

PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	Measuring quality of life of people with pre-dementia and dementia and their caregivers: a systematic review protocol
AUTHORS	Landeiro, Filipa; Walsh, Katie; Ghinai, Isaac; Mughal, Seher; Nye, Elsbeth; Wace, Helena; Roberts, Nia; Lecomte, Pascal; Wittenberg, Raphael; Wolstenholme, Jane; Handels, Ron; Roncancio-Diaz, Emilse; Potashman, Michele; Tockhorn-Heidenreich, Antje; Gray, Alastair

VERSION 1 – REVIEW

REVIEWER	Anne Marie Mork Rokstad Norwegian National Advisory Unit on Ageing and Health, Tønsberg, Norway Molde University College, Molde, Norway
REVIEW RETURNED	13-Sep-2017

GENERAL COMMENTS	I have a comment on the use of words in the introduction. I find the use of the term "devastating global disease" (page 4, line 37) very negatively loaded and I have the same comment on the use of "causes abnormalities in behaviour" (page 4, line 50) I have only two questions for the authors to consider: Will the review present a comparison of QoL in different care settings ex: home-dwelling people, day care attendees or people receiving residential care? Will there be made meta- analyses of the findings if possible?
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REVIEWER	Heehyul Moon University of Louisville, USA
REVIEW RETURNED	11-Oct-2017

GENERAL COMMENTS	The reviewer provide a marked copy with additional comments. Please contact the publisher for full details
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VERSION 1 – AUTHOR RESPONSE

Reviewer: 1

Reviewer Name: Anne Marie Mork Rokstad

Institution and Country: Norwegian National Advisory Unit on Ageing and Health, Tønsberg, Norway, Molde University College, Molde, Norway Please state any competing interests: None declared

Please leave your comments for the authors below

I have a comment on the use of words in the introduction. I find the use of the term "devastating global disease" (page 4, line 37) very negatively loaded and I have the same comment on the use of "causes abnormalities in behaviour" (page 4, line 50).

Thank you for your comment. We agree with you and have now removed the word "devastating" from the text. The term "causes abnormalities in behaviour" has now been changed to "causes behavioural changes".

I have only two questions for the authors to consider: Will the review present a comparison of QoL in different care settings ex: home-dwelling people, day care attendees or people receiving residential care?

Yes, the review will establish a comparison between the QoL of people living in the community, people living in care homes, people attending day care centres and people living in mixed settings (i.e. studies where the sample included both people living in the community and people living in care homes).

The following text has been added to the methods section on page 12:

"A narrative synthesis of all relevant studies will be provided discussing differences in QoL measurements, by instrument used to estimate it, type of dementia, disease severity, setting, (...)"

Will there be made meta- analyses of the findings if possible?

Yes, if possible a meta-analyses will be conducted.

The following text has been added to the methods section on page 12:

"If feasible, a meta-analysis of the findings will be conducted."

Reviewer: 2

Reviewer Name: Heehyul Moon

Institution and Country: University of Louisville, USA Please state any competing interests: None declared'

Please leave your comments for the authors below

The protocol focused on quality of life measurements on patients with dementia and their caregivers. The methods are clearly presented. Researchers, clinicians and policy makers can get benefits from this proposed study. The authors need to determine how to deal with measured validity and reliability.

This review is on quality of life of both patients and caregivers measured using health-related quality of life (HRQoL) measures only. You made a very valid point about us not defining quality of life in the paper, which we will address below. We expect the studies in this review to be using validated tools. Nevertheless, we are using the Effective Public Health Practice Project Quality Assessment tool to assess whether the study has used valid and reliable tools and this will be reported in the final manuscript.

Also some QoL measures which were specifically developed for QoL of patients with dementia have been used to assess caregivers QoL. The authors need to state how they will synthesize it in the protocol.

As per the comment above, we will only be looking at HRQoL, which was not made clear in the protocol. In instances where HRQoL measures specifically developed for patients with dementia have been used to assess caregivers' HRQoL, the results will be reported separately from the other measures. In general, the HRQoL results will be presented separately according to the instruments that were used to measure the HRQoL.

Reply to the comments on the attached manuscript:

Comment 1 on page 4

Why the 28th April?

The 28th April 2017 was the date when we ran the searches on the databases.

Comment 2 on page 4

Is it in general?

Yes, this is of all cases in general.

Comment 3 on page 5

Please provide reference. Please identify the definition of QoL. QoL is different from well-being and is beyond health.

Thank you for this comment. In fact, as stated above, we did not previously make it clear in the text that we are only looking at HRQoL. We have now amended the text accordingly.

We have made the following changes to the text on page 5:

“The cognitive and functional decline associated with dementia may have a profound impact on the health-related quality of life (HRQoL) of both patients and those who care for them. HRQoL, defined as the way health is empirically estimated to affect QoL, is a multi-dimensional concept that includes domains related to physical, mental, emotional, and social functioning. HRQoL is now recognised as an increasingly valued health outcome measure in dementia.”

Furthermore, we have changed all previous references to QoL to HRQoL.

Comment 4 on page 5

Please provide citation for international policy priority.

A citation has now been added to the text.

Comment 5 on page 5

“as caring for people with dementia often places a heavy mental, physical, financial, and social burden on them.” Please provide references.

References have now been added to the text.

Comment 6 on page 5

“Great demands are placed on caregivers who are often elderly themselves.” Please provide references.

References have now been added to the text.

Comment 7 on page 6

“As a result caregivers might find themselves neglecting their own health and QoL. This could

ultimately impact on the quality of the care that they provide for people with dementia.” Is that due to their multiple roles or lack of services to patients?

What we mean by the sentence above is that, as described in the literature, the role of caregiving for people with dementia has been linked to mood disorders, cognitive decline, disrupted sleep, and increased social isolation and loneliness for the caregivers^{1 2}. If the health and HRQoL of the caregivers is being affected in these ways, they may not be able to provide the same level of care as if they were in perfect health.

Comment 8 on page 6

“However, apart from Shearer et al.⁶, none of these reviews report measurements for QoL of these patients or caregivers.” I was wondering if the authors searched for literature reviews on this topic.

We searched for literature reviews on HRQoL of people with dementia and their caregivers but in a non-systematic way. The main findings of this search are reported on page 6.

Comment 9 on page 7

“The focus of this review is on adult populations reporting to have either pre-dementia”. The authors explained in page 8 but need to provide a definition or examples.

Thank you for this comment. We have changed the text to the following on page 7:

“What is the HRQoL for people with dementia across all stages of disease severity, from its preceding state of pre-dementia (including pre-clinical AD – biomarker positive but pre-symptomatic -, early symptoms, MCI, or prodromal AD), through to diagnosed dementia and end of life?”

We have also changed the title to indicate that we are looking at pre-dementia as well as dementia.

Comment 10 on page 7

“and their main caregivers.” Please identify main caregiver.

We have removed the word “main” from the text.

Comment 11 on page 8

“A wide range of instruments have been developed to measure QoL.” Need to identify what QoL is.

We have now addressed this comment (see comment 3 above).

Comment 12 on page 8

“Whereas generic QoL measures are universal and cover general health aspects”. Again, QoL is more than general health outcomes.

We have now addressed this comment (see comment 3 above).

Comment 13 on page 9 and 10

“Central Register of Controlled Trials (CENTRAL), Database of Abstracts of Reviews of Effects (DARE), NHS Economic Evaluation Database (NHS EED)” Provide descriptions in these databases.

Please see below the descriptions of the databases:

The Cochrane Central Register of Controlled Trials (CENTRAL) is a highly concentrated source of reports of randomised and quasi-randomised controlled trials. The majority of CENTRAL records are taken from bibliographic databases (mainly MEDLINE and Embase), but records are also derived from other published and unpublished sources. More information about this database can be found at: <http://www.cochranelibrary.com/about/central-landing-page.html>

The Database of Abstracts of Reviews of Effects (DARE) contains details of systematic reviews that evaluate the effects of healthcare interventions and the delivery and organisation of health services. DARE also contains reviews of the wider determinants of health such as housing, transport, and social care where these impact directly on health, or have the potential to impact on health. More information about this database can be found at: <http://community.cochrane.org/editorial-and-publishing-policy-resource/overview-cochrane-library-and-related-content/databases-included-cochrane-library/database-abstracts-reviews-effects-dare>

The NHS Economic Evaluation Database (EED) contains economic evaluations of healthcare interventions. Economic evaluations are studies in which a comparison of two or more interventions or care alternatives is undertaken and in which both the costs and outcomes of the alternatives are examined. This includes cost-benefit analyses, cost-utility analyses, and cost-effectiveness analyses. More information can be found at: <http://community.cochrane.org/editorial-and-publishing-policy-resource/overview-cochrane-library-and-related-content/databases-included-cochrane-library/nhs-economic-evaluation-database>

These three databases are part of the Cochrane Group and have well-established web sites with full descriptions. Consequently we do not propose adding descriptions of each database in the manuscript, unless the editor suggests otherwise.

Comment 14 on page 13

“The main focus of our research is on Alzheimer’s disease, the most common form of dementia, but given the lack of diagnostic accuracy and the recognised overlap between different causes of dementia, all forms of dementia will be considered.” Need to make it clear at the beginning.

Thank you for this comment. We have added the following text to page 8:

“Our main interest is in AD, the most common cause of dementia, but given the lack of diagnostic accuracy and the recognised overlap between different causes of dementia, all causes will be considered.”

References

1. Joling KJ, van Hout HP, Schellevis FG, et al. Incidence of depression and anxiety in the spouses of patients with dementia: a naturalistic cohort study of recorded morbidity with a 6-year follow-up. *The American journal of geriatric psychiatry : official journal of the American Association for Geriatric Psychiatry* 2010;18(2):146-53.
2. Vitaliano PP, Murphy M, Young HM, et al. Does caring for a spouse with dementia promote cognitive decline? A hypothesis and proposed mechanisms. *J Am Geriatr Soc* 2011;59(5):900-8.

VERSION 2 – REVIEW

REVIEWER	Anne Marie Mork Rokstad Norwegian National Advisory Unit on Ageing and Health, Tønsberg, Norway and Molde University College, Molde, Norway
REVIEW RETURNED	05-Jan-2018

GENERAL COMMENTS	The author's have made adequate responses to my previous comments and the manuscript should be accepted for publication.
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REVIEWER	Heehyul Moon University of Louisville, USA
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REVIEW RETURNED	13-Feb-2018
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GENERAL COMMENTS	The revision looks good.
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