Reviewer’s report

Title: Caregivers’ perspectives and experiences of withdrawing acetylcholinesterase inhibitors and memantine in advanced dementia: a qualitative analysis of an online discussion forum

Version: 0 Date: 09 Nov 2018

Reviewer: Ian Maidment

Reviewer’s report:

This is an interesting paper using an innovative methodology (indeed the authors could easily write a methods paper). My main concerns are:

1. More detail on the search strategy is required.

2. The analysis doesn't do justice to the very rich dataset.

Abstract

Could themes 3 to 6 be grouped as a single theme, because essentially they are about symptoms after cognitive enhancer has been stopped (see later comments).

Background

Minor point - Rivastigmine is also licensed for PDD.

To be consistent the background should probably also mention the license for memantine.

Page 4 - is a very long paragraph and should be separated into shorter paragraphs.

Method

The clarity of the methods would be improved with greater use of sub-headings.

How was the search strategy on page 6 developed (this is critical because the data generated is very dependent on the terms)? Equally importantly why were certain terms e.g. Aricept® not included? How were mis-spellings, which are likely to be common on discussion boards, accounted for (NB: found later this is acknowledged as a limitation)?
Should probably mention that framework analysis is often used if the researcher has existing knowledge (as in this case)?

Could the project be reported against some type of EQUATOR guidance? If no relevant guidance exists, this should be acknowledged.

Again very long paragraph on page 6 - generally recommended that maximum of about 150 words per paragraph.

Why was Alzheimer's Society approval needed if the web-site was in the public domain?

Were any quality control measures introduced for the qualy analysis e.g. checking by second researcher?

Results

See earlier comments with regards to themes 3 to 6.

Overall, I feel that the analysis could have been more intuitive and doesn't really do justice to the rich dataset.

Theme 1 doesn't currently "fit" with the overall analysis; it is about the influence of others on the caregiver. Because of this some of the concepts within this theme repeat other concepts (e.g. efficacy). Put another way either the analysis should focus on the influence of others (e.g. medics, friends, internet etc) on the carer views, or focus on what the carer actually observes (the other themes).

The second quote on page 8 is rich in emotion, which the accompanying text doesn't bring out (other researchers have also found med man in dementia to be emotive e.g. https://www.ncbi.nlm.nih.gov/pubmed/28105781)

Same section - generally in qualy research three quotes aren't linked together as here without accompanying explanation for each quote.

Isn't the next quote Evelyn more about side-effects and risk/benefit.

How was the quote on page 10 identified if Ebixa wasn't a search term?

An alternative approach to the analysis would be to use the themes on page 10. Impact on: BPSD, physical condition and functional status, side effects, overall impression.

Isn't the quote from Robin on page 11 also about the opinion of others (e.g. why was it put in this category, but not the first one. Whereas other dual themed quotes have been put in the first category. How did the authors decide whereabouts to place dual themed quotes?).
Page 11. The underpinning data to justify the statement "the majority" needs presentation.

Again the next quote Christine is about the opinion of others in addition to deterioration.

Doesn't the quote from Hannah illustrate the complexity of determining whether the meds are helping (a fundamental problem)?

Discussion

I'm not convinced that a large RCT for discontinuation of cognitive enhancers is required. Such a trial would be complex, expensive and almost impossible to run (e.g. matching placebos etc). There is increasingly acknowledgement that the meds have limited benefit: http://english.prescrire.org/en/81/168/55126/0/NewsDetails.aspx

If the Doody study is referenced the authors should state that the study was open label and sponsored by the manufacturer: https://jamanetwork.com/journals/jamaneurology/fullarticle/778748

The section on burden could be expanded: there are some more recent references which discuss this e.g. https://www.ncbi.nlm.nih.gov/pubmed/28105781; https://www.ncbi.nlm.nih.gov/pubmed/29047339 (secondary data analysis).

Indeed the whole discussion could have greater focus on the emotive nature of this area (which probably partly explains the wide variation found).

Limitations: could the authors comment on the demographics of members of the AS in general.

Are the methods appropriate and well described?
If not, please specify what is required in your comments to the authors.

No

Does the work include the necessary controls?
If not, please specify which controls are required in your comments to the authors.

Yes

Are the conclusions drawn adequately supported by the data shown?
If not, please explain in your comments to the authors.

Yes

Are you able to assess any statistics in the manuscript or would you recommend an additional statistical review?
If an additional statistical review is recommended, please specify what aspects require further assessment in your comments to the editors.

Not relevant to this manuscript

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