Reviewer’s report

Title: Measuring Dementia Carers’ Unmet Need for Services - an exploratory mixed method study

Version: 1 Date: 21 February 2010

Reviewer: Jill Manthorpe

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Measuring dementia carers unmet need for services

Thank you for the opportunity to read this interesting and timely article. It is well written and structured.

I hope the comments below will of assistance in revising this article. These are minor essential revisions.

1. In the abstract, the second sentence needs some minor amendment, I think the words ‘be a’ need to be inserted, and perhaps the word ‘growing’ should be inserted before the words ‘stress in carers’. In the final sentence I think that the word ‘service’ might be deleted. In both the abstract and in the first sentence of the background I wonder if the word ‘appropriate’ is needed. Is this meaning effective or beneficial? There are some apostrophes that need to be moved in the first paragraph of the background section.

2. It may be a matter of style but I would recommend that the use of Persons with Dementia is revised to people with dementia and that the abbreviation is not needed. Likewise, the use of the term institutionalisation is very pejorative. Without saying so this frames care homes as ‘institutions’ and all the connotations that this term brings. I think that delaying entry to care homes might be more neutral.

3. Page 4 of the article uses Brodaty’s typology and this works well. I think that replacing the word ‘issues’ by problems might be better.

4. In the penultimate paragraph of the background section, there is reference to health services; this might be broadened to say ‘health and social care services’. Here Bradshaw’s typology of need is introduced. In my view since this is not just about social and health care users or carers (words not really in use at the time of its development), I would recommend that when outlining what is the essence of comparative need that the comparison is between one group and another. Bradshaw was often referring to poverty in his work, so he used it often as the poor compared to the better off.

5. The methods section is well explained and the sizeable nature of the study emerges, with the number of repeat visits and contacts. The heading ‘Qualitative data on socio-cultural context’ does not make sense – should the word ‘on’ be
‘in’? – Perhaps this can be revised. It does not seem to relate to the content. I am not sure that we need to know that the psychologist was trained (page 8) but this is a minor matter! In the sentence prior to the section on analysis, there is a description on the progressive engagement of the researcher with the carers, however, there is nothing about their disengagement and withdrawal from quite an intensive relationship. How was this handled? What could others learn from this for future research? Did any matters arise where researchers felt that they were acting as confidantes?

6. The section headed Results, uses the term Subject which I think might better be termed participant. I note that Table 1 is headed participants but that the column uses the term subject, this might be amended. I was not sure by what was meant by dementia ‘cause’ (page 11). Overall the results are reported clearly and the mix of methods works well.

7. In the discussion section, the use of the term ‘genuinely’ suggests that some moral judgement is being made. This might need to be clarified. On page 18, the paragraph headed ‘The sample group...’ refers to costs of public health care but not social care – or the public purse. In the following sentence the phrase ‘cost to carers’ is used, suggesting that this is a financial cost which does not seem to accord with the data about these mainly spouse carers. Is this use of carers’ costs meant to cover more than financial matters?

8. In the following paragraph, the phrase ‘service decision making participation’ is a little hard to understand and could be clarified.

9. The limitations of the study are fairly assessed and acknowledged at the end of the discussion section.

10. My other comments relates to the information given in table 1, where I think that the 5 ‘relatives’ could be described in greater detail eg if they were adult children, and that the ‘Other’ (one in number) could be explained; was this a neighbour or a friend?

11. Overall, this is a sound article which may be useful to other researchers in describing the methods of a small but intensive study. It is useful in drawing attention to the problematic concept of need, and to the ways in which formal assessments may be useful if they are more inclined to listen to what carers are saying.

12. There are some minor matters needing attention in the references; the full details of reference number 35 are required and there are inconsistencies in the references to the journal ‘Dementia’. Web links to references numbers 21 and 22 would be helpful.

I hope these comments are helpful to the authors and thank them for enabling me to learn of their interesting and timely work.

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

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