Reviewer's report

**Title:** A taboo within a stigma? A qualitative study of managing incontinence in people with dementia living at home

**Version:** 1  **Date:** 25 August 2011

**Reviewer:** Barbara Workman

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Review of A Taboo within a stigma? A Qualitative study of managing incontinence in people with dementia living at home

This is an interesting paper and documents findings of the carers perspective on managing incontinence in people with dementia. You have addressed the hypothesis with an appropriate study design, and although numbers of study participants are small, there does appear to be evidence of themes emerging from the interviews. My comments below have been divided as requested into discretionary, minor and major revisions. Within each heading I have attempted to follow through the sequence of the paper, however this is not invariable as some comments impact on a number of sections of the paper.

In the results section there is good clear listing of the themes identified, followed by sections discussing the perspectives and problem solving by the carers. Carer developed strategies and issues of acceptability second paragraph give a good clear description of the need for carers to adjust their problem solving with progression of the disease. Further comments on this section are below under major compulsory revisions.

The section Seeking help from health professionals is helpful and gives a balanced report on the good and the not so good and Consequences for Carers……..also gives an indication on the strength of the theme by the use of ‘all the carers reported’ or ‘most also reported’

The last 2 case reports in this section are very powerful and give the reader a very good insight into the burden of caring for a loved one under these circumstances.

Discussion paragraph 3 gives a good summary particularly the sentence on problems changing over time and I would suggest this sentence be included in the abstract.

**Discretionary Revisions**

Background paragraph 2 first sentence please specify what abilities refer to – is this cognitive, personal care etc. Second sentence please review as the point being made is not clear.

Background paragraph 3, you report reference 21 as specifying that clinicians, carers and residents have different views on what is acceptable in continence
care, however you do not report what these differences are. It would be helpful to the reader if you could expand on reporting this previous work. The subsequent sentence I think you are trying to say that there is little evidence from previous work that the carer’s perspectives have been available to inform and guide professional input. I suggest editorial revision of this sentence.

Minor Essential Revisions

Background paragraph 1, you specify the person with dementia is PWD however this abbreviation is not used subsequently throughout the paper. I suggest using the abbreviation or removing it.

In background paragraph 2 you are talking about studies which give an indication of prevalence of incontinence in dementia. You mention the UK study of 15,000 people reference 14. In the following sentence you report 2/3 people with dementia live in their own homes. There is no mention of incontinence, and I wonder if there should be more to this sentence. The subsequent sentence on evidence from Australia refers to reference 17 which is Alzheimer’s Association (USA). The subsequent reference 18 is the Australian Institute of Health and Welfare. Please check and correct the attribution to references.

Major Compulsory Revisions

Methods, first paragraph you report a purposive sample to ensure diversity in gender, relationship, ethnicity and socioeconomic group. In the table 1 are 12 British, 9 other and 11 not specified with respect to ethnicity. In the results there is no mention of any analysis of ethnicity in the themes and whether ethnicity impacts on carers coping styles or problem solving. I don’t know if the 9 other were all of different ethnicity or all of the same nationality, and how this relates to gender as there may be some nationalities or cultures where care by a same gender carer is very important. Similarly there is no analysis of whether socioeconomic group has any influence on perspective. I recommend that an analysis is included or these characteristics of the sample are removed as non contributory.

Results, Carer developed strategies and issues of acceptability third paragraph discusses that some people with dementia found prompts to be unacceptable for various reasons. This needs to be put into perspective for the reader. Are there some people who do find this acceptable? Does it depend on the stage of the disease? What proportion found it unacceptable? Reading this as it stands suggests that this is a strategy that would be best avoided. There needs to be further analysis of this section. Similarly for paragraph 4 on assistance with intimate assistance. Is this common? Do most people find this a difficulty or is it only rare? Does this relate to gender issues or ethnicity issues? Providing a balance of the extent of this issue in the group who participated would give greater strength to this as an issue. Also what do carers do to overcome this? Similar comments for the next paragraph on male relatives assisting female dementia sufferers – is this rare or common? All these comments also relate to the results section in the abstract in which there is insufficient balance given to
identifying the problems and the extent to which the problems apply to the whole population studied.

**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 no competing interests