

PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	Psychometric properties and use of the DEMQOL suite of instruments in research: a systematic review protocol
AUTHORS	Hoben, Matthias; Chamberlain, Stephanie; O'Rourke, Hannah; Elliott, Brittany; Shrestha, Shovana; Devkota, Rashmi; Thorne, Trina; Lam, Jenny; Banerjee, Sube; Hughes, Laura; Estabrooks, Carole

VERSION 1 – REVIEW

REVIEWER	Darshini Ayton Monash University
REVIEW RETURNED	10-Jul-2020

GENERAL COMMENTS	<p>This is a really important review - both for research and practice. In the introduction - line 54 (page 4) - the terms feasible, acceptable, applicable and appropriate are used; line 33 (page 5) the terms reliably, validly and feasibly are used; it would be good to have a bit more explanation of these terms, particularly as they map to the research questions.</p> <p>Separate out acceptability and feasibility as while there is some overlap - there are different approaches to measuring/assessing these concepts.</p> <p>For research question 2 - I would separate out the development and psychometric properties, and acceptability and feasibility as separate questions.</p> <p>Methods Line 22 - we will include non-peer reviewed reports (gray literature)- but it is not clear how these will be sourced? If you are searching the gray literature systematically include this search strategy. If you are only sourcing gray literature that comes up in reference lists of the academic articles - make this clear.</p> <p>Quality appraisal section is great</p> <p>Data extraction - not clear how your second research question in relation to acceptability and feasibility will be captured in your data extraction. The analyses section is more robust but the categories/variables should be described in data extraction.</p>
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REVIEWER	Dr Andrew Harding Lancaster University, UK
REVIEW RETURNED	03-Aug-2020

GENERAL COMMENTS	Thank you for inviting me to review this interesting review protocol, which seeks to chart the use of the DEMQOL suite of instruments and find evidence for its acceptability and feasibility. Generally I found this this protocol to be well written, interesting and,
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	<p>importantly, scientifically well designed.</p> <p>However, there are a few points that the authors may wish to consider to strengthen this manuscript:</p> <p>1) I would value a more fully rounded discussion in the opening paragraphs about the concept of 'health quality of life' and 'quality of life' more broadly. For example, what do the authors see as the key differences between the two? What other concepts are important? Where do emergent concepts such as 'social health' come in? Historically who has decided what domains are important and worthy of measurement?</p> <p>2) Given the authors are interested in the acceptability of DEMQOL, how are the authors planning to utilise new core outcome set research in this area (see reference below)? Core outcome sets attain consensus from key stakeholders on the most important outcomes to be measured in all effectiveness trials (as a minimum) and also recommends how core outcomes should be measured. Specifically in dementia a new systematic review of measurement instruments compares core outcome set items against the items and content of many outcome measurement instruments, including DEMQOL, to see if tools adequately capture 13 core outcome items. It is an interesting questions as to whether this core outcome set work can and should function as a form of acceptability criteria - given that this work assesses DEMQOL items against a set of core outcomes deemed to be very important by key stakeholders (including people living with dementia). At the very least the authors should consider the findings of this review and discuss it the introduction.</p> <p>Andrew J E Harding, Hazel Morbey, Faraz Ahmed, Carol Opdebeeck, Ruth Elvish, Iracema Leroi, Paula R Williamson, John Keady, Siobhan Reilly. Core outcome set for nonpharmacological community-based interventions for people living with dementia at home: A Systematic Review of Outcome Measurement Instruments, <i>The Gerontologist</i>, , gnaa071, https://doi.org/10.1093/geront/gnaa071</p> <p>I wish the authors the best of luck in completing and publishing this important and interesting work.</p>
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REVIEWER	Elizaveta Sopina SDU, Denmark
REVIEW RETURNED	14-Aug-2020

GENERAL COMMENTS	<p>Broad/general comments:</p> <p>Thank you for the opportunity to review this paper. This protocol for a systematic review is well written, and thorough in describing the methods for finding, screening and extracting data from studies. The suggested approach is sound and should sufficiently address the research questions set. The topic is important: with a growing incidence/prevalence of dementia, evaluating outcome measures for dementia is fundamental to key decision making processes in the area.</p> <p>The largest flaw of this study is that it sets out to review only one tool/outcome measure. There are a number of dementia-specific HRQoL/QoL tools, and establishing the</p>
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	<p>feasibility/acceptability/psychometric properties of one tool does not allow to draw direct comparisons between the tools or to select the best performing/most acceptable tool. While doing a review of all available outcome measures might be much more intensive and laborious, it would provide a much more comprehensive overview of the situation. This is not a request for amendment in the protocol, but something the authors should be mindful of in going ahead with the review.</p> <p>The selection of DEMQOL as the focus of the review does not come across as entirely justified. Why not another measure? Please provide a more qualified justification, perhaps by highlighting it's benefits against the other dementia-specific HRQoL/QoL tools.</p> <p>Minor comments/suggestions:</p> <ul style="list-style-type: none">- On page 7, line 12, you mention that the DEMQOL suite has strong psychometric properties (and this is referred to further on in the introduction section). Please provide evidence of this in Table 1 – for example, add one or two rows for psychometric property information on reliability and validity that is currently known – this would provide some further justification for selecting DEMQOL- P 11, line 26- it is stated that foreign language studies will not be excluded. Please state how foreign language studies will be approached – will translations be made? By whom? Will the entire paper be translated?- The authors should consider including the COSMIN checklist for PROMs in their quality appraisal toolkit https://www.cosmin.nl/tools/guideline-conducting-systematic-review-outcome-measures/?portfolioCats=19
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VERSION 1 – AUTHOR RESPONSE

Reviewer 1

Comment	Response
<p>In the introduction - line 54 (page 4) - the terms feasible, acceptable, applicable and appropriate are used; line 33 (page 5) the terms reliably, validly and feasibly are used; it would be good to have a bit more explanation of these terms, particularly as they map to the research questions.</p> <p>Separate out acceptability and feasibility as while there is some overlap - there are different approaches to measuring/assessing these concepts.</p> <p>For research question 2 - I would separate out the development and psychometric properties, and acceptability and feasibility as separate questions.</p>	<p>Thank you very much for these thoughtful considerations. We added definitions of reliability, validity, feasibility, acceptability and appropriateness to the introduction (p. 6) and detailed operationalizations to the methods section (inclusion/exclusion criteria, table 3).</p> <p>We revised the manuscript throughout, so we now consistently use the terms feasibility, acceptability and appropriateness.</p> <p>We separated out a) development, b) psychometrics and c) feasibility, acceptability and appropriateness in question 2 as 3 separate sub-questions. (p. 11)</p>
<p>Line 22 - we will include non-peer reviewed reports (gray literature)- but it is not clear how these will be sourced? If you are searching the gray literature systematically include this search strategy. If you are only sourcing gray literature that comes up in reference lists of the academic articles - make this clear.</p>	<p>Thank you for pointing out this lack of clarity. We revised the text so we hope it is clearer now that we will include gray literature that comes up as part of the search strategy we specified. (p. 13)</p>
<p>Data extraction - not clear how your second research question in relation to acceptability and feasibility will be captured in your data extraction. The analyses section is more robust but the categories/variables should be described in data extraction</p>	<p>We agree with the reviewer that more clarity was needed related to how we define and operationalize each of the outcomes – and thank you again for pointing this out. We think that this request is addressed by (a) more clearly defining each of the terms used (as per our responses above), (b) adding an additional category (study outcomes) to our inclusion/exclusion table (inclusion/exclusion criteria, table 3) and (c) restructuring and rewording our list of categories to be extracted. We now refer explicitly to table 3 for an exact operationalization of the study outcomes to be extracted. (p. 14-16)</p>

Reviewer 2

Comment	Response
<p>I would value a more fully rounded discussion in the opening paragraphs about the concept of 'health quality of life' and 'quality of life' more broadly. For example, what do the authors see as the key differences between the two? What other concepts are important? Where do emergent concepts such as 'social health' come in? Historically who has decided what domains are important and worthy of measurement?</p>	<p>Thank you for pointing out these important conceptual issues. We added more details on how QoL is commonly defined, conceptual problems and our chosen definition, as well as, a discussion of how HRQoL relates to and differs from QoL. We also discuss subjective perceptions versus objective indicators and we pointed out that a person's subjective perception is key since objective indicators may influence this subjective perception but they are not the same. People with severe impairment and symptoms can have good self-perceived QoL and people with good functionality and little symptoms can have poor self-perceived QoL. (p. 4/5)</p>
<p>Given the authors are interested in the acceptability of DEMQOL, how are the authors planning to utilise new core outcome set research in this area (see reference below)? Core outcome sets attain consensus from key stakeholders on the most important outcomes to be measured in all effectiveness trials (as a minimum) and also recommends how core outcomes should be measured. Specifically in dementia a new systematic review of measurement instruments compares core outcome set items against the items and content of many outcome measurement instruments, including DEMQOL, to see if tools adequately capture 13 core outcome items. It is an interesting questions as to whether this core outcome set work can and should function as a form of acceptability criteria - given that this work assesses DEMQOL items against a set of core outcomes deemed to be very important by key stakeholders (including people living with dementia). At the very least the authors should consider the findings of this review and discuss it the introduction.</p> <p>Andrew J E Harding, Hazel Morbey, Faraz Ahmed, Carol Opdebeeck, Ruth Elvish, Iracema Leroy, Paula R Williamson, John Keady, Siobhan Reilly. Core outcome set for nonpharmacological community-based interventions for people living with dementia at home: A Systematic Review of Outcome Measurement Instruments, <i>The Gerontologist</i>, , gnaa071, https://doi.org/10.1093/geront/gnaa071</p>	<p>Thank you for this interesting and very important perspective. Addressing one of reviewer 1's comments, we now defined and operationalized our outcomes of reliability, validity, feasibility, acceptability and appropriateness more precisely. Looking at these definitions, we think that the issues raised here (stakeholders' [experts'] ratings of the relevance/importance of each DEMQOL item and whether/to what extent the DEMQOL includes items that are considered core) fits well within the category that we call content validity. In the reference suggested by the reviewer (thank you for bringing this to our attention), this is called 'face validity' – a term that corresponds to what we call content validity. Therefore, we think these issues are different from the concept of acceptability as we are defining it (i.e. users' rating of whether using the DEMQOL is easy and doable). That said, the suggested review and any other study discussing how good a fit the set of DEMQOL items is with what is considered core by experts (researchers, care staff, decision makers, people with dementia and their families) will be included in our study since this focus fits our eligibility criterion of studies assessing content validity of the DEMQOL.</p> <p>Reviews/studies like the one suggested will be part of the actual review. While our research focus includes whether experts think that DEMQOL items adequately reflect what is considered core in clinical effectiveness trials, our research focus is also broader. Expert ratings suggesting that DEMQOL items do not adequately reflect what is considered core for clinical effectiveness trials is important to note. However, there may be areas of use of the DEMQOL (other than clinical effectiveness trials) that DEMQOL items are considered important for by experts (e.g. assessment of HRQoL in nursing home residents – a setting</p>

	<p>very different from clinical settings with unique stakeholders and context conditions). For these reasons, we think that not discussing this specific issue in our review protocol introduction is advisable (since otherwise we would have to discuss various other aspects and perspectives too). However, the issue of core outcome sets for clinical effectiveness trials and how the DEMQOL does or does not fit into these core outcome sets will be an important part of our actual review – in the main analyses, as well as, in the discussion section.</p>
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Reviewer 3

Comment	Response
<p>The largest flaw of this study is that it sets out to review only one tool/outcome measure. There are a number of dementia-specific HRQoL/QoL tools, and establishing the feasibility/acceptability/psychometric properties of one tool does not allow to draw direct comparisons between the tools or to select the best performing/most acceptable tool. While doing a review of all available outcome measures might be much more intensive and laborious, it would provide a much more comprehensive overview of the situation. This is not a request for amendment in the protocol, but something the authors should be mindful of in going ahead with the review.</p>	<p>We agree with the reviewer that some more clarification on the benefit of just focusing on one, rather than multiple QoL assessments is needed. Thank you for pointing that out. We added more information to the introduction, illustrating that there are already various reviews comparing multiple QoL or HRQoL assessment instruments for people with dementia. However, focusing on various tools does not allow to assess how each of these tools has been used and evaluated in detail – and especially a comprehensive focus on feasibility, acceptability, and appropriateness in addition to psychometric characteristics will not be possible focusing on multiple tools at the same time. (p. 5-8)</p>
<p>The selection of DEMQOL as the focus of the review does not come across as entirely justified. Why not another measure? Please provide a more qualified justification, perhaps by highlighting it's benefits against the other dementia-specific HRQoL/QoL tools.</p>	<p>Generally, we think that starting with either one of the many QoL or HRQoL tools available would be highly valuable. We believe that reviews like the one we propose are highly needed for each available tool – and researchers need to start somewhere. However, there are a couple of strong arguments we can make for selecting the DEMQOL as a starting point and we elaborated and added to the ones we had already listed in our introduction. (p. 7/8) In addition, we added a statement on the involvement of the public in this systematic review, and we highlight that a team of decision makers, representatives of care organizations, people with dementia and their family/friend caregivers highlighted that focusing on the DEMQOL in this systematic review was a key priority. (p. 12)</p>
<p>On page 7, line 12, you mention that the DEMQOL suite has strong psychometric properties (and this is referred to further on in the introduction section). Please provide evidence of this in Table 1 – for example, add one or two rows for psychometric property information on reliability and validity that is currently known – this would provide some further justification for selecting DEMQOL</p>	<p>We agree with the reviewer and added some details to table 2 (former table 1) (p. 8/9)</p>
<p>P 11, line 26- it is stated that foreign language studies will not be excluded. Please state how foreign language studies will be approached – will translations be made? By whom? Will the entire paper be translated?</p>	<p>We added some more details on our approach to include studies of all languages to the methods section (inclusion/exclusion criteria). (p. 13/14)</p>
<p>The authors should consider including the COSMIN checklist for PROMs in their quality appraisal toolkit https://www.cosmin.nl/tools/guideline-conducting-systematic-review-outcomemeasures/?portfolio-Cats=19</p>	<p>Thank you for this great suggestion. We added to COSMIN checklist to assess risk of bias of psychometric studies. (p. 16/17)</p>

VERSION 2 – REVIEW

REVIEWER	Dr Andrew Harding Lancaster University, UK
REVIEW RETURNED	10-Nov-2020
GENERAL COMMENTS	All comments have been addressed or critically engaged with by the authors. I have no further comments to make.