxy assessments. This relates to the inherent problem in defining HRQL in dementia, an important issue raised
by the authors in the introduction. If a patient cannot self-report their HRQL or reflect on it, should that rating serve as the gold standard? For instance, if a patient is clearly confined to bed, yet they report that they have no problems with mobility, should that disconnect with reality still serve as the gold standard because the patient says it is? For these types of reasons, proxy ratings may be a valid complement to the patient’s rating without agreeing with it. This raises a related issue – the validity of the assessment can depend on the application of the assessment – how will the proxy assessment be used? If for the purpose of substituted judgment, then the patient may be the gold standard, and the desired perspective should be consistent with the application (proxy-patient perspective). If it is to inform clinical decision, e.g. an assessment to inform whether the patient should receive physical therapy, then the proxy-proxy perspective (e.g. a proxy rating of the patient from the caregiver’s perspective) may be important and valid. The purpose of the HRQL assessment receives little mention in the paper and may further inform the discussion section.

8. I am aware of some evidence to support your findings on projection bias in stroke. Pain and depression in caregivers systematically biased assessments, which could be considered a form of “projection bias” (Hung SY et al, 2006, J Clin Epid).

These findings are important to those with closely related interests. If the above comments are addressed, the paper is accepted for publication in my view.

It is not necessary for a statistician to review the analysis.

I have no competing interests related to the content of this manuscript.