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Psychometric properties and use of the DEMQOL suite of instruments in research: a systematic review protocol

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ABSTRACT

Introduction

Dementia is a global public health issue and a major risk factor for poor quality of life among older adults. In the absence of a cure, enhancing Health-related Quality of life (HRQoL) of people with dementia is the primary goal of care. Robust measurement of HRQoL is a prerequisite to effective improvement. The DEMQOL suite of instruments is considered among the best available to measure HRQoL in people with dementia; however, no review has systematically and comprehensively examined the use of the DEMQOL instruments in research and summarized evidence to determine its acceptability for use in research and practice.

Methods and analysis

We will systematically search twelve electronic databases and search reference lists of all included studies. We will include systematically conducted reviews, as well as, quantitative and qualitative research studies that report on the development, validation or use in research studies of any of the DEMQOL instruments. Two reviewers will independently screen all studies for eligibility, and assess the quality of each included study using one of four validated checklists appropriate for different study designs. Discrepancies at all stages of the review will be resolved by consensus. We will use descriptive statistics (frequencies, proportions, ranges), content analysis of narrative data, and vote counting (for the measures of association) to summarize the data elements. Using narrative synthesis, we will summarize what is known about the development, validation, acceptability/feasibility and use of the DEMQOL. Our review methods will follow the reporting and conduct guidelines of the Cochrane Handbook for Systematic Reviews of Interventions and the Preferred Reporting Items for Systematic Reviews and Meta-Analysis.

Ethics and dissemination

Ethical approval is not required as this project does not involve primary data collection. We will disseminate our findings through peer-reviewed publications and conference presentations.

Registration

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STRENGTHS AND LIMITATIONS

- In contrast to systematic reviews synthesizing evidence on multiple HRQoL instruments, our review will investigate in detail the evidence available on one specific instrument to measure dementia-related health-related quality of life (HRQoL) – the DEMQOL suite of instruments – allowing for a sufficiently detailed analysis of all relevant aspects of the selected instrument.
- We will identify, evaluate and synthesize evidence on the psychometric properties of the DEMQOL suite of instruments, its feasibility/acceptability and on how it was used in research studies – which is a prerequisite to determine its strengths and weaknesses for use in research and care practice, and to identify important research gaps.
- We will apply best practices in conducting systematic reviews, guided by the Cochrane Handbook of Systematic Reviews and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.
- We expect that we will not be able to conduct meta-analyses since we likely will not be able to identify a minimum of 3 studies investigating the same outcome using comparable methods.

INTRODUCTION

Health-related Quality of life (HRQoL) is a key outcome in dementia care and research.[1-3] With no dementia cure or disease-modifying treatment available, maximizing HRQoL of people with dementia is the overarching goal of care.[4-6] Dementia is an umbrella term for a set of progressive, degenerative brain disorders that successively diminish a person's cognitive and functional abilities. Dementia is associated with troubling neuro-psychiatric symptoms, and is, ultimately, fatal.[7 8] Currently, 50 million people worldwide are living with dementia[9] – 500,000 in Canada,[10] 5.7 million in the US[11] and 9.6 million in the EU.[12] Numbers are expected to more than triple by 2050.[9]

People with dementia experience decline in physical function and mental health, and associated poor HRQoL.[7 13] HRQoL is defined as an individual's perception of the impact a health condition has on that individual's life.[14] HRQoL and common dementia symptoms (cognitive and physical impairment and neuro-psychiatric symptoms) are related, but they are not the same.[15] People with dementia can have good HRQoL despite severe cognitive and physical impairment, and people with mild dementia symptoms can have poor HRQoL.[15] Therefore, measuring a person's perceptions of how symptoms affect their life (HRQoL), rather than just dementia symptom severity, can provide more specific information about how to best promote well-being in ways that are most meaningful to the person with dementia.

Multiple instruments have been developed to measure HRQoL in people with dementia.[2 16 17] Evidence for reliability and validity for many of these instruments is poor and, in general, there is high heterogeneity in terms of the tools' theoretical foundations, domains measured, and how they apply to different levels of dementia severity.[2 16 17] It is unclear which of these instruments is most feasible, acceptable, applicable or appropriate for use in research and

practice;[2] the authors of a systematic review on dementia-specific QoL and HRQoL instruments concluded that none of the instruments they assessed should be used without further research.[16] However, among the available instruments to measure HRQoL in people with dementia, the DEMQOL suite of instruments[18] is considered one of the best given its relatively strong theoretical foundations and psychometric properties.[2] The DEMQOL and its variations (proxy versions, preference-based indices for use in economic evaluation, and translations into various languages; Table 1)[19] are among the most popular instruments to measure HRQoL in research with people with dementia. As of May 23, 2020, the developers had documented 89 studies that used the DEMQOL suite of instruments.[20] Furthermore, with the DEMQOL-CH,[21] a version is now available that can be completed by staff caring for residents with dementia living in congregate care settings such as nursing homes or assisted/supportive living. This is important because the majority of these residents have dementia that is severe enough to limit their ability to self-report,[22-27] and often residents do not have a family/friend carer who visits and who could provide a proxy assessment.[28] A tool that can be reliably, validly and feasibly completed by care staff opens the possibility of routine HRQoL assessment –an important prerequisite for improving residents' HRQoL.

Table 1: Overview of DEMQOL versions and their characteristics

	DEMQOL	**DEMQOL-Proxy**	**DEMQOL-U**	**DEMQOL-Proxy-U**	**DEMQOL-CH**
Year of publication	2005	2005	2013	2013	2019
Target group	Persons with mild to moderate dementia (MMSE ≥ 10)	Persons with all stages of dementia (up to severe)	Same as DEMQOL	Same as DEMQOL-Proxy	Persons with all stages of dementia (up to severe)
Mode of administration	Interview of person with dementia	Interview of proxy of person with dementia	NA (DEMQOL scores are used and turned into preference-based [utility] values)	NA (DEMQOL-Proxy scores are used and turned into preference-based [utility] values)	Completed by care staff proxy of person with dementia

Number of items	28	31	5 (selected 1 item out of each identified domain)	4 (selected 1 item out of each identified domain, other than daily activities)	31
Domains (factors) based on factor analyses	Daily activities Memory Negative emotion Positive emotion	Functioning Emotion	Cognition Negative emotion Positive emotion Social relationships Loneliness	Cognition Negative emotion Daily activities Positive emotion Appearance	Functioning Positive emotions Negative emotions Engagement
Scoring	Items are scored on a 4-point Likert scale ranging from 1–4; Positive items are scored reversely so lower scores always indicate worse HRQoL; item scores are summed (possible range 28–112)	Items are scored on a 4-point Likert scale ranging from 1–4; Positive items are scored reversely so lower scores always indicate worse HRQoL; item scores are summed (possible range 31–124)	Based on a health state classification system and population-based preference values, a score between 0 (death) and 1 (full health) is generated	Based on a health state classification system and population-based preference values, a score between 0 (death) and 1 (full health) is generated	Items are scored on a 4-point Likert scale ranging from 1–4; Positive items are scored reversely so lower scores always indicate worse HRQoL; item scores are summed (possible range 31–124)

MMSE: Mini Mental State Examination

In their review, Bowling et al.[2] report some limited evidence for acceptability/feasibility of the DEMQOL and DEMQOL-Proxy. Acceptability/feasibility means that (a) the tool can be completed easily and within a time frame that is acceptable to participants; (b) instructions, items and response scales are clear to participants; (c) the number of items missed or answered incorrectly is minimal; and (d) no extensive resources are needed to complete the instrument (time, money, training). Evidence for internal consistency reliability is very good and some limited evidence is available on the tools' test-retest reliability. The DEMQOL and DEMQOL-Proxy were developed based on robust theory and a rigorous process of tool development that included (a) a review of available conceptualizations of QoL and HRQoL, (b) a review of available measures of HRQoL in dementia, (c) qualitative interviews with people with dementia

and their families, and (d) the development of a conceptual framework for dementia-related HRQoL.[18 29] Therefore, its content validity was considered acceptable. Some limited evidence (largely correlation-based with rather small effect sizes) was available on convergent and discriminant validity and evidence on the tools' factor structure, responsiveness and respondent burden was also limited. No evidence was available on known group differences and on psychometric properties of cultural and language adaptations of these tools.[2] The DEMQOL-CH is based on the DEMQOL-Proxy with similar findings related to its reliability and validity.[21]

While reviews of HRQoL tools exist, none sufficiently analyze all relevant aspects to understand whether the tool is psychometrically sound, and acceptable/feasible for use in research and practice. How a tool is used can help to inform an understanding of its acceptability/feasibility, by looking at elements such as time required to administer the tool, participants' ability to understand and complete the tool, or amounts of missing data. Assessing whether HRQoL is associated with other variables as anticipated can be helpful in establishing validity evidence. No HRQoL tool has been rigorously assessed on these grounds, using a comprehensive review of the literature. In this review we will assess how the DEMQOL tools have been used in research studies. Specifically, we will answer the following research questions:

1. How has the DEMQOL system been used in research?
    a. What research questions did studies using the DEMQOL system investigate?
    b. Which study settings and populations did studies using the DEMQOL system focus on?
    c. What is the quality of the research using the DEMQOL system?

2. What evidence is available on the development, psychometric properties and acceptability/feasibility of the DEMQOL suite of instruments?

METHODS AND ANALYSIS

Review design

We will conduct a systematic mixed-methods synthesis of research.[30] Our review methods and presentation of results will follow the *Cochrane Handbook of Systematic Reviews of Interventions*[31] and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.[32] This paper follows the PRISMA-P reporting guidelines for systematic review protocols.[33] We started the review in Jan 2019. Currently we are finalizing the screening of full texts. The review is scheduled to be completed by Dec 2020.

Search strategy

Supported by a scientific librarian, we will search the databases MEDLINE, EMBASE, PsycInfo, Journals@ovid, CINAHL, Abstracts in Social Gerontology, Academic Search Complete, Cochrane Library, Scopus, Web of Science, ProQuest Dissertations & Theses Global and Science Direct. We will search the terms DEMQOL or DEM-QOL or Dementia Quality of Life scale in the database default fields including title, abstract, MeSH/subject heading and author-supplied keyword fields, as well as, in the full-text of records (Appendix 1). We will not limit our search based on language and year of publication, and we will search the time frame covered by the data bases. We will search reference lists of all included studies for additional references.

Data management

We will manage references using Rayyan[34] – a free reference management software designed for literature reviews that facilitates online collaboration and blinding of reviewers during screening

activities. All references including abstracts will be uploaded to Rayyan and title/abstract and full-text screening will be done using this software. All team members will receive training on the application of Rayyan prior to the screening, and we will conduct regular meetings and calibration exercises to improve application of the inclusion and exclusion criteria.

Inclusion and exclusion criteria

Our primary inclusion criterion (Table 2) is whether the study either (a) reports on the development or validation of any of the DEMQOL versions available or (b) used any of the DEMQOL versions to assess study outcomes. Original studies of any design or systematically conducted reviews are eligible. We will include non-peer reviewed reports (gray literature) if the reference meets our inclusion criteria. We will include studies regardless of the country of origin, publication language, study setting or population. Studies that assessed HRQoL as a study outcome, using either of the DEMQOL instruments will be included regardless of the research question(s) and regardless of whether HRQoL was the main study outcome (dependent variable), an independent variable (predictor) or a covariate to adjust models.

Table 2: Inclusion and exclusion criteria

	Inclusion criteria	**Exclusion criteria**
Study focus	• Studies reporting on the development or validation of any version of the DEMQOL. DEMQOL versions include: - DEMQOL - DEMQOL-Proxy - DEMQOL-U - DEMQOL-Proxy-U - DEMQOL-CH • Studies using any of the DEMQOL versions to assess study outcomes – regardless of whether HRQoL was the main study outcome (dependent variable) or whether HRQoL was used as an independent variable or a covariate to adjust statistical models	• Studies only mentioning a DEMQOL version without having used the tool to assess study outcomes • Studies using the C-DEMQOL which is a tool to assess the QoL of caregivers of people with dementia, not a dementia-specific HRQoL tool. • Studies using QoL assessment tools other than any of the DEMQOL versions
Study design	• Primary empirical quantitative research and research protocols, regardless of the research design: - Randomised trials	• Non-empirical work (editorials, opinion texts, theoretical discussions)

	- Non-randomised trials - On-group pre-post studies - Cohort studies - Case control studies - Cross-sectional studies • Qualitative studies: - Qualitative interviews - Focus groups - Ethnographic observations - Qualitative case studies • Mixed methods studies • Systematically conducted reviews: - Meta-analyses - Systematic reviews - Realist reviews - Integrative reviews - Scoping reviews - Narrative reviews if they report the search strategy, data bases searched, inclusion/exclusion criteria of references, screening process and analysis/synthesis methods	• Non-systematic (selective) reviews. We will, however, screen reference lists of those reviews for eligible studies

Study screening

After removal of duplicates, team member pairs will independently screen titles and abstracts of retrieved references. Discrepancies will be discussed in the group and resolved by consensus. Full texts will be retrieved for included references and for references with insufficient information in the title/abstract to decide upon inclusion. Full text screening will follow the same method as title/abstract screening.

Quality appraisal

To assess risk for bias of each included study, we will use one of four validated checklists, as appropriate for the respective study design (Appendix 2):

- Systematically conducted reviews: Assessment of Multiple Systematic Reviews (AMSTAR) tool.[35-38]
- Clinical studies with or without a control group and with or without randomized allocation of participants: Quality Assessment Tool for Quantitative Studies (QATQS).[39 40]

- Cross-Sectional studies: Estabrooks' Quality Assessment and Validity Tool for Cross-Sectional Studies, which is based on established criteria for assessing quality of research studies.[41 42]
- Qualitative studies: Critical Appraisal Skills Program (CASP) Qualitative Research Checklist.[43]

Studies will be assessed independently by two team members and discrepancies resolved by consensus. We will score overall quality of each study, using a method we have previously used in various systematic reviews.[44-48] As per the developer of this method,[49] we will calculate the ratio of the obtained score to the maximum possible score for each study (possible range: 0-1). The maximum possible score varies depending on the checklist used and the number of checklist items applicable. We will rank studies as weak (≤ 0.50), low moderate (0.51-0.66), high moderate (0.67-0.79), or strong (≥ 0.80). We will also summarise and describe the key areas of weakness for all studies within each type of research design.

Data extraction

Our study team collaboratively adapted and pretested data extraction templates (Appendix 3), successfully used in previous systematic reviews.[50 51] One team member will extract study details into the template, and a second team member will double check the extracted information and discrepancies will be resolved by consensus. We will extract: first author; year of publication; title; journal name (or type of reference such as thesis, report, textbook); country of study; study aim(s), goal(s), purpose(s) or question(s); study design; study setting and sample; DEMQOL version(s) used; how the DEMQOL was used in that study (i.e. to validate the DEMQOL, as dependent study outcome or as covariate); other study outcome(s) assessed; and main results as they related to the DEMQOL.

Contacting authors for additional details

If a study does not report enough details, we will contact the study authors by email and invite them to clarify or add information to inform inclusion or exclusion of this study, risk for bias assessments and/or data extractions. In the case of non-response, we will send out reminders after 7, 10, and 13 days.

Analyses

To address research question 1, we will first conduct a thematic analysis[52] of narrative data (e.g. types of research questions asked) from the studies that used the DEMQOL to assess research outcomes, converting narrative to categorical data. Using figures and tables, we will descriptively present the number and proportion of studies that represent each category – e.g. DEMQOL version used, types of research questions asked, participant groups included, country of origin, study setting, study design, risk for bias category, etc.

To address research question 2, we will use descriptive statistics and narrative synthesis to summarize the proportion of studies that have assessed each of the elements below, and the range of results from studies reporting on the development or validation of any of the DEMQOL versions. Organized according to DEMQOL version, we will report results of different reliability, validity and feasibility/acceptability assessments. Reliability assessments include (a) internal consistency reliability (Cronbach's α), (b) inter-rater reliability or test-retest reliability (e.g. κ statistics, correlation coefficients, intra-class correlation coefficients), and (c) multiple method reliability (e.g. correlations of self-report and proxy assessments). Validity assessments include (a) content validity (e.g. expert opinions, content validity scores), (b) response process validity (e.g. assessments of whether target persons understand the DEMQOL items as intended), (c) validity based on exploratory or confirmatory factor analyses (e.g. evidence on whether items

reflect an overall scale or subscales), (d) validity based on item response theory models (e.g. evidence on item difficulty and discrimination), and (e) construct validity assessing whether outcomes known to be associated with HRQoL are associated as hypothesized with the DEMQOL (correlation coefficients, regression parameters, results of structural equation models). Feasibility/acceptability assessments include (a) participant's quantitative or qualitative ratings of ease or difficulty to complete the DEMQOL, (b) time to complete, (c) response and missing item patterns, and (d) costs of administration.

For qualitative results we will conduct a content analysis of the key themes and supporting data related to the respective outcome and whether the content of these themes varied across studies. For quantitative results we will report the range of scores, and the number and proportion of studies reporting statistically significant positive associations, statistically negative associations and statistically non-significant associations for a certain study outcome (vote counting). We will not attempt to synthesize study findings statistically (meta-analyses) since our research questions are descriptive, overall effect sizes across studies are not part of our two research questions, and study variables and populations are likely to be heterogenous enough that meta-analysis would not be appropriate.

ETHICS AND DISSEMINATION

Ethics approval will not be needed for this study as we will not collect primary data from individuals or organizations. Data of studies included in this systematic review cannot be linked to individuals or organizations. We intend to publish findings of the review in a peer-reviewed journal (will be made available on the DEMQOL website), and present findings at an international peer-reviewed conference. We will prepare a lay summary of the findings for knowledge users on what is known about the DEMQOL suite of instruments, and

recommendations for use in practice. Results of this review will synthesize information on how DEMQOL has been used and how its psychometric properties have been described or evaluated in various studies, which will enable researchers who want to use DEMQOL tool in future to evaluate its psychometric properties.

AUTHORS' CONTRIBUTIONS

MH, CAE, SAC, HMO, SB, and LH developed the research question, the systematic review design, and planned and designed the study protocol. MH is leading the systematic review project. MH in collaboration with a scientific librarian developed and tested the search strategy. Guided by MH and SAC, BE, SS, RD, TT, and JL tested and refined the search strategy and adapted the screening and data extraction templates. All authors critically read and commented on the manuscript and approved its submission.

COMPETING INTERESTS

None declared.

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Appendix 1: Search Strategy

1. Ovid MEDLINE, EMBASE and PsycInfo

The following terms will be searched in the database default fields including title, abstract, MeSH/subject heading and author-supplied keyword fields:

demqol OR dem-qol* OR dementia quality of life scale*

2. Journals@Ovid

The following terms will be searched in the full-text of records:

demqol OR dem-qol* OR dementia quality of life scale*

3. EBSCO CINAHL/Academic Search Complete/Abs in Soc Gerontology

TX(demqol OR "dem-qol*" OR "dementia quality of life scale")*
(TX searches all database fields and full-text when full-text is available within the database)

4. ProQuest Dissertations & Theses Global

Following terms will be searched in the full-text of records:

(demqol OR dem-qol* OR "dementia quality of life scale")*
AND
(dementia OR alzheimer)*

5. HAPI (Health & Psychosocial Instruments)

Following terms will be searched in the database default fields. Results will be browsed and any items not retrieved from other databases will be selected.

demqol OR dem-qol* OR dementia quality of life scale*

6. Wiley Online Library

The following terms will be searched in the full-text of records. Results will be browsed and any items not retrieved from database searching will be selected:

demqol OR dem-qol* OR "dementia quality of life scale"*

7. ScienceDirect

The following terms will be searched in the full-text of records:

demqol OR dem-qol OR "dementia quality of life scale"

8. Google Scholar

The following terms will be searched in the full-text of records. The first 10 pages of results and any items not retrieved from database searching will be selected

demqol OR dem-qol OR "dementia quality of life scale"

Appendix 2: Checklists used to assess methodological quality (risk for bias) of included studies)

1. Quality and Validity Assessment for Systematic Reviews and Meta-Analyses

*Required

Reviewer Information

Initials of Reviewer (including middle name(s) if applicable) *

Examples: Matthias Hoben = MH; Stephanie A Chamberlain (SAC)

Your answer

General Study Information

Study Title *

Copy-paste from paper so both reviewers enter the exact same information

Your answer

Name of First Author *

Enter as last name, first name

Your answer

Year of Publication *

Your answer

Journal *

For references not published in a journal enter whether the reference is a textbook, report, thesis, etc.

Your answer

Study Quality

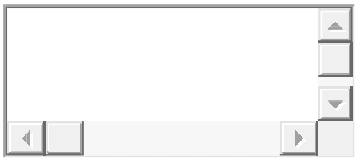
1. Was an 'a priori' design provided? *

The research question and inclusion criteria should be established before the conduct of the review. Note: Need to refer to a protocol, ethics approval, or pre-determined/a priori published research objectives to score a "yes."

Yes
No
Can't answer
Not applicable

Question 1 Notes/Rationale

Your answer



2. Was there duplicate study selection and data extraction? *

There should be at least two independent data extractors and a consensus procedure for disagreements should be in place. Note: 2 people do study selection, 2 people do data extraction, consensus process or one person checks the other's work.

Yes
No
Can't answer
Not applicable

Question 2 Notes/Rationale

Your answer

3. Was a comprehensive literature search performed? *

At least two electronic sources should be searched. The report must include years and databases used (e.g., Central, EMBASE, and MEDLINE). Key words and/or MESH terms must be stated and where feasible the search strategy should be provided. All searches should be supplemented by consulting current contents, reviews, textbooks, specialized registers, or experts in the particular field of study, and by reviewing the references in the studies found. Note: If at least 2 sources + one supplementary strategy used, select "yes" (Cochrane register/Central counts as 2 sources; a grey literature search counts as supplementary).

Yes
No
Can't answer
Not applicable

Question 3 Notes/Rationale

Your answer

4. Was the status of publication (i.e. grey literature) used as an inclusion criterion? *

The authors should state that they searched for reports regardless of their publication type. The authors should state whether or not they excluded any reports (from the systematic review), based on their publication status, language etc. Note: If review indicates that there was a search for “grey literature” or “unpublished literature,” indicate “yes.” SINGLE database, dissertations, conference proceedings, and trial registries are all considered grey for this purpose. If searching a source that contains both grey and non-grey, must specify that they were searching for grey/unpublished lit.

Yes
No
Can't answer
Not applicable

Question 4 Notes/Rationale

Your answer

5. Was a list of studies (included and excluded) provided? *

A list of included and excluded studies should be provided. Note: Acceptable if the excluded studies are referenced. If there is an electronic link to the list but the link is dead, select “no.”

Yes
No
Can't answer
Not applicable

Question 5 Notes/Rationale

Your answer

6. Were the characteristics of the included studies provided? *

In an aggregated form such as a table, data from the original studies should be provided on the participants, interventions and outcomes. The ranges of characteristics in all the studies analyzed e.g., age, race, sex, relevant socioeconomic data, disease status, duration, severity, or other diseases should be reported. Note: Acceptable if not in table format as long as they are described as above.

Yes
No
Can't answer
Not applicable

Question 6 Notes/Rationale

Your answer

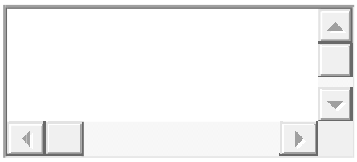
7. Was the scientific quality of the included studies assessed and documented? *

'A priori' methods of assessment should be provided (e.g., for effectiveness studies if the author(s) chose to include only randomized, double-blind, placebo controlled studies, or allocation concealment as inclusion criteria); for other types of studies alternative items will be relevant. Note: Can include use of a quality scoring tool or checklist, e.g., Jadad scale, risk of bias, sensitivity analysis, etc., or a description of quality items, with some kind of result for EACH study ("low" or "high" is fine, as long as it is clear which studies scored "low" and which scored "high"; a summary score/range for all studies is not acceptable).

Yes
No
Can't answer
Not applicable

Question 7 Notes/Rationale

Your answer



8. Was the scientific quality of the included studies used appropriately in formulating conclusions? *

The results of the methodological rigor and scientific quality should be considered in the analysis and the conclusions of the review, and explicitly stated in formulating recommendations. Note: Might say something such as "the results should be interpreted with caution due to poor quality of included studies." Cannot score "yes" for this question if scored "no" for question 7.

Yes
No
Can't answer
Not applicable

Question 8 Notes/Rationale

Your answer

9. Were the methods used to combine the findings of studies appropriate? *

For the pooled results, a test should be done to ensure the studies were combinable, to assess their homogeneity (i.e., Chi-squared test for homogeneity, I-squared). If heterogeneity exists a random effects model should be used and/or the clinical appropriateness of combining should be taken into consideration (i.e., is it sensible to combine?). Note: Indicate “yes” if they mention or describe heterogeneity, i.e., if they explain that they cannot pool because of heterogeneity/variability between interventions.

Yes
No
Can't answer
Not applicable

Question 9 Notes/Rationale

Your answer

10. Was the likelihood of publication bias assessed? *

An assessment of publication bias should include a combination of graphical aids (e.g., funnel plot, other available tests) and/or statistical tests (e.g., Egger regression test, Hedges-Olken). Note: If no test values or funnel plot included, score “no”. Score “yes” if mentions that publication bias could not be assessed because there were fewer than 10 included studies.

Yes
No
Can't answer
Not applicable

Question 10 Notes/Rationale

Your answer

11. Was the conflict of interest included? *

Potential sources of support should be clearly acknowledged in both the systematic review and the included studies. Note: To get a "yes," must indicate source of funding or support for the systematic review AND for each of the included studies.

Yes
No
Can't answer
Not applicable

Question 11 Notes/Rationale

Your answer

2. Quality Assessment Tool for Quantitative Studies (QATQS)

*Required

Reviewer Information

1. Name of Reviewer*

.....

2. **First or second review***

Tick all that apply.

- [ ] First review
- [ ] Second review

General Study Information

3. Study Title *

.....

4. Name of First Author *

.....

5. Year of Publication *

6. Journal *

For references not published in a journal enter if it is a textbook, report, thesis, etc.

.....

A) Selection Bias

7. (Q1) Are the individuals selected to participate in the study likely to be representative of the target population? *

Tick all that apply.

- [ ] Very likely
- [ ] Somewhat likely
- [ ] Not likely
- [ ] Can't tell

8. (Q2) What percentage of selected individuals agreed to participate? *

Tick all that apply.

- [ ] 80 - 100% agreement
- [ ] 60 - 79% agreement
- [ ] Less than 60% agreement
- [ ] Not applicable
- [ ] Can't tell

9. Overall rating of this section *

See dictionary

Tick all that apply.

- [ ] Strong
- [ ] Moderate
- [ ] Weak

B) Study Design

10. Indicate the study design *

Tick all that apply.

- [ ] Randomized controlled trial
- [ ] Controlled clinical trial
- [ ] Cohort analytic (two group pre + post)
- [ ] Case-control
- [ ] Cohort (one group pre + post (before after))
- [ ] Interrupted time series
- [ ] Can't tell
- [ ] Other: .....

11. Was study described as randomized? *

If 'No', go to Component C

Tick all that apply.

- [ ] No
- [ ] Yes

12. If 'Yes', was the method of randomization described? *

See dictionary

Tick all that apply.

- [ ] No
- [ ] Yes
- [ ] Not applicable (if 'No' to question 'Was study described as randomized?')

13. If 'Yes', was the method appropriate? *

See dictionary

Tick all that apply.

- [ ] No
- [ ] Yes
- [ ] Not applicable (if 'No' to question 'Was study described as randomized?')

14. Overall rating of this section *

See dictionary

Tick all that apply.

- [ ] Strong
- [ ] Moderate
- [ ] Weak

C) Confounders

15. **(Q1) Were there important differences between groups prior to the intervention? ***

Tick all that apply.

- [ ] Yes
- [ ] No
- [ ] Can't tell

16. The following are examples of confounders: *

Check all that apply

Tick all that apply.

- [ ] Race
- [ ] Sex
- [ ] Marital status/family
- [ ] Age
- [ ] SES (income or class)
- [ ] Education
- [ ] Health status
- [ ] Pre-intervention score on outcome measure
- [ ] Other:

17. (Q2) If yes, indicate the percentage of relevant confounders that were controlled (either in the design (e.g. stratification, matching) or analysis)? *

Tick all that apply.

- [ ] 80 - 100% (most)
- [ ] 60 - 79% (some)
- [ ] Less than 60% (few or none)
- [ ] Can't tell

18. Overall rating of this section *

See dictionary

Tick all that apply.

- [ ] Strong
- [ ] Moderate
- [ ] Weak

D) Blinding

19. (Q1) Was (were) the outcome assessor(s) aware of the intervention or exposure status of participants? *

Tick all that apply.

- [ ] Yes
- [ ] No
- [ ] Can't tell

***20.* (Q2) Were the study participants aware of the research question? ***

Tick all that apply.

- [ ] Yes
- [ ] No
- [ ] Can't tell

21. Overall rating of this section *

See dictionary

Tick all that apply.

- [ ] Strong
- [ ] Moderate
- [ ] Weak

E) Data Collection Methods

22. **(Q1) Were data collection tools shown to be valid?** *

Tick all that apply.

- [ ] Yes
- [ ] No
- [ ] Can't tell

23. **(Q2) Were data collection tools shown to be reliable?** *

Tick all that apply.

- [ ] Yes
- [ ] No
- [ ] Can't tell

24. Overall rating of this section *

See dictionary

Tick all that apply.

- [ ] Strong
- [ ] Moderate
- [ ] Weak

F) Withdrawals and Drop-Outs

25. (Q1) Were withdrawals and drop-outs reported in terms of numbers and/or reasons per group? *

Tick all that apply.

- [ ] Yes
- [ ] No
- [ ] Can't tell
- [ ] Not applicable (i.e., one time surveys or interviews)

26. (Q2) Indicate the percentage of participants completing the study. (If the percentage differs by groups, record the lowest). *

Tick all that apply.

- [ ] 80 - 100%
- [ ] 60 - 79%
- [ ] Less than 60%
- [ ] Can't tell
- [ ] Not applicable (i.e., retrospective case-control)

27. Overall rating of this section *

See dictionary

Tick all that apply.

- [ ] Strong
- [ ] Moderate
- [ ] Weak
- [ ] Not Applicable

G) Intervention Integrity

28. (Q1) What percentage of participants received the allocated intervention or exposure of interest? *

Tick all that apply.

- [ ] 80 - 100%
- [ ] 60 - 79%
- [ ] Less than 60%
- [ ] Can't tell

29. **(Q2) Was the consistency of the intervention measured?**

Tick all that apply.

- [ ] Yes
- [ ] No
- [ ] Can't tell

30. (Q3) Is it likely that subjects received an unintended intervention (contamination or co-intervention) that may influence the results? *

Tick all that apply.

- [ ] Yes
- [ ] No
- [ ] Can't tell

H) Analyses

31. **(Q1) Indicate the unit of allocation** *

Tick all that apply.

- [ ] Community
- [ ] Organization/institution
- [ ] Practice/office
- [ ] Individual

32. (Q2) Indicate the unit of analysis *

Tick all that apply.

- [ ] Community
- [ ] Organization/institution
- [ ] Practice/office
- [ ] Individual

33. (Q3) Are the statistical methods appropriate for the study design? *

Tick all that apply.

- [ ] Yes
- [ ] No
- [ ] Can't tell

34. (Q4) Is the analysis performed by intervention allocation status (i.e. intention to treat) rather than the actual intervention received? *

Tick all that apply.

- [ ] Yes
- [ ] No
- [ ] Can't tell

Global Rating For This Paper

For this global rating refer to the overall ratings of sections A-F

35. *

Tick all that apply.

- [ ] Strong (no weak ratings)
- [ ] Moderate (one weak rating)
- [ ] Weak (two or more weak ratings)

3. Estabrooks' Quality Assessment and Validity Tool for Cross-Sectional Studies

*Required

Reviewer Information

1. Name of Reviewer*

.....

2. **First or second review?**

* *Check all that apply.*

- [ ] First review
- [ ] Second review

General Study Information

3. Study Title*

.....

4. Name of First Author *

.....

5. Year of Publication*

6. Journal *

For references not published in a journal enter if it is a textbook, report, thesis, etc.

.....

Sampling

N/A can only be selected if the respective item is not applicable to the design of the study

1. Was probability sampling used? *

Most researchers probably used a convenience sample, i.e., studying all the nurses available to them in one or more setting(s) that agreed to participate (which would be the option 'No'). Select 'Yes' if the authors stated that they used a probabilistic sample. Select 'No' if the authors stated that they used a convenience sample or if they did not report the use of probabilistic sample.
Check all that apply.

- [ ] Yes
- [ ] No

2. Are the individuals selected to participate in the study likely to be representative of the target population? *

Select 'Very Likely' if the authors have done everything reasonably possible to ensure that the target population is represented. Select 'Somewhat Likely' if participants may not be representative (i.e., if they are referred from a source within a target population even if it is in a systematic manner. Select 'Not Likely' if participants are probably not representative if they are self-referred or are volunteers or if you can not tell.
Check all that apply.

- [ ] Very likely
- [ ] Somewhat likely
- [ ] Not likely

3. Was sample size justified to obtain appropriate power? *

Select 'Yes' if one or more of the following are present: a) sample size is justified based on appropriate power calculations (power=80); b) using a multivariate approach 10 cases per IV are used; c) using several correlations or t-tests, a sample of 80 or more reflects adequate power; d) study has sufficient statistical power to detect clinically important effects as statistically significant and record power > 80. Select 'No' if: a) Sample size and power are not reported; b) the above cut-offs are not met.
Check all that apply.

- [ ] Yes
- [ ] No

4. Was sample drawn from more than one site? *

This refers to physical location – multiple groups belonging to the same system count as multi-site. Several units within the same hospital do not count as multi-site, but several hospitals within the same system or region do. Select 'Yes' if the assumptions made above are accomplished. Select 'No' if the assumptions made above are not accomplished, or not reported.
Check all that apply.

- [ ] Yes
- [ ] No

5. If there were groups in the study, is there a statement that groups are matched in design or statistically adjusted? *

Select 'Yes, matched in design' if the authors stated clearly that the groups were matched (i.e. gender, unit). Select 'Yes, statistically adjusted' if groups were statistically adjusted for confounder variables (i.e. use of covariance). Select 'Yes, matched in design and statistically adjusted' if the authors clearly report having done both, a) and b). Select 'No, not matched/adjusted' if authors did not state that groups were matched or adjusted. Select 'N/A' if the study included only one group.
Check all that apply.

- [ ] Yes, matched in design
- [ ] Yes, statistically adjusted
- [ ] Yes, matched in design and statistically adjusted
- [ ] No, not matched/adjusted
- [ ] N/A

6. In case of surveys: was the response rate > 50%? *

Response rate is operationally defined as the number of people who participated divided by the number of people who were sampled (e.g., given or sent or offered a questionnaire). If not reported, information that allows calculation will be sought and the same rule applied. Select 'Yes' if the response rate is more than 50%. Select 'No' if the response rate is less than 50% or not reported. Select 'N/A' if the study was not a survey.
Check all that apply.

- [ ] Yes
- [ ] No
- [ ] N/A

Measurement

7. How was (were) the dependent variable(s) measured? *

Check all that apply.

- [ ] Directly measured (i.e., observed) or taken from an administrative database or chart
- [ ] Self-reported

8. Did the researchers use instruments with reported reliability and validity (previously or for this study)? *

Select option 1 if researchers report reliability indices for each research tool they used, and instruments are reliable (intra-rater and/or inter-rater reliability of the outcomes measure was ICC > 0.70 or kappa ≥ 0.70 or at least 80% agreement; Internal consistency [Cronbach's Alpha] for a scale is > 0.70). Select option 2 if the researchers report validity assessments for each research tool they used and the tools are valid (some form of validation was described for the tools used, e.g., face, content, response process, construct, concurrent validity). Select option 3 if the researchers report reliability indices and validity assessments for each research tool they used and tools are reliable and valid. Select option 4 if researchers do not report any reliability indices or validity assessments for the used research tools or tools are not reliable and valid.
Check all that apply.

- [ ] Reliability indices
- [ ] Validity assessments
- [ ] Both, reliability indices and validity assessments
- [ ] No

Statistical Analysis

N/A can only be selected if the respective item is not applicable to the design of the study

9. Was (were) the statistical test (s) used appropriate for the main outcome (i.e., research use)? *

Take into account the assumptions that need to be met for certain statistical tests. For example, a t-test requires continuous, normally distributed variables and is inappropriate when the outcomes are categorical.

Check all that apply.

- [ ] Yes
- [ ] No

10. Were p values reported? *

Select N/A if the study was just descriptive and did not intend to assess any statistical associations

Check all that apply.

- [ ] Yes
- [ ] No
- [ ] N/A

11. Were confidence intervals reported? *

Select N/A if the study was just descriptive and did not intend to assess any statistical associations

Check all that apply.

- [ ] Yes
- [ ] No
- [ ] N/A

12. Were missing data managed appropriately? *

Select 'N/A' if you are certain there are not missing data.

Check all that apply.

- [ ] Yes
- [ ] No
- [ ] N/A

4. **Critical Appraisal Skills Program (CASP) Qualitative Research Checklist**
*Required

Reviewer Information

Name of Reviewer*

.....

First or second review*
Tick all that apply.

- [ ] First review
- [ ] Second review

General Study Information

Study Title *

Name of First Author *

.....

Year of Publication *

.....

Journal *
For references not published in a journal enter if it is a textbook, report, thesis, etc.

.....

Study Quality

1. Was there a clear statement of the aims of the research? *
Hint: Consider a) What was the goal of the research? Why it was thought important? c) Its relevance
Tick all that apply.

- [ ] Yes
- [ ] Can't tell
- [ ] No

Comments to question 1 (Optional)

.....

2. Is a qualitative methodology appropriate? *

Hint: Consider a) If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants. b) Is qualitative research the right methodology for addressing the research goal?

Tick all that apply.

- [ ] Yes
- [ ] Can't tell
- [ ] No

Comments to question 2

(Optional)

.....

3. Was the research design appropriate to address the aims of the research? *

Hint: Consider if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)?

Tick all that apply.

- [ ] Yes
- [ ] Can't tell
- [ ] No

Comments to question 3

(Optional)

.....

4. Was the recruitment strategy appropriate to the aims of the research? *

Hint: Consider a) If the researcher has explained how the participants were selected. b) If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study. c) If there are any discussions around recruitment (e.g. why some people chose not to take part).

Tick all that apply.

- [ ] Yes
- [ ] Can't tell
- [ ] No

Comments to question 4

(Optional)

.....

5. Was the data collected in a way that addressed the research issue? *

Hint: Consider a) If the setting for data collection was justified. b) If it is clear how data were collected (e.g. focus group ,semi-structured interview etc.). c) If the researcher has justified the methods chosen. d) If the researcher has made the methods explicit (e.g.for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)? e) If methods were modified during the study. If so, has the researcher explained how and why? f) If the form of data is clear (e.g. tape recordings, video material, notes etc). g) If the researcher has discussed saturation of data

Tick all that apply.

- [ ] Yes
- [ ] Can't tell
- [ ] No

Comments to question 5

(Optional)

.....

6. Has the relationship between researcher and participants been adequately considered? *

Hint: Consider a) If the researcher critically examined their own role, potential bias and influence during (1) Formulation of the research questions (2) Data collection, including sample recruitment and choice of location. b) How the researcher responded to events during the study and whether they considered the implications of any changes in the research design.

Tick all that apply.

- [ ] Yes
- [ ] Can't tell
- [ ] No

Comments to question 6

(Optional)

.....

7. Have ethical issues been taken into consideration? *

Hint: Consider a) If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained. b) If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study). c) If approval has been sought from the ethics committee

Tick all that apply.

- [ ] Yes
- [ ] Can't tell
- [ ] No

Comments to question 7

(Optional)

.....

8. Was the data analysis sufficiently rigorous? *

Hint: Consider a) If there is an in-depth description of the analysis process. b) If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data? c) Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process. d) If sufficient data are presented to support the findings. e) To what extent contradictory data are taken into account. f) Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation.

Tick all that apply.

- [ ] Yes
- [ ] Can't tell
- [ ] No

Comments to question 8 (Optional)

.....

9. Is there a clear statement of findings? *

Hint: Consider a) If the findings are explicit. b) If there is adequate discussion of the evidence both for and against the researchers arguments. c) If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation,more than one analyst). d) If the findings are discussed in relation to the original research question.

Tick all that apply.

- [ ] Yes
- [ ] Can't tell
- [ ] No

Comments **to question 9** (Optional)

.....

10. How valuable is the research? *

Hint: Consider a) If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy?, or relevant research-based literature? b) If they identify new areas where research is necessary. c) If the researchers have discussed whether or how thefindings can be transferred to other populations or considered other ways the research may be used.

Tick all that apply.

- [ ] Yes
- [ ] Can't tell
- [ ] No

Comments to question 10 (Optional)

.....

Appendix 3: Data extraction templates

DEMQOL Data Extraction Form - Psychometric Studies

*Required

Study Characteristics

1. Initial of person entering data (including middle names, if applicable) *
   Examples are: Matthias Hoben = MH: Stephanie A Chamberlain = SAC

2. First Author *
   Enter as: last name, first name

3. Country of Origin

4. Language

5. Year of Publication *

6. Journal

For references not published in a journal enter whether the references is a text book, report, thesis, etc.

7. Title of Study *

Copy-paste from paper so both reviewers enter the exact same information

8. Study Purpose(s) *

Extract the author's stated primary and secondary purposes. This may be in the form of a purpose statement, research question(s), or primary and secondary objectives, and is typically found in the introduction or at the beginning of the methods section. Only state what's specifically related to the objective, don't need to report methods or sampling.

Study design

9. Select the design applicable *

Mark only one oval.

- RCT
- Controlled Trial
- Pre-Post
- Cohort
- Case-control
- Cross-sectional
- Qualitative
- Mixed
- Others

10. If Mixed design, provide description

Mark only one oval.

- Exploratory sequential design - study begins with qualitative data collection methods (interviews, observations), followed by some quantitative methods
- Explanatory sequential design - study begins with quantitative methods followed by qualitative methods
- Concurrent- both quantitative and qualitative methods are conducted in parallel

11. If others, provide description

12. Method of data collection - Quantitative *

Tick all that apply.

- [ ] Participant-completed survey/questionnaire
- [ ] Researcher-completed survey/questionnaire with participant (structured participant interview)
- [ ] Researcher-completed survey/questionnaire with proxy (structured proxy interview)
- [ ] Structured observational
- [ ] Structured chart review
- [ ] N/A
- [ ] Other: _____

13. Method of data collection - Qualitative *

Tick all that apply.

- [ ] Semi-structured interview
- [ ] Focus group
- [ ] Chart review
- [ ] Ethnographic observation
- [ ] N/A
- [ ] Other: _____

Sample

State the sample size, and separately for each arm of the study (e.g., control, treatment1, treatment2), if applicable

14. Sample size *

How many people were asked to participate.

15. Sample size

How many people actually participated and provided data.

16. Age (Age range, Mean age) *

Extract the average (mean or median) age, or the percentage of participants in different age categories identified in the article.

17. Gender/Sex *

Extract the percentage of the sample that was female/women and/or male/men

Settings (Check all that apply)

Refers to the settings from which the participants were recruited from. Terminology may vary across studies (for example, some studies may refer to study sites or facilities).

18. Site (check all that apply) *

Tick all that apply.

- [ ] Long-term care/Nursing homes
- [ ] Day program
- [ ] Private home
- [ ] Senior's apartment
- [ ] Supportive or assisted living
- [ ] Home care
- [ ] Hospital
- [ ] Unspecified community setting

Other: [ ] _____

19. Number of Sites *

Were the number of sites specified?

Mark only one oval.

- ◯ Yes
- ◯ No

20. Number of Sites *

For those who agreed to participate in the study.

_____

21. Number of Sites *

For those who were included in the data analysis.

_____

Cognitive Impairment

This involves: name of the tool used to measure cognitive health status, level of cognitive health status

22. Tool used for assessing cognitive status (state name or not specified) *

Please keep responses succinct, abbreviations are acceptable. For example: MMSE, MoCA.

23. Operationalized definitions of each stage in the study *

Labelled as mild, moderate or severe (Usually reported in terms of range of scores that are used to categorize participants into each stage. For example: Mild 19–24; Moderate 10–18; Severe 0–9 (Do not provide a narrative response. Keep your response as succinct as possible).

24. Percentage of participants described as having mild, moderate or severe cognitive impairment *

25. Scores of overall cognitive impairment and/or of the cognitive impairment stages (mild, moderate, severe) reported in the study *

Report whatever the authors report, e.g., means and standard deviations, median and inter-quartile range, numbers, etc.

DEMQOL Version Used

26. DEMQOL Instruments Version(s) used *

Tick all that apply.

- [ ] DEMQOL
- [ ] DEMQOL-Proxy
- [ ] DEMQOL-CH
- [ ] DEMQOL-U
- [ ] DEMQOL Proxy- U
- [ ] C-DEMQOL

27. DEMQOL Language *

Study Outcomes

28. Additional Study Variables Assessed Other Than The DEMQOL *

Please list all measurement tools used by the research team and the outcomes assessed by these tools. No numerical values. For example: GDS- Depression

Psychometric properties of the instrument

How DEMQOL was used by the authors in the study. It may have been used in more than one way.

29. Reliability (Internal consistency) *

Assesses how tool items are inter-correlated (usually reporting Cronbach's alpha). Report reliability in the form of numerical value given for internal consistency. If not reported, please respond as 'not reported'.

30. Reliability (Test-retest) *

Assesses correlation of scores measured by the same person at different times (usually as Kappa, intra-cross correlation, or similar correlation coefficients). Report reliability in the form of numerical value given for test- retest. If not reported, please respond as 'not reported'.

31. Reliability (Inter-rater) *

Assesses correlation of scores measured by two or more independent raters at the same time (usually as Kappa, intra-cross correlation, or similar correlation coefficients). Report reliability in the form of numerical value given for inter-rater. If not reported, please respond as 'not reported'.

32. Reliability (Inter-method) *

Assesses correlation of scores obtained by different assessment methods (e.g observations vs self-report or self-report vs proxy). Usually as Kappa, intra-cross correlation, or similar correlation coefficients. Report reliability in the form of numerical value given for inter-method. If not reported, please respond as 'not reported'.

33. Validity (Content validity) *

Assessed by ratings given by content experts (usually researchers or clinicians). Ratings may either be qualitative, or quantitative using standardized scales to assess relevance and comprehensibility of each item based on content experts perceptions. Report numerical value given for content validity. If not reported, please respond as 'not reported'.

34. Validity (Response Process validity) *

Summarize the findings related to how well target persons understood the questionnaire. If not reported, please respond as 'not reported'.

35. Validity (Factorial or Internal Structure Validity) *

Report whether exploratory or confirmatory factor analyses were conducted, report the number of factors found and model fit indices (if reported). If not reported, please respond as 'not reported'.

36. Validity (Relationship with other variables) *

Statistical modelling is used to test pre-specified hypotheses. To be specific, models assess whether known predictors of QOL are associated with QOL as measured by the DEMQOL as expected. Or models assess whether QOL as measured by the DEMQOL are associated with known consequences of poor QOL such as reduced social engagement and depression. Report the numerical value(s) given for the relationship with other variables. If not reported, please respond as 'not reported'.

37. Feasibility or Acceptability *

Must be reported in the results section because it needs to be scientifically assessed. If not reported, please respond as 'not reported'.

DEMQOL Data Extraction Form - non-Psychometric Studies

*Required

Study Characteristics

1. Initial of person entering data (including middle names, if applicable) *

   Examples are: Matthias Hoben = MH: Stephanie A Chamberlain = SAC

2. First Author *

   Enter as: last name, first name

3. Country of Origin

4. Language

5. Year of Publication *

6. Journal

For references not published in a journal enter whether the references is a text book, report, thesis, etc.

7. Title of Study *

Copy-paste from paper so both reviewers enter the exact same information

8. Study Purpose(s) *

Extract the author's stated primary and secondary purposes. This may be in the form of a purpose statement, research question(s), or primary and secondary objectives, and is typically found in the introduction or at the beginning of the methods section. Only state what's specifically related to the objective, don't need to report methods or sampling.

Study design

9. Select the design applicable *

Mark only one oval.

- RCT *Skip to question 12*
- Controlled Trial *Skip to question 12*
- Pre-Post *Skip to question 12*
- Cohort *Skip to question 12*
- Case-control *Skip to question 12*
- Cross-sectional *Skip to question 12*
- Qualitative *Skip to question 12*
- Mixed *Skip to question 10*
- Others *Skip to question 11*

Specify mixed

10. If Mixed design, provide description *

Mark only one oval.

- Exploratory sequential design - study begins with qualitative data collection methods (interviews, observations), followed by some quantitative methods
- Explanatory sequential design - study begins with quantitative methods followed by qualitative methods
- Concurrent- both quantitative and qualitative methods are conducted in parallel

Skip to question 12

Specify other

11. If others, provide description *

Methods of data collection

12. Method of data collection - Quantitative *

Tick all that apply.

- [ ] Participant-completed survey/questionnaire
- [ ] Researcher-completed survey/questionnaire with participant (structured participant interview)
- [ ] Researcher-completed survey/questionnaire with proxy (structured proxy interview)
- [ ] Structured observational
- [ ] Structured chart review
- [ ] N/A
- [ ] Other: _____

13. Method of data collection - Qualitative *

Tick all that apply.

- [ ] Semi-structured interview
- [ ] Focus group
- [ ] Chart review
- [ ] Ethnographic observation
- [ ] N/A
- [ ] Other: _____

Settings

Refers to the settings from which the participants were recruited from. Terminology may vary across studies (for example, some studies may refer to study sites or facilities). Check all that apply.

14. Setting(s) *

Check all that apply

Tick all that apply.

- [ ] Long-term care/Nursing homes
- [ ] Day program
- [ ] Private home
- [ ] Senior's apartment
- [ ] Supportive or assisted living
- [ ] Home care
- [ ] Hospital
- [ ] Unspecified community setting

Other: [ ] _____

15. Number of sites approached *

For each setting specified above, enter the number of sites that were asked to participate. For example, if researchers approached 12 nursing homes and 11 assisted living facilities, enter: NHs: 12; AL: 11. If this number is not reported, enter: not reported. If the study included more than one study arm, give the site numbers separately for each arm of the study (e.g., control, treatment1, treatment2).

_____

16. Number of sites agreed to participate *

For each setting specified above, enter the number of sites that agreed to participate. For example, if 10 nursing homes and 8 assisted living facilities agreed to participate, enter: NHs: 10; AL: 8. If this number is not reported, enter: not reported. If the study included more than one study arm, give the site numbers separately for each arm of the study (e.g., control, treatment1, treatment2).

_____

17. Number of sites included in data analyses *

For each setting specified above, enter the number of sites that were included in the data analyses. For example, if 8 nursing homes and 7 assisted living facilities were included in the data analyses, enter: NHs: 8; AL: 7. If this number is not reported, enter: not reported. If the study included more than one study arm, give the site numbers separately for each arm of the study (e.g., control, treatment1, treatment2).

_____

Sample

Refers to the recruited individuals (e.g., patients, residents, family/friend caregivers, care aides, nurses, ...)

18. Number of persons approached *

For each participant group, enter the number of persons that were asked to participate. For example, if researchers approached 200 nursing home residents and 48 care aides, enter: NH residents: 200; care aides: 48. If this number is not reported, enter: not reported. If the study included more than one study arm, give the participant numbers separately for each arm of the study (e.g., control, treatment1, treatment2).

19. Number of persons agreed to participate *

For each participant group, enter the number of persons that agreed to participate. For example, if 150 nursing home residents and 24 care aides agreed to participate, enter: NH residents: 150; care aides: 24. If this number is not reported, enter: not reported. If the study included more than one study arm, give the participant numbers separately for each arm of the study (e.g., control, treatment1, treatment2).

20. Number of persons included in data analyses *

For each participant group, enter the number of persons that were included in the data analyses. For example, if 140 nursing home residents and 20 care aides were included in the analyses, enter: NH residents: 140; care aides: 20. If this number is not reported, enter: not reported. If the study included more than one study arm, give the participant numbers separately for each arm of the study (e.g., control, treatment1, treatment2).

21. Age

Extract the average (mean or median) age, or the percentage of participants in different age categories identified in the article. If the study inlcudes multiple participant groups, do this by participant group and if the study includes multiple study arms do this by study arm.

22. Sex

Extract the percentage of the sample that was female/women and/or male/men. If the study inlcudes multiple participant groups, do this by participant group and if the study includes multiple study arms do this by study arm.

Cognitive Impairment

This involves: name of the tool used to measure cognitive health status, level of cognitive health status

23. Tool used for assessing cognitive status (state name or not specified) *

Please keep responses succinct, abbreviations are acceptable. For example: MMSE, MoCA.

24. Operationalized definitions of each stage in the study *

Labelled as mild, moderate or severe (Usually reported in terms of range of scores that are used to categorize participants into each stage. For example: Mild 19–24; Moderate 10–18; Severe 0–9 (Do not provide a narrative response. Keep your response as succinct as possible).

25. Percentage of participants described as having mild, moderate or severe cognitive impairment *

26. Scores of overall cognitive impairment and/or of the cognitive impairment stages (mild, moderate, severe) reported in the study *

Report whatever the authors report, e.g., means and standard deviations, median and inter-quartile range, numbers, etc.

DEMQOL Version

27. DEMQOL Instruments Version(s) used *

Check all that apply

Tick all that apply.

- [ ] DEMQOL
- [ ] DEMQOL-Proxy
- [ ] DEMQOL-CH
- [ ] DEMQOL-U
- [ ] DEMQOL Proxy- U
- [ ] C-DEMQOL

28. DEMQOL Language

_____

Use of DEMQOL

29. How was the DEMQOL used in this study

Check all that apply

Tick all that apply.

- [ ] As a dependent variable - i.e. study assessing factors associated with QoL or how QoL differs between groups
- [ ] As an independent variable or study covariate - i.e. study assessed how QoL influences other study outcomes

Other Dependent Variables

Don't list the DEMQOL here. Only list dependent variables other than DEMQOL scores.

30. Dependent variables (other than DEMQOL) *

Please list all measurement tools used by the research team and the outcomes assessed by these tools. No numerical values. For example: Depression (GDS). If no dependent variables other than the DEMQOL were included, enter: NA.

_____

_____

_____

_____

_____

Other Study Variables

Don't list the DEMQOL here. Only list independent variables and model covariates other than DEMQOL scores.

31. Independent variables (other than DEMQOL) *

These are variables that are included in the analysis and statistical outcomes ARE reported (e.g. regression coefficients, correlations, etc.) Please list all measurement tools used by the research team and the outcomes assessed by these tools. No numerical values. For example: Depression (GDS). If no independent variables were included, enter: NA.

32. Modelling covariates (other than DEMQOL) *

These are variables that are included in the analysis and statistical outcomes are NOT reported. Please list all measurement tools used by the research team and the outcomes assessed by these tools. No numerical values. For example: Depression (GDS). If no model covariates were included, enter: NA.

Main Findings

33. Main findings of the study

Google Forms

PRISMA-P (Preferred Reporting Items for Systematic review and Meta-Analysis Protocols) 2015 checklist: recommended items to address in a systematic review protocol*

Section and topic	Item No	Checklist item	Location
ADMINISTRATIVE INFORMATION			
Title:			
Identification	1a	Identify the report as a protocol of a systematic review	Title Page (pg. 1)
Update	1b	If the protocol is for an update of a previous systematic review, identify as such	NA
Registration	2	If registered, provide the name of the registry (such as PROSPERO) and registration number	Registration (pg. 2)
Authors:			
Contact	3a	Provide name, institutional affiliation, e-mail address of all protocol authors; provide physical mailing address of corresponding author	Title Page (pg. 1)
Contributions	3b	Describe contributions of protocol authors and identify the guarantor of the review	Authors' contributions (pg. 15)
Amendments	4	If the protocol represents an amendment of a previously completed or published protocol, identify as such and list changes; otherwise, state plan for documenting important protocol amendments	NA
Support:			
Sources	5a	Indicate sources of financial or other support for the review	Funding (pg. 15)
Sponsor	5b	Provide name for the review funder and/or sponsor	Funding (pg. 15)
Role of sponsor or funder	5c	Describe roles of funder(s), sponsor(s), and/or institution(s), if any, in developing the protocol	Funding (pg. 15)
INTRODUCTION			
Rationale	6	Describe the rationale for the review in the context of what is already known	Introduction (pg. 4-8)
Objectives	7	Provide an explicit statement of the question(s) the review will address with reference to participants, interventions, comparators, and outcomes (PICO)	Introduction (pg. 7-8)
METHODS			
Eligibility criteria	8	Specify the study characteristics (such as PICO, study design, setting, time frame) and report characteristics (such as years considered, language, publication status) to be used as criteria for eligibility for the review	Review design (pg. 8) Inclusion and exclusion criteria (pg.9)
Information sources	9	Describe all intended information sources (such as electronic databases, contact with study authors, trial registers or other grey literature sources) with planned dates of coverage	Search strategy (pg. 8) Contacting authors for additional details (pg. 12)

Search strategy	10	Present draft of search strategy to be used for at least one electronic database, including planned limits, such that it could be repeated	Search strategy (pg. 8)
Study records:			
Data management	11a	Describe the mechanism(s) that will be used to manage records and data throughout the review	Data management (pg. 7)
Selection process	11b	State the process that will be used for selecting studies (such as two independent reviewers) through each phase of the review (that is, screening, eligibility and inclusion in meta-analysis)	Data extraction (pg. 11)
Data collection process	11c	Describe planned method of extracting data from reports (such as piloting forms, done independently, in duplicate), any processes for obtaining and confirming data from investigators	Data extraction (pg. 11)
Data items	12	List and define all variables for which data will be sought (such as PICO items, funding sources), any pre-planned data assumptions and simplifications	Data extraction (pg. 11) No pre-planned assumptions or simplifications
Outcomes and prioritization	13	List and define all outcomes for which data will be sought, including prioritization of main and additional outcomes, with rationale	Analyses (pg. 12-13)
Risk of bias in individual studies	14	Describe anticipated methods for assessing risk of bias of individual studies, including whether this will be done at the outcome or study level, or both; state how this information will be used in data synthesis	Quality appraisal (pg. 10-11)
Data synthesis	15a	Describe criteria under which study data will be quantitatively synthesised	Analyses (pg. 12-13)
	15b	If data are appropriate for quantitative synthesis, describe planned summary measures, methods of handling data and methods of combining data from studies, including any planned exploration of consistency (such as I^2, Kendall's τ)	Analyses (pg. 12 – 13)
	15c	Describe any proposed additional analyses (such as sensitivity or subgroup analyses, meta-regression)	Analyses (pg. 12-13)
	15d	If quantitative synthesis is not appropriate, describe the type of summary planned	Analyses (pg. 12-13)
Meta-bias(es)	16	Specify any planned assessment of meta-bias(es) (such as publication bias across studies, selective reporting within studies)	Quality appraisal (pg. 10-11)
Confidence in cumulative evidence	17	Describe how the strength of the body of evidence will be assessed (such as GRADE)	Quality appraisal (pg. 10-11)

*** It is strongly recommended that this checklist be read in conjunction with the PRISMA-P Explanation and Elaboration (cite when available) for important clarification on the items. Amendments to a review protocol should be tracked and dated. The copyright for PRISMA-P (including checklist) is held by the PRISMA-P Group and is distributed under a Creative Commons Attribution Licence 4.0.**

From: Shamseer L, Moher D, Clarke M, Ghersi D, Liberati A, Petticrew M, Shekelle P, Stewart L, PRISMA-P Group. Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015: elaboration and explanation. BMJ. 2015 Jan 2;349(jan02 1):g7647.

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Psychometric properties and use of the DEMQOL suite of instruments in research: a systematic review protocol

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Primary Subject Heading:	Nursing
Secondary Subject Heading:	Geriatric medicine
Keywords:	Dementia < NEUROLOGY, Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, GERIATRIC MEDICINE

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Psychometric properties and use of the DEMQOL suite of instruments in research: a systematic review protocol

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Word count: 2,327

ABSTRACT

Introduction

Dementia is a public health issue and a major risk factor for poor quality of life among older adults. In the absence of a cure, enhancing Health-related Quality of life (HRQoL) of people with dementia is the primary goal of care. Robust measurement of HRQoL is a prerequisite to effective improvement. The DEMQOL suite of instruments is considered among the best available to measure HRQoL in people with dementia; however, no review has systematically and comprehensively examined the use of the DEMQOL in research and summarized evidence to determine its feasibility, acceptability and appropriateness for use in research and practice.

Methods and analysis

We will systematically search twelve electronic databases and reference lists of all included studies. We will include systematically conducted reviews, as well as, quantitative and qualitative research studies that report on the development, validation or use in research studies of any of the DEMQOL instruments. Two reviewers will independently screen all studies for eligibility, and assess the quality of each included study using one of four validated checklists appropriate for different study designs. Discrepancies at all stages of the review will be resolved by consensus. We will use descriptive statistics (frequencies, proportions, ranges), content analysis of narrative data, and vote counting (for the measures of association) to summarize the data elements. Using narrative synthesis, we will summarize what is known about the development, validation, feasibility, acceptability, appropriateness and use of the DEMQOL. Our review methods will follow the reporting and conduct guidelines of the Cochrane Handbook for Systematic Reviews of Interventions and the Preferred Reporting Items for Systematic Reviews and Meta-Analysis.

Ethics and dissemination

Ethical approval is not required as this project does not involve primary data collection. We will disseminate our findings through peer-reviewed publications and conference presentations.

Registration

PROSPERO: CRD42020157851; April 28, 2020;

https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42020157851

STRENGTHS AND LIMITATIONS

- In contrast to systematic reviews synthesizing evidence on multiple HRQoL instruments, our review will investigate in detail the evidence available on one specific instrument to measure dementia-related health-related quality of life (HRQoL) – the DEMQOL suite of instruments – allowing for a sufficiently detailed analysis of all relevant aspects of the selected instrument.
- We will identify, evaluate and synthesize evidence on the psychometric properties of the DEMQOL suite of instruments, its feasibility, acceptability, appropriateness and on how it was used in research studies – which is a prerequisite to determine its strengths and weaknesses for use in research and care practice, and to identify important research gaps.
- We will apply best practices in conducting systematic reviews, guided by the Cochrane Handbook of Systematic Reviews and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.
- We expect that we will not be able to conduct meta-analyses since we likely will not be able to identify a minimum of 3 studies investigating the same outcome using comparable methods.

INTRODUCTION

Health-related Quality of life (HRQoL) is a key outcome in dementia care and research.[1-3] With no dementia cure or disease-modifying treatment available, maximizing HRQoL of people with dementia is the overarching goal of care.[4-6] Dementia is an umbrella term for a set of progressive, degenerative brain disorders that successively diminish a person's cognitive and functional abilities. Dementia is associated with troubling neuro-psychiatric symptoms, and is, ultimately, fatal.[7 8] Currently, 50 million people worldwide are living with dementia[9] – 500,000 in Canada,[10] 5.7 million in the US[11] and 9.6 million in the EU.[12] Numbers are expected to more than triple by 2050.[9] People with dementia experience decline in physical function and mental health, often associated with poor HRQoL.[7 13]

Although often used interchangeably, QoL and HRQoL are related but distinct concepts.[14] QoL has been conceptualized as a person's *overall general well-being*, including physical, material, social, and emotional components, rated based on the person's subjective perception (self-report) but may also include objective indicators (e.g. observation of someone's behaviour or affect).[14] QoL is influenced by factors that interact in complex ways: physical health, psychological state, personal beliefs, social relationships and environmental features.[1] Often terms like "well-being", "life satisfaction" or "comfort" are either used to define QoL, treated as synonymous to QoL or considered similar but distinct concepts.[15] Authors disagree on whether QoL should be rated purely based on a person's individual perception (self-report) or if it also should include objective indicators (e.g. observation of someone's behaviour or affect).[14] Therefore, it is critical that authors clearly report the definition underlying their research. Our understanding of QoL is based on the World Health Organization's definition of QoL as "*an*

individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns."[16(p. 1405)]

Building on the concept of QoL but narrowing the focus, HRQoL in contrast is defined as an individual's perception of the impact a *health condition* has on that individual's life.[17] This is the definition that the DEMQOL suite of instruments[18] is based on – a set of questionnaires to measure HRQoL in people with dementia. The DEMQOL suite of instruments will be the focus of this review. HRQoL and common dementia symptoms (cognitive and physical impairment and neuro-psychiatric symptoms) are related, but they are not the same.[19] People with dementia can have good HRQoL despite severe cognitive and physical impairment, and people with mild dementia symptoms can have poor HRQoL.[19] Therefore, measuring a person's perceptions of how symptoms affect their life (HRQoL), rather than just dementia symptom severity, can provide more specific information about how to best promote well-being in ways that are most meaningful to the person with dementia.

Systematic reviews are available on a) tools to assess HRQoL in people with dementia in general[2 20] or b) in care homes,[3 21] c) generic QoL tools for use in care homes,[22] and d) QoL and HRQoL tools that have been used in clinical trials for interventions targeting people living with dementia or cognitive impairment.[23] These reviews have identified 34 tools to assess QoL or HRQoL in people with dementia (table 1). Another popular tool not captured in any of these reviews is the interRAI QoL module.[24] Evidence for reliability and validity for many of these instruments is poor and, in general, there is high heterogeneity in terms of the tools' theoretical foundations, domains measured, and how they apply to different levels of dementia severity.[2 20 21] It is unclear which of these instruments is most feasible, acceptable or appropriate for use in research and practice.[2]In line with best practice standards for evaluating the psychometric

properties of research tools,[25] we define reliability as statistical measures that indicate how closely two equivalent forms of a tool correlate. Validity, according to these standards, is "the degree to which evidence and theory support the interpretations of test scores for proposed uses of tests".[25(p. 11)] Feasibility, acceptability and appropriateness are implementation outcomes – i.e. outcomes that reflect tool users' experiences with using the tool and their perception of whether the tool can and should be used in the future.[26] We provide detailed definitions and operationalizations of each of these terms in the methods section (inclusion/exclusion criteria).

Table 1: Overview of tools available to assess QoL or HRQoL in people with dementia

Acronym	Full name
--	Activity and Affect rating scales
ACSA	Anamnestic Comparative Self-Assessment Scale
ADRQL	Alzheimer Disease Related Quality of Life
BASQID	Bath Assessment of Subjective Quality of Life in Dementia
--	Byrne–MacLean QoL Index
CBS	Cornell-Brown Scale
CDQLP	Community Dementia Quality of Life Profile
COOP/WONCA	Cooperative Functional Health Assessment Charts/World Organization of National Colleges, Academies and Academic Associations of General Practitioners/Family Physicians
DCM	Dementia Care Mapping
DEMQOL	--
DQoL	Dementia Quality of life
EQ-5D/EQ-15D	--
H.I.L.DE.	Heidelberg Instrument to assess Quality of Life in people with dementia
HUI3	Health Utilities Index Mark 3
MCQ	Mild Cognitive Impairment Questionnaire
OQOLD(A)	Observing Quality of Life in Dementia (also a version for advanced (A) dementia available)
PDS	Progressive Deterioration Scale
PES-AD	Pleasant Events Schedule
PGC-ARS	Philadelphia Geriatric Center Affect Rating Scale
PGCMS	Philadelphia Geriatric Centre Moral Scale
--	Psychosocial Quality of Life Domains Measure
PWB-CIP	Psychological Well-Being in Cognitively Impaired Persons
QLA-P	Quality of Life Assessment – Patient
QOL-AD	Quality of Life in Alzheimer's Disease
QOL-D	Quality of Life in Dementia
QOLAS	Quality of Life Assessment Schedule
--	Quality of Life Face Scale
QOLS	Quality of Life Scales
QUALID	Quality of Life in Late-stage Dementia
QUALIDEM	Quality of life instrument for proxy completion
RSOC-QoL	Resident and Staff Observation Checklist-Quality of Life
SF-12/SF-36	--

-- Vienna List

Previous reviews have attempted to give an overview of measurement properties and usability across and between QoL tools. However, none sufficiently analyze all relevant aspects to understand a) a certain tool's conceptual characteristics, b) whether that tool is psychometrically sound, feasible, acceptable and appropriate for use in research and practice, and c) how that tool has been used in research as of now. Therefore, we believe that systematic reviews examining one selected QoL tool in detail are needed.

In this review, we chose to focus on the DEMQOL suite of instruments[18] for the following reasons. First, the DEMQOL suite is specifically designed to measure HRQoL among people with dementia. Generic QoL tools (e.g. EQ5D[27], SF-12[28], interRAI QoL module[24]) often work poorly to capture the perspective of people with dementia.[18] Second, among the available instruments to measure HRQoL in people with dementia, the DEMQOL suite is considered one of the best given its relatively strong theoretical foundations and psychometric properties (table 2).[2] The DEMQOL and DEMQOL-Proxy were developed based on robust theory and a rigorous process of tool development that included a) a review of available conceptualizations of QoL and HRQoL, b) a review of available measures of HRQoL in dementia, c) qualitative interviews with people with dementia and their families, and d) the development of a conceptual framework for dementia-related HRQoL.[18 29] Therefore content validity is acceptable. In their review, Bowling et al.[2] report evidence for acceptability and feasibility of the DEMQOL and DEMQOL-Proxy. Evidence is also available on convergent and discriminant validity.[2] Evidence on the tools' factor structure, responsiveness and respondent burden is limited.[2] No evidence is available on known group differences and on psychometric properties of cultural and language adaptations of these tools.[2] The DEMQOL-CH is based on the DEMQOL-Proxy with similar findings related to its reliability and validity.[30] Third, the DEMQOL and its variations (proxy versions, preference-

based indices for use in economic evaluation, and translations into various languages; Table 2)[31] are among the most popular instruments to measure HRQoL in research with people with dementia. As of May 23, 2020, the developers had documented 89 studies that used the DEMQOL suite of instruments.[32] Fourth, with the DEMQOL-CH,[30] a version is now available that can be completed by staff caring for residents with dementia living in congregate care settings such as nursing homes or assisted/supportive living. This is important because the majority of these residents have dementia that is severe enough to limit their ability to self-report,[33-38] and often residents do not have a family/friend carer who visits and who could provide a proxy assessment.[39] A tool that can be completed by care staff in a way that is reliable, valid, feasible, acceptable and appropriate opens the possibility of routine HRQoL assessment – an important prerequisite for improving residents' HRQoL.

Table 2: Overview of DEMQOL versions and their characteristics

	DEMQOL	**DEMQOL-Proxy**	**DEMQOL-U**	**DEMQOL-Proxy-U**	**DEMQOL-CH**
Year of publication	2005	2005	2013	2013	2019
Target group	Persons with mild to moderate dementia (MMSE ≥ 10)	Persons with all stages of dementia (up to severe)	Same as DEMQOL	Same as DEMQOL-Proxy	Persons with all stages of dementia (up to severe)
Mode of administration	Interview of person with dementia	Interview of proxy of person with dementia	NA (DEMQOL scores are used and turned into preference-based [utility] values)	NA (DEMQOL-Proxy scores are used and turned into preference-based [utility] values)	Completed by care staff proxy of person with dementia
Number of items	28	31	5 (selected 1 item out of each identified domain)	4 (selected 1 item out of each identified domain, other than daily activities)	31
Domains (factors) based on factor analyses	Daily activities Memory Negative emotion Positive emotion	Functioning Emotion	Cognition Negative emotion Positive emotion	Cognition Negative emotion Daily activities Positive emotion	Functioning Positive emotions Negative emotions Engagement

			Social relationships Loneliness	Appearance	
Scoring	Items are scored on a 4-point Likert scale ranging from 1–4; Positive items are scored reversely so lower scores always indicate worse HRQoL; item scores are summed (possible range 28–112)	Items are scored on a 4-point Likert scale ranging from 1–4; Positive items are scored reversely so lower scores always indicate worse HRQoL; item scores are summed (possible range 31–124)	Based on a health state classification system and population-based preference values, a score between 0 (death) and 1 (full health) is generated	Based on a health state classification system and population-based preference values, a score between 0 (death) and 1 (full health) is generated	Items are scored on a 4-point Likert scale ranging from 1–4; Positive items are scored reversely so lower scores always indicate worse HRQoL; item scores are summed (possible range 31–124)
Reliability					
Internal consistency	α=0.87	α=0.87-0.92	NA	NA	α=0.90
Test re-test	ICC=0.76	ICC=0.67-0.84	NA	NA	ICC=0.72
Utility scores	NA	NA	0.243-0.986	0.363-0.937	NA
Validity	Correlations with QOLAD scores (r=0.54) and DQOL items (r=0.29-0.45)	Correlations with QOLAD-caregiver scores (r=0.52)			Correlations with DCM scores (r=0.34-0.67)

DCM: Dementia Care mapping; DQoL: Dementia Quality of life; ICC: Intra Class Correlation; MMSE: Mini Mental State Examination; QOL-AD: Quality of Life in Alzheimer's Disease

No dementia-specific QoL or HRQoL tool has been rigorously and comprehensively assessed for reliability, validity, feasibility, acceptability, appropriateness and use in research, using a comprehensive review of the literature. Therefore, focusing on the DEMQOL suite of instruments, in this review we will answer the following research questions:

1. How has the DEMQOL system been used in research?
    a. What research questions did studies using the DEMQOL system investigate?
    b. Which study settings and populations did studies using the DEMQOL system focus on?
    c. What is the quality of the research using the DEMQOL system?
2. How has the DEMQOL system been evaluated?

a. What evidence is available on the development of the DEMQOL system?
b. What are the psychometric properties of the DEMQOL system?
c. What is the evidence on the DEMQOL system's feasibility, acceptability and appropriateness?

METHODS AND ANALYSIS

Review design

We will conduct a systematic mixed-methods synthesis of research.[40] Our review methods and presentation of results will follow the *Cochrane Handbook of Systematic Reviews of Interventions*[41] and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.[42] This paper follows the PRISMA-P reporting guidelines for systematic review protocols.[43] We started the review in Jan 2019. Currently we are finalizing the screening of full texts. The review is scheduled to be completed by March 2021.

Patient and public involvement

This systematic review is part of a larger research program on routinely measuring and improving the HRQoL in people with dementia living in congregate settings. On October 09, 2019, our research team convened a policy-level forum on QoL in the Canadian province of Alberta,[44] including health systems level and health ministry level key decision makers, representatives from care organizations, people with dementia and their family/friend caregivers. The purpose of the forum was to develop a framework for improving QoL for persons with moderate to severe dementia living in congregate care settings. Perspectives of people with dementia and their family/friend caregivers were central throughout all discussions. Two key outcomes of this forum included a) a mandate to conduct this systematic review in order to further explore suitability of the DEMQOL suite of instruments for routine use in congregate

care settings, and b) formation of a QoL workgroup to further advance the QoL work started by our team. This workgroup includes representatives of all stakeholder groups involved in the QoL forum and oversees the various activities of our team, including this systematic review. We will feed back results of this review to the QoL workgroup and to the larger team on an ongoing basis, and this review will inform further research projects and activities to improve QoL of people with dementia living in congregate care settings.

Search strategy

Supported by a scientific librarian, we will search the databases MEDLINE, EMBASE, PsycInfo, Journals@ovid, CINAHL, Abstracts in Social Gerontology, Academic Search Complete, Cochrane Library, Scopus, Web of Science, ProQuest Dissertations & Theses Global Google Scholar and Science Direct. We will search the terms DEMQOL or DEM-QOL or Dementia Quality of Life scale in the database default fields including title, abstract, MeSH/subject heading and author-supplied keyword fields, as well as, in the full-text of records (Appendix 1). We will not limit our search based on language and year of publication, and we will search the time frame covered by the data bases. We will search reference lists of all included studies for additional references.

Data management

We will manage references using Rayyan[45] – a free reference management software designed for literature reviews that facilitates online collaboration and blinding of reviewers during screening activities. All references including abstracts will be uploaded to Rayyan and title/abstract and full-text screening will be done using this software. All team members will receive training on the application of Rayyan prior to the screening, and we will conduct regular meetings and calibration exercises to improve application of the inclusion and exclusion criteria.

Inclusion and exclusion criteria

Our primary inclusion criterion (Table 3) is whether the study either (a) reports on the development, validation or assessment of feasibility, acceptability or appropriateness of any of the DEMQOL versions available or (b) used any of the DEMQOL versions to assess study outcomes. Original studies of any design or systematically conducted reviews are eligible. If the search specified above identifies non-peer reviewed references (gray literature) we will include these references if they meet our inclusion criteria. We will include studies regardless of the country of origin, publication language, study setting or population. Languages spoken among members of our study team include: Chinese, English, French, German, Nepalese, and Urdu. Our networks include colleagues who speak Danish, Dutch, Farsi, Italian, Norwegian, Portuguese, Spanish, and Swedish, who will help us to assess eligibility of studies in these languages. Should we encounter studies with no English abstract in languages other than those listed, we will further leverage our networks to find a colleague who speaks this language. We have successfully applied this approach in previous literature reviews.[46 47] Studies that assessed HRQoL as a study outcome, using either of the DEMQOL instruments will be included regardless of the research question(s) and regardless of whether HRQoL was the main study outcome (dependent variable), an independent variable (predictor) or a covariate to adjust models.

Table 3: Inclusion and exclusion criteria

	Inclusion criteria	Exclusion criteria
Study focus	• Studies reporting on the development, validation or user rating (feasibility, acceptability, appropriateness) of any version of the DEMQOL. DEMQOL versions include: - DEMQOL - DEMQOL-Proxy - DEMQOL-U - DEMQOL-Proxy-U - DEMQOL-CH	• Studies only mentioning a DEMQOL version without having used the tool to assess study outcomes • Studies using the C-DEMQOL which is a tool to assess the QoL of caregivers of people with dementia, not a dementia-specific HRQoL tool. • Studies using QoL assessment tools other than any of the DEMQOL versions

	• Studies using any of the DEMQOL versions to assess study outcomes – regardless of whether HRQoL was the main study outcome (dependent variable) or whether HRQoL was used as an independent variable or a covariate to adjust statistical models	
Study design	• Primary empirical quantitative research and research protocols, regardless of the research design: - Randomised trials - Non-randomised trials - On-group pre-post studies - Cohort studies - Case control studies - Cross-sectional studies • Qualitative studies: - Qualitative interviews - Focus groups - Ethnographic observations - Qualitative case studies • Mixed methods studies • Systematically conducted reviews: - Meta-analyses - Systematic reviews - Realist reviews - Integrative reviews - Scoping reviews - Narrative reviews if they report the search strategy, data bases searched, inclusion/exclusion criteria of references, screening process and analysis/synthesis methods	• Non-empirical work (editorials, opinion texts, theoretical discussions) • Non-systematic (selective) reviews. We will, however, screen reference lists of those reviews for eligible studies
Study outcomes	**DEMQOL development** • Studies reporting on the theoretical foundations, methods and processes used to develop any of the DEMQOL versions **DEMQOL reliability** • Test re-test reliability: agreement (κ statistics, correlation coefficients, intra-class correlation coefficients) of DEMQOL scores obtained by the same person using the same DEMQOL version repeatedly to assess HRQoL of the same client[25] • Inter-rater reliability: agreement (κ statistics, correlation coefficients, intra-class correlation coefficients) of DEMQOL scores obtained by two independent raters, using the same DEMQOL version at the same time to assess HRQoL of the same client[25] • Internal consistency reliability: agreement among DEMQOL items thought to form a scale (Cronbach's α)[25] • Multiple method reliability: agreement among DEMQOL scores obtained using different modes of administration (e.g. correlations of	• Studies reporting none of the outcomes listed as inclusion criteria

	self-report and proxy assessments or paper-based versus electronic)[25] **DEMQOL validity** • Content validity: experts' quantitative or qualitative ratings of whether DEMQOL items are relevant and adequately reflect the construct of interest (dementia-specific HRQoL)[25] • Response process validity: qualitative rating based on cognitive interviews of whether DEMQOL users (persons with dementia, their proxies, data collectors) understand the DEMQOL stems, items and rating scales as intended; response and missing item patterns are quantitative proxy outcomes of participants' response processes • Structural validity: evidence on whether items reflect an overall scale or subscales, based on based on confirmatory or exploratory factor analyses (factor loadings, model fit parameters)[25] • Item functioning: evidence on item difficulty and discrimination, based on item response theory models[25] • Construct validity: evidence on whether outcomes known to be associated with HRQoL are associated as hypothesized with DEMQOL items (correlation coefficients, regression parameters, results of structural equation models)[25] **DEMQOL feasibility** • Quantitative or qualitative user ratings of whether either of the DEMQOL versions can be successfully used within an organization or setting given existing resources (e.g. effort, time to complete, costs of administration)[26] **DEMQOL acceptability** • Quantitative or qualitative user ratings of whether any of the DEMQOL versions and their use are agreeable, palatable, or satisfactory[26] **DEMQOL appropriateness** • Quantitative or qualitative user ratings of whether any of the DEMQOL versions can effectively help achieve a common purpose giving existing conditions and whether that tool is consistent with users' norms and values[26] **DEMQOL use** • We will include any study that assessed outcomes other than those specified above (regardless of the outcomes) if any of the DEMQOL versions was used to assess	

	HRQoL in that study, and HRQoL was included as one of the study outcomes.	

Study screening

After removal of duplicates, team member pairs will independently screen titles and abstracts of retrieved references. Discrepancies will be discussed in the group and resolved by consensus. Full texts will be retrieved for included references and for references with insufficient information in the title/abstract to decide upon inclusion. Full text screening will follow the same method as title/abstract screening.

Quality appraisal

To assess the risk of bias of each included study assessing the reliability or validity of one of the DEMQOL tools, we will use the validated COSMIN risk of bias checklist for systematic reviews of Patient-Reported Outcome Measures.[48] To assess the risk of bias of each other included study, we will use one of four validated checklists, as appropriate for the respective study design:

- Systematically conducted reviews: Assessment of Multiple Systematic Reviews (AMSTAR) tool.[49-52]
- Clinical studies with or without a control group and with or without randomized allocation of participants: Quality Assessment Tool for Quantitative Studies (QATQS).[53 54]
- Cross-Sectional studies: Estabrooks' Quality Assessment and Validity Tool for Cross-Sectional Studies, which is based on established criteria for assessing quality of research studies.[55 56]
- Qualitative studies: Critical Appraisal Skills Program (CASP) Qualitative Research Checklist.[57]

Studies will be assessed independently by two team members and discrepancies resolved by consensus. We will score overall quality of each study, using a method we have previously used

in various systematic reviews.[58-62] As per the developer of this method,[63] we will calculate the ratio of the obtained score to the maximum possible score for each study (possible range: 0-1). The maximum possible score varies depending on the checklist used and the number of checklist items applicable. We will rank studies as weak (≤ 0.50), low moderate (0.51-0.66), high moderate (0.67-0.79), or strong (≥ 0.80). We will also summarise and describe the key areas of weakness for all studies within each type of research design.

Data extraction

Our study team collaboratively adapted and pretested data extraction templates (Appendix 2), successfully used in previous systematic reviews.[46 47] One team member will extract study details into the template, and a second team member will double check the extracted information and discrepancies will be resolved by consensus. We will extract:

- First author;
- Year of publication
- Title
- Journal name (or type of reference such as thesis, report, textbook)
- Country of study
- Study aim(s), goal(s), purpose(s) or question(s) and which of our review questions these refer to (i.e. development of the DEMQOL; assessments of its reliability and/or validity; assessments of its feasibility, acceptability, appropriateness; use of the DEMQOL as dependent study outcome or as covariate
- Study design
- Study setting and sample
- DEMQOL version(s) used

- Dependent study variables and how they were measured (if applicable)
- Independent study variables and how they were measured (if applicable)
- Main results as they relate to the development of either of the DEMQOL versions; DEMQOL reliability, validity; DEMQOL feasibility, acceptability, appropriateness; DEMQOL use (operationalized as per table 3)

Contacting authors for additional details

If a study does not report enough details, we will contact the study authors by email and invite them to clarify or add information to inform inclusion or exclusion of this study, risk for bias assessments and/or data extractions. In the case of non-response, we will send out reminders after 7, 10, and 13 days.

Analyses

To address research question 1, we will first conduct a thematic analysis[64] of narrative data (e.g. types of research questions asked) from the studies that used the DEMQOL to assess research outcomes, converting narrative to categorical data. Using figures and tables, we will descriptively present the number and proportion of studies that represent each category – e.g. DEMQOL version used, types of research questions asked, participant groups included, country of origin, study setting, study design, risk for bias category, etc.

To address research question 2, we will use descriptive statistics and narrative synthesis to summarize the proportion of studies that have assessed each of the elements outlined in table 3 (development, reliability, validity, feasibility, acceptability, appropriateness of any of the DEMQOL versions), and the range of results reported by these studies. We will operationalize these results as per table 3 and report them by DEMQOL version used.

For qualitative results we will conduct a content analysis of the key themes and supporting data related to the respective outcome and whether the content of these themes varied across studies. For quantitative results we will report the range of scores, and the number and proportion of studies reporting statistically significant positive associations, statistically negative associations and statistically non-significant associations for a certain study outcome (vote counting). We will not attempt to synthesize study findings statistically (meta-analyses) since our research questions are descriptive, overall effect sizes across studies are not part of our two research questions, and study variables and populations are likely to be heterogenous enough that meta-analysis would not be appropriate.

ETHICS AND DISSEMINATION

Ethics approval will not be needed for this study as we will not collect primary data from individuals or organizations. Data of studies included in this systematic review cannot be linked to individuals or organizations. We intend to publish findings of the review in a peer-reviewed journal (will be made available on the DEMQOL website), and present findings at an international peer-reviewed conference. We will prepare a lay summary of the findings for knowledge users on what is known about the DEMQOL suite of instruments, and recommendations for use in practice. Results of this review will synthesize information on how DEMQOL has been used and how its psychometric properties have been described or evaluated in various studies, which will enable researchers who want to use DEMQOL tool in future to evaluate its psychometric properties.

AUTHORS' CONTRIBUTIONS

MH, CAE, SAC, HMO, SB, and LH developed the research question, the systematic review design, and planned and designed the study protocol. MH is leading the systematic review project. MH in collaboration with a scientific librarian developed and tested the search strategy. Guided by MH and SAC, BE, SS, RD, TT, and JL tested and refined the search strategy and adapted the screening and data extraction templates. All authors critically read and commented on the manuscript and approved its submission.

COMPETING INTERESTS

None declared.

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Appendix 1: Search Strategy

1. Ovid MEDLINE, EMBASE and PsycInfo

The following terms will be searched in the database default fields including title, abstract, MeSH/subject heading and author-supplied keyword fields:

demqol OR dem-qol* OR dementia quality of life scale*

2. Journals@Ovid

The following terms will be searched in the full-text of records:

demqol OR dem-qol* OR dementia quality of life scale*

3. EBSCO CINAHL/Academic Search Complete/Abs in Soc Gerontology

TX(demqol OR "dem-qol*" OR "dementia quality of life scale")*
(TX searches all database fields and full-text when full-text is available within the database)

4. ProQuest Dissertations & Theses Global

Following terms will be searched in the full-text of records:

(demqol OR dem-qol* OR "dementia quality of life scale")*
AND
(dementia OR alzheimer)*

5. HAPI (Health & Psychosocial Instruments)

Following terms will be searched in the database default fields. Results will be browsed and any items not retrieved from other databases will be selected.

demqol OR dem-qol* OR dementia quality of life scale*

6. Wiley Online Library

The following terms will be searched in the full-text of records. Results will be browsed and any items not retrieved from database searching will be selected:

demqol OR dem-qol* OR "dementia quality of life scale"*

7. ScienceDirect

The following terms will be searched in the full-text of records:

demqol OR dem-qol OR "dementia quality of life scale"

8. Google Scholar

The following terms will be searched in the full-text of records. The first 10 pages of results and any items not retrieved from database searching will be selected

demqol OR dem-qol OR "dementia quality of life scale"

Appendix 2: Data extraction templates

DEMQOL Data Extraction Form - Psychometric Studies

*Required

Study Characteristics

1. Initial of person entering data (including middle names, if applicable) *
   Examples are: Matthias Hoben = MH: Stephanie A Chamberlain = SAC

2. First Author *
   Enter as: last name, first name

3. Country of Origin

4. Language

5. Year of Publication *

6. Journal

For references not published in a journal enter whether the references is a text book, report, thesis, etc.

7. Title of Study *

Copy-paste from paper so both reviewers enter the exact same information

8. Study Purpose(s) *

Extract the author's stated primary and secondary purposes. This may be in the form of a purpose statement, research question(s), or primary and secondary objectives, and is typically found in the introduction or at the beginning of the methods section. Only state what's specifically related to the objective, don't need to report methods or sampling.

Study design

9. Select the design applicable *

Mark only one oval.

- RCT
- Controlled Trial
- Pre-Post
- Cohort
- Case-control
- Cross-sectional
- Qualitative
- Mixed
- Others

10. If Mixed design, provide description

Mark only one oval.

- Exploratory sequential design - study begins with qualitative data collection methods (interviews, observations), followed by some quantitative methods
- Explanatory sequential design - study begins with quantitative methods followed by qualitative methods
- Concurrent- both quantitative and qualitative methods are conducted in parallel

11. If others, provide description

12. Method of data collection - Quantitative *

Tick all that apply.

- [ ] Participant-completed survey/questionnaire
- [ ] Researcher-completed survey/questionnaire with participant (structured participant interview)
- [ ] Researcher-completed survey/questionnaire with proxy (structured proxy interview)
- [ ] Structured observational
- [ ] Structured chart review
- [ ] N/A
- [ ] Other: _____

13. Method of data collection - Qualitative *

Tick all that apply.

- [ ] Semi-structured interview
- [ ] Focus group
- [ ] Chart review
- [ ] Ethnographic observation
- [ ] N/A
- [ ] Other: _____

Sample

State the sample size, and separately for each arm of the study (e.g., control, treatment1, treatment2), if applicable

14. Sample size *

How many people were asked to participate.

15. Sample size

How many people actually participated and provided data.

16. Age (Age range, Mean age) *

Extract the average (mean or median) age, or the percentage of participants in different age categories identified in the article.

17. Gender/Sex *

Extract the percentage of the sample that was female/women and/or male/men

Settings (Check all that apply)

Refers to the settings from which the participants were recruited from. Terminology may vary across studies (for example, some studies may refer to study sites or facilities).

18. Site (check all that apply) *

Tick all that apply.

- [ ] Long-term care/Nursing homes
- [ ] Day program
- [ ] Private home
- [ ] Senior's apartment
- [ ] Supportive or assisted living
- [ ] Home care
- [ ] Hospital
- [ ] Unspecified community setting

Other: [ ] _____

19. Number of Sites *

Were the number of sites specified?

Mark only one oval.

- ◯ Yes
- ◯ No

20. Number of Sites *

For those who agreed to participate in the study.

_____

21. Number of Sites *

For those who were included in the data analysis.

_____

Cognitive Impairment

This involves: name of the tool used to measure cognitive health status, level of cognitive health status

22. Tool used for assessing cognitive status (state name or not specified) *

Please keep responses succinct, abbreviations are acceptable. For example: MMSE, MoCA.

23. Operationalized definitions of each stage in the study *

Labelled as mild, moderate or severe (Usually reported in terms of range of scores that are used to categorize participants into each stage. For example: Mild 19–24; Moderate 10–18; Severe 0–9 (Do not provide a narrative response. Keep your response as succinct as possible).

24. Percentage of participants described as having mild, moderate or severe cognitive impairment *

25. Scores of overall cognitive impairment and/or of the cognitive impairment stages (mild, moderate, severe) reported in the study *

Report whatever the authors report, e.g., means and standard deviations, median and inter-quartile range, numbers, etc.

DEMQOL Version Used

26. DEMQOL Instruments Version(s) used *

Tick all that apply.

- [ ] DEMQOL
- [ ] DEMQOL-Proxy
- [ ] DEMQOL-CH
- [ ] DEMQOL-U
- [ ] DEMQOL Proxy- U
- [ ] C-DEMQOL

27. DEMQOL Language *

Study Outcomes

28. Additional Study Variables Assessed Other Than The DEMQOL *

Please list all measurement tools used by the research team and the outcomes assessed by these tools. No numerical values. For example: GDS- Depression

Psychometric properties of the instrument

How DEMQOL was used by the authors in the study. It may have been used in more than one way.

29. Reliability (Internal consistency) *

Assesses how tool items are inter-correlated (usually reporting Cronbach's alpha). Report reliability in the form of numerical value given for internal consistency. If not reported, please respond as 'not reported'.

30. Reliability (Test-retest) *

Assesses correlation of scores measured by the same person at different times (usually as Kappa, intra-cross correlation, or similar correlation coefficients). Report reliability in the form of numerical value given for test- retest. If not reported, please respond as 'not reported'.

31. Reliability (Inter-rater) *

Assesses correlation of scores measured by two or more independent raters at the same time (usually as Kappa, intra-cross correlation, or similar correlation coefficients). Report reliability in the form of numerical value given for inter-rater. If not reported, please respond as 'not reported'.

32. Reliability (Inter-method) *

Assesses correlation of scores obtained by different assessment methods (e.g observations vs self-report or self-report vs proxy). Usually as Kappa, intra-cross correlation, or similar correlation coefficients. Report reliability in the form of numerical value given for inter-method. If not reported, please respond as 'not reported'.

33. Validity (Content validity) *

Assessed by ratings given by content experts (usually researchers or clinicians). Ratings may either be qualitative, or quantitative using standardized scales to assess relevance and comprehensibility of each item based on content experts perceptions. Report numerical value given for content validity. If not reported, please respond as 'not reported'.

34. Validity (Response Process validity) *

Summarize the findings related to how well target persons understood the questionnaire. If not reported, please respond as 'not reported'.

35. Validity (Factorial or Internal Structure Validity) *

Report whether exploratory or confirmatory factor analyses were conducted, report the number of factors found and model fit indices (if reported). If not reported, please respond as 'not reported'.

36. Validity (Relationship with other variables) *

Statistical modelling is used to test pre-specified hypotheses. To be specific, models assess whether known predictors of QOL are associated with QOL as measured by the DEMQOL as expected. Or models assess whether QOL as measured by the DEMQOL are associated with known consequences of poor QOL such as reduced social engagement and depression. Report the numerical value(s) given for the relationship with other variables. If not reported, please respond as 'not reported'.

37. Feasibility or Acceptability *

Must be reported in the results section because it needs to be scientifically assessed. If not reported, please respond as 'not reported'.

DEMQOL Data Extraction Form - non-Psychometric Studies

*Required

Study Characteristics

1. Initial of person entering data (including middle names, if applicable) *
   Examples are: Matthias Hoben = MH: Stephanie A Chamberlain = SAC

2. First Author *
   Enter as: last name, first name

3. Country of Origin

4. Language

5. Year of Publication *

6. Journal

For references not published in a journal enter whether the references is a text book, report, thesis, etc.

7. Title of Study *

Copy-paste from paper so both reviewers enter the exact same information

8. Study Purpose(s) *

Extract the author's stated primary and secondary purposes. This may be in the form of a purpose statement, research question(s), or primary and secondary objectives, and is typically found in the introduction or at the beginning of the methods section. Only state what's specifically related to the objective, don't need to report methods or sampling.

Study design

9. Select the design applicable *

Mark only one oval.

- RCT *Skip to question 12*
- Controlled Trial *Skip to question 12*
- Pre-Post *Skip to question 12*
- Cohort *Skip to question 12*
- Case-control *Skip to question 12*
- Cross-sectional *Skip to question 12*
- Qualitative *Skip to question 12*
- Mixed *Skip to question 10*
- Others *Skip to question 11*

Specify mixed

10. If Mixed design, provide description *

Mark only one oval.

- Exploratory sequential design - study begins with qualitative data collection methods (interviews, observations), followed by some quantitative methods
- Explanatory sequential design - study begins with quantitative methods followed by qualitative methods
- Concurrent- both quantitative and qualitative methods are conducted in parallel

Skip to question 12

Specify other

11. If others, provide description *

Methods of data collection

12. Method of data collection - Quantitative *

Tick all that apply.

- [ ] Participant-completed survey/questionnaire
- [ ] Researcher-completed survey/questionnaire with participant (structured participant interview)
- [ ] Researcher-completed survey/questionnaire with proxy (structured proxy interview)
- [ ] Structured observational
- [ ] Structured chart review
- [ ] N/A
- [ ] Other: _____

13. Method of data collection - Qualitative *

Tick all that apply.

- [ ] Semi-structured interview
- [ ] Focus group
- [ ] Chart review
- [ ] Ethnographic observation
- [ ] N/A
- [ ] Other: _____

Settings

Refers to the settings from which the participants were recruited from. Terminology may vary across studies (for example, some studies may refer to study sites or facilities). Check all that apply.

14. Setting(s) *

Check all that apply

Tick all that apply.

- [ ] Long-term care/Nursing homes
- [ ] Day program
- [ ] Private home
- [ ] Senior's apartment
- [ ] Supportive or assisted living
- [ ] Home care
- [ ] Hospital
- [ ] Unspecified community setting

Other: [ ] _____

15. Number of sites approached *

For each setting specified above, enter the number of sites that were asked to participate. For example, if researchers approached 12 nursing homes and 11 assisted living facilities, enter: NHs: 12; AL: 11. If this number is not reported, enter: not reported. If the study included more than one study arm, give the site numbers separately for each arm of the study (e.g., control, treatment1, treatment2).

_____

16. Number of sites agreed to participate *

For each setting specified above, enter the number of sites that agreed to participate. For example, if 10 nursing homes and 8 assisted living facilities agreed to participate, enter: NHs: 10; AL: 8. If this number is not reported, enter: not reported. If the study included more than one study arm, give the site numbers separately for each arm of the study (e.g., control, treatment1, treatment2).

_____

17. Number of sites included in data analyses *

For each setting specified above, enter the number of sites that were included in the data analyses. For example, if 8 nursing homes and 7 assisted living facilities were included in the data analyses, enter: NHs: 8; AL: 7. If this number is not reported, enter: not reported. If the study included more than one study arm, give the site numbers separately for each arm of the study (e.g., control, treatment1, treatment2).

_____

Sample

Refers to the recruited individuals (e.g., patients, residents, family/friend caregivers, care aides, nurses, ...)

18. Number of persons approached *

For each participant group, enter the number of persons that were asked to participate. For example, if researchers approached 200 nursing home residents and 48 care aides, enter: NH residents: 200; care aides: 48. If this number is not reported, enter: not reported. If the study included more than one study arm, give the participant numbers separately for each arm of the study (e.g., control, treatment1, treatment2).

19. Number of persons agreed to participate *

For each participant group, enter the number of persons that agreed to participate. For example, if 150 nursing home residents and 24 care aides agreed to participate, enter: NH residents: 150; care aides: 24. If this number is not reported, enter: not reported. If the study included more than one study arm, give the participant numbers separately for each arm of the study (e.g., control, treatment1, treatment2).

20. Number of persons included in data analyses *

For each participant group, enter the number of persons that were included in the data analyses. For example, if 140 nursing home residents and 20 care aides were included in the analyses, enter: NH residents: 140; care aides: 20. If this number is not reported, enter: not reported. If the study included more than one study arm, give the participant numbers separately for each arm of the study (e.g., control, treatment1, treatment2).

21. Age

Extract the average (mean or median) age, or the percentage of participants in different age categories identified in the article. If the study inlcudes multiple participant groups, do this by participant group and if the study includes multiple study arms do this by study arm.

22. Sex

Extract the percentage of the sample that was female/women and/or male/men. If the study inlcudes multiple participant groups, do this by participant group and if the study includes multiple study arms do this by study arm.

Cognitive Impairment

This involves: name of the tool used to measure cognitive health status, level of cognitive health status

23. Tool used for assessing cognitive status (state name or not specified) *

Please keep responses succinct, abbreviations are acceptable. For example: MMSE, MoCA.

24. Operationalized definitions of each stage in the study *

Labelled as mild, moderate or severe (Usually reported in terms of range of scores that are used to categorize participants into each stage. For example: Mild 19–24; Moderate 10–18; Severe 0–9 (Do not provide a narrative response. Keep your response as succinct as possible).

25. Percentage of participants described as having mild, moderate or severe cognitive impairment *

26. Scores of overall cognitive impairment and/or of the cognitive impairment stages (mild, moderate, severe) reported in the study *

Report whatever the authors report, e.g., means and standard deviations, median and inter-quartile range, numbers, etc.

DEMQOL Version

27. DEMQOL Instruments Version(s) used *

Check all that apply

Tick all that apply.

- [ ] DEMQOL
- [ ] DEMQOL-Proxy
- [ ] DEMQOL-CH
- [ ] DEMQOL-U
- [ ] DEMQOL Proxy- U
- [ ] C-DEMQOL

28. DEMQOL Language

_____

Use of DEMQOL

29. How was the DEMQOL used in this study

Check all that apply

Tick all that apply.

☐ As a dependent variable - i.e. study assessing factors associated with QoL or how QoL differs between groups

☐ As an independent variable or study covariate - i.e. study assessed how QoL influences other study outcomes

Other Dependent Variables

Don't list the DEMQOL here. Only list dependent variables other than DEMQOL scores.

30. Dependent variables (other than DEMQOL) *

Please list all measurement tools used by the research team and the outcomes assessed by these tools. No numerical values. For example: Depression (GDS). If no dependent variables other than the DEMQOL were included, enter: NA.

_____

_____

_____

_____

_____

Other Study Variables

Don't list the DEMQOL here. Only list independent variables and model covariates other than DEMQOL scores.

31. Independent variables (other than DEMQOL) *

These are variables that are included in the analysis and statistical outcomes ARE reported (e.g. regression coefficients, correlations, etc.) Please list all measurement tools used by the research team and the outcomes assessed by these tools. No numerical values. For example: Depression (GDS). If no independent variables were included, enter: NA.

32. Modelling covariates (other than DEMQOL) *

These are variables that are included in the analysis and statistical outcomes are NOT reported. Please list all measurement tools used by the research team and the outcomes assessed by these tools. No numerical values. For example: Depression (GDS). If no model covariates were included, enter: NA.

Main Findings

33. Main findings of the study

Google Forms

PRISMA-P (Preferred Reporting Items for Systematic review and Meta-Analysis Protocols) 2015 checklist: recommended items to address in a systematic review protocol*

Section and topic	Item No	Checklist item	Location
ADMINISTRATIVE INFORMATION			
Title:			
Identification	1a	Identify the report as a protocol of a systematic review	Title Page (pg. 1)
Update	1b	If the protocol is for an update of a previous systematic review, identify as such	NA
Registration	2	If registered, provide the name of the registry (such as PROSPERO) and registration number	Registration (pg. 3)
Authors:			
Contact	3a	Provide name, institutional affiliation, e-mail address of all protocol authors; provide physical mailing address of corresponding author	Title Page (pg. 1)
Contributions	3b	Describe contributions of protocol authors and identify the guarantor of the review	Authors' contributions (pg. 19)
Amendments	4	If the protocol represents an amendment of a previously completed or published protocol, identify as such and list changes; otherwise, state plan for documenting important protocol amendments	NA
Support:			
Sources	5a	Indicate sources of financial or other support for the review	Funding (pg. 19)
Sponsor	5b	Provide name for the review funder and/or sponsor	Funding (pg. 19)
Role of sponsor or funder	5c	Describe roles of funder(s), sponsor(s), and/or institution(s), if any, in developing the protocol	Funding (pg. 19)
INTRODUCTION			
Rationale	6	Describe the rationale for the review in the context of what is already known	Introduction (pg. 4-9)
Objectives	7	Provide an explicit statement of the question(s) the review will address with reference to participants, interventions, comparators, and outcomes (PICO)	Introduction (pg. 9-10)
METHODS			
Eligibility criteria	8	Specify the study characteristics (such as PICO, study design, setting, time frame) and report characteristics (such as years considered, language, publication status) to be used as criteria for eligibility for the review	Review design (pg. 10) Inclusion and exclusion criteria (pg. 12-15)
Information sources	9	Describe all intended information sources (such as electronic databases, contact with study authors, trial registers or other grey literature sources) with planned dates of coverage	Search strategy (pg. 11) Contacting authors for additional details (pg. 17)

Search strategy	10	Present draft of search strategy to be used for at least one electronic database, including planned limits, such that it could be repeated	Search strategy (pg. 11)
Study records:			
Data management	11a	Describe the mechanism(s) that will be used to manage records and data throughout the review	Data management (pg. 11)
Selection process	11b	State the process that will be used for selecting studies (such as two independent reviewers) through each phase of the review (that is, screening, eligibility and inclusion in meta-analysis)	Study screening, quality appraisal, data extraction (pg. 15-17)
Data collection process	11c	Describe planned method of extracting data from reports (such as piloting forms, done independently, in duplicate), any processes for obtaining and confirming data from investigators	Data extraction (pg. 16-17)
Data items	12	List and define all variables for which data will be sought (such as PICO items, funding sources), any pre-planned data assumptions and simplifications	Inclusion and exclusion criteria (pg. 12-15) No pre-planned assumptions or simplifications
Outcomes and prioritization	13	List and define all outcomes for which data will be sought, including prioritization of main and additional outcomes, with rationale	Inclusion and exclusion criteria (pg. 12-15) Analyses (pg. 17-18)
Risk of bias in individual studies	14	Describe anticipated methods for assessing risk of bias of individual studies, including whether this will be done at the outcome or study level, or both; state how this information will be used in data synthesis	Quality appraisal (pg. 15-16)
Data synthesis	15a	Describe criteria under which study data will be quantitatively synthesised	NA, Analyses (pg. 17-18)
	15b	If data are appropriate for quantitative synthesis, describe planned summary measures, methods of handling data and methods of combining data from studies, including any planned exploration of consistency (such as I^2, Kendall's τ)	NA, Analyses (pg. 17-18)
	15c	Describe any proposed additional analyses (such as sensitivity or subgroup analyses, meta-regression)	Analyses (pg. 17-18)
	15d	If quantitative synthesis is not appropriate, describe the type of summary planned	Analyses (pg. 17-18)
Meta-bias(es)	16	Specify any planned assessment of meta-bias(es) (such as publication bias across studies, selective reporting within studies)	Quality appraisal (pg. 15-16)
Confidence in cumulative evidence	17	Describe how the strength of the body of evidence will be assessed (such as GRADE)	Quality appraisal (pg. 15-16)

*** It is strongly recommended that this checklist be read in conjunction with the PRISMA-P Explanation and Elaboration (cite when available) for important clarification on the items. Amendments to a review protocol should be tracked and dated. The copyright for PRISMA-P (including checklist) is held by the PRISMA-P Group and is distributed under a Creative Commons Attribution Licence 4.0.**

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