



BMJ Open 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 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 summarised evidence to determine its feasibility, acceptability and appropriateness for use in research and practice.

Methods and analysis We will systematically search 12 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 summarise the data elements. Using narrative synthesis, we will summarise 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.

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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, maximising HRQoL of

Strengths and limitations of this study

- In contrast to systematic reviews synthesising evidence on multiple health-related quality of life (HRQoL) instruments, our review will investigate in detail the evidence available on one specific instrument to measure dementia-related 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 synthesise 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 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 three studies investigating the same outcome using comparable methods.

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 dementia⁹—500 000 in Canada,¹⁰ 5.7 million in the USA¹¹ and 9.6 million in the EU.¹² Numbers are expected to be 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 conceptualised 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 (eg, 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 (eg, 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 WHO'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' (The WHOQOL Group,¹⁶ p1405).

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 instruments¹⁸ 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 homes²² 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

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

Continued

Table 1 Continued

Acronym	Full name
SF-12/SF-36	–
–	Vienna List

HRQoL, health-related quality of life.

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’ (AERA *et al.*,²⁵ p11). Feasibility, acceptability and appropriateness are implementation outcomes—that is, 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 operationalisations of each of these terms in the methods section (inclusion/exclusion criteria).

Previous reviews have attempted to give an overview of measurement properties and usability across and between QoL tools. However, none sufficiently analyse 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 instruments¹⁸ for the following reasons. First, the DEMQOL suite is specifically designed to measure HRQoL among people with dementia. Generic QoL tools (eg, EQ5D,²⁷ SF-12,²⁸ interRAI QoL module²⁴) 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 conceptualisations 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 23 May 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.

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 finalising 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 programme on routinely measuring and improving

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 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 to 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 to 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 to 4; Positive items are scored reversely so lower scores always indicate worse HRQoL; item scores are summed (possible range 31–124)
Reliability					
Internal consistency	$\alpha=0.87$	$\alpha=0.87-0.92$	NA	NA	$\alpha=0.90$
Test-retest	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 QOL-AD scores ($r=0.54$) and DQOL items ($r=0.29-0.45$)	Correlations with QOL-AD-caregiver scores ($r=0.52$)			Correlations with DCM scores ($r=0.34-0.67$)

DCM, Dementia Care Mapping; DQoL, Dementia Quality of Life; HRQoL, health-related quality of life; ICC, Intraclass correlation; MMSE, Mini Mental State Examination; QOL-AD, Quality of Life in Alzheimer's Disease.

the HRQoL in people with dementia living in congregate settings. On 09 October 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 organisations, 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 fulltext of records (online supplemental 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 Rayyan⁴⁵—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 fulltext 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 (grey 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.

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 on 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 randomised 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 Programme (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 (online supplemental 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

Table 3 Inclusion and exclusion criteria

	Inclusion criteria	Exclusion criteria
Study focus	<ul style="list-style-type: none"> ▲ Studies reporting on the development, validation or user rating (feasibility, acceptability, appropriateness) of any version of the DEMQOL. DEMQOL versions include: <ul style="list-style-type: none"> - 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 	<ul style="list-style-type: none"> ▲ 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	<ul style="list-style-type: none"> ▲ Primary empirical quantitative research and research protocols, regardless of the research design: <ul style="list-style-type: none"> - Randomised trials - Non-randomised trials - On-group pre–post studies - Cohort studies - Case control studies - Cross-sectional studies ▲ Qualitative studies: <ul style="list-style-type: none"> - Qualitative interviews - Focus groups - Ethnographic observations - Qualitative case studies ▲ Mixed methods studies ▲ Systematically conducted reviews: <ul style="list-style-type: none"> - 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 	<ul style="list-style-type: none"> ▲ Non-empirical work (editorials, opinion texts, theoretical discussions) ▲ Non-systematic (selective) reviews. We will, however, screen reference lists of those reviews for eligible studies

Continued

Table 3 Continued

Inclusion criteria	Exclusion criteria
<p>Study outcomes</p> <p>DEMQOL development</p> <ul style="list-style-type: none"> ▶ Studies reporting on the theoretical foundations, methods and processes used to develop any of the DEMQOL versions <p>DEMQOL reliability</p> <ul style="list-style-type: none"> ▶ Test re-test reliability: agreement (κ statistics, correlation coefficients, intraclass correlation coefficients) of DEMQOL scores obtained by the same person using the same DEMQOL version repeatedly to assess HRQoL of the same client²⁵ ▶ Inter-rater reliability: agreement (κ statistics, correlation coefficients, intraclass 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 client²⁵ ▶ 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 (eg, correlations of self-report and proxy assessments or paper-based vs. electronic)²⁵ <p>DEMQOL validity</p> <ul style="list-style-type: none"> ▶ 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 models²⁵ ▶ Construct validity: evidence on whether outcomes known to be associated with HRQoL are associated as hypothesised with DEMQOL items (correlation coefficients, regression parameters, results of structural equation models)²⁵ <p>DEMQOL feasibility</p> <ul style="list-style-type: none"> ▶ Quantitative or qualitative user ratings of whether either of the DEMQOL versions can be successfully used within an organisation or setting given existing resources (eg, effort, time to complete, costs of administration)²⁶ <p>DEMQOL acceptability</p> <ul style="list-style-type: none"> ▶ Quantitative or qualitative user ratings of whether any of the DEMQOL versions and their use are agreeable, palatable or satisfactory²⁶ <p>DEMQOL appropriateness</p> <ul style="list-style-type: none"> ▶ 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 values²⁶ <p>DEMQOL use</p> <ul style="list-style-type: none"> ▶ 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 	<ul style="list-style-type: none"> ▶ Studies reporting none of the outcomes listed as inclusion criteria

HRQoL, health-related quality of life.

- ▶ 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 (ie, 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 (operationalised 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 analysis⁶⁴ of narrative data (eg, 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—for example, DEMQOL version used, types of research questions asked, participant groups included, country of origin, study setting, study design, risk for bias category and so on.

To address research question 2, we will use descriptive statistics and narrative synthesis to summarise 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 operationalise 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

synthesise 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 organisations. Data of studies included in this systematic review cannot be linked to individuals or organisations. 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 synthesise 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.

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Contributors 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.

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Competing interests None declared.

Patient consent for publication Not required.

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REFERENCES

- 1 Kwasky AN, Harrison BE, Whall AL. Quality of life and dementia: an integrated review of literature. *Alzheimer's Care Today* 2010;11:186–95.
- 2 Bowling A, Rowe G, Adams S, et al. Quality of life in dementia: a systematically conducted narrative review of dementia-specific measurement scales. *Aging Ment Health* 2015;19:13–31.
- 3 Robertson S, Cooper C, Hoe J, et al. Proxy rated quality of life of care home residents with dementia: a systematic review. *Int Psychogeriatr* 2017;29:569–81.
- 4 Livingston G, Sommerlad A, Orgeta V, et al. Dementia prevention, intervention, and care. *Lancet* 2017;390:2673–734.
- 5 Pickett J, Bird C, Ballard C, et al. A roadmap to advance dementia research in prevention, diagnosis, intervention, and care by 2025. *Int J Geriatr Psychiatry* 2018;33:900–6.
- 6 van der Steen JT, Radbruch L, Hertogh CPM, et al. White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European association for palliative care. *Palliat Med* 2014;28:197–209.
- 7 Haaksma ML, Leoutsakos J-MS, Bremer JAE, et al. The clinical course and interrelations of dementia related symptoms. *Int Psychogeriatr* 2018;30:859–66.
- 8 Kua EH, Ho E, Tan HH, et al. The natural history of dementia. *Psychogeriatrics* 2014;14:196–201.
- 9 Alzheimer's Disease International. World Alzheimer report 2018: the state of the art of dementia research. London New frontiers; 2018.
- 10 Alzheimer Society of Canada. Understanding dementia: 2017–2018 impact report; 2018.
- 11 Alzheimer's Association. 2018 Alzheimer's disease facts and figures. *Alzheimer's & Dementia* 2018;14:367–429.
- 12 OECD, European Union. Health at a glance: Europe 2016 – state of health in the EU cycle. Paris OECD Publishing; 2016.
- 13 Martyr A, Nelis SM, Quinn C, et al. Living well with dementia: a systematic review and correlational meta-analysis of factors associated with quality of life, well-being and life satisfaction in people with dementia. *Psychol Med* 2018;48:2130–9.
- 14 Karimi M, Brazier J. Health, health-related quality of life, and quality of life: what is the difference? *Pharmacoeconomics* 2016;34:645–9.
- 15 Pinto S, Fumincelli L, Mazzo A, et al. Comfort, well-being and quality of life: discussion of the differences and similarities among the concepts. *Porto Biomed J* 2017;2:6–12.
- 16 The WHOQOL Group. The world Health organization quality of life assessment (WHOQOL): position paper from the world Health organization. *Soc Sci Med* 1995;41:1403–9.
- 17 Bullinger M, Anderson R, Cella D, et al. Developing and evaluating cross-cultural instruments from minimum requirements to optimal models. *Qual Life Res* 1993;2:451–9.
- 18 Smith S, Lamping D, Banerjee S, et al. Measurement of health-related quality of life for people with dementia: development of a new instrument (DEMQOL) and an evaluation of current methodology. *Health Technol Assess* 2005;9:1–93.
- 19 Banerjee S, Smith SC, Lamping DL, et al. Quality of life in dementia: more than just cognition. An analysis of associations with quality of life in dementia. *J Neurol Neurosurg Psychiatry* 2006;77:146–8.
- 20 Dichter MN, Schwab CGG, Meyer G, et al. Linguistic validation and reliability properties are weak investigated of most dementia-specific quality of life measurements—a systematic review. *J Clin Epidemiol* 2016;70:233–45.
- 21 Hughes LJ, Farina N, Page TE, et al. Psychometric properties and feasibility of use of dementia specific quality of life instruments for use in care settings: a systematic review. *Int Psychogeriatr* 2019;1–15 (published Online First: 2019/01/04).
- 22 Aspden T, Bradshaw SA, Playford ED, et al. Quality-Of-Life measures for use within care homes: a systematic review of their measurement properties. *Age Ageing* 2014;43:596–603.
- 23 Yang F, Dawes P, Leroi I, et al. Measurement tools of resource use and quality of life in clinical trials for dementia or cognitive impairment interventions: a systematically conducted narrative review. *Int J Geriatr Psychiatry* 2018;33:e166–76.
- 24 interRAI. Self-Reported quality of life (QOL). Available: <https://www.interrai.org/quality-of-life.html> [Accessed 15 Aug 2019].
- 25 AERA, APA, NCME. *Standards for educational and psychological testing*. 6th ed. Washington, DC, 2014.
- 26 Proctor E, Silmere H, Raghavan R, et al. Outcomes for implementation research: conceptual distinctions, measurement challenges, and research agenda. *Adm Policy Ment Health* 2011;38:65–76.
- 27 EQ-5D. Available: <https://euroqol.org/2020-02-27>
- 28 12-Item short form survey (SF-12). Available: https://www.rand.org/health-care/surveys_tools/mos/12-item-short-form.html [Accessed 27 Feb 2020].
- 29 Smith SC, Lamping DL, Banerjee S, et al. Development of a new measure of health-related quality of life for people with dementia: DEMQOL. *Psychol Med* 2007;37:737–46.
- 30 Hughes LJ, Farina N, Page TE, et al. Adaptation of the DEMQOL-Proxy for routine use in care homes: a cross-sectional study of the reliability and validity of DEMQOL-CH. *BMJ Open* 2019;9:e028045.
- 31 DEMQOL: dementia quality of life measure. Available: <https://www.bsms.ac.uk/research/neuroscience/cds/research/demqol.aspx> [Accessed 31 Mar 2019].
- 32 Feeney Y, Russell A, Farina N. The DEMQOL bibliography. *Zenodo*2020.
- 33 Alzheimer's Association. 2020 Alzheimer's disease facts and figures. *Alzheimer's & Dementia* 2020;16:391–460.
- 34 Canadian Institute for Health Information (CIHI). Dementia in long-term care, 2019. Available: <https://www.cihi.ca/en/dementia-in-canada/dementia-across-the-health-system/dementia-in-long-term-care> [Accessed 23 Jul 2019].
- 35 Bartfay E, Bartfay WJ, Gorey KM. Prevalence and correlates of potentially undetected dementia among residents of institutional care facilities in Ontario, Canada, 2009–2011. *Int J Geriatr Psychiatry* 2013;28:1086–94.
- 36 Maxwell CJ, Amuah JE, Hogan DB, et al. Elevated hospitalization risk of assisted living residents with dementia in Alberta, Canada. *J Am Med Dir Assoc* 2015;16:568–77.
- 37 Zimmerman S, Sloane PD, Reed D. Dementia prevalence and care in assisted living. *Health Aff* 2014;33:658–66.
- 38 Prince M, Knapp M, Guerchet M. *Dementia UK: update*. London: Alzheimer's Society, 2014.
- 39 Chamberlain S, Baik S, Estabrooks C. Going it alone: a scoping review of Unbefriended older adults. *Can J Aging* 2018;37:1–11.
- 40 Harden A. Mixed-Methods systematic reviews: integrating quantitative and qualitative findings 2010:1–8.
- 41 Higgins JPT, Green S, eds. *Cochrane handbook for systematic review of interventions versions 5.1.0*. The Cochrane collaboration, 2011.
- 42 Moher D, Liberati A, Tetzlaff J, et al. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS Med* 2009;6:e1000097.
- 43 Shamseer L, Moher D, Clarke M, et al. Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015: elaboration and explanation. *BMJ*2015;349:g7647.
- 44 Translating Research in Elder Care (TREC). Policy forum on quality of life for residents living with dementia, 2020. Available: https://trecresearch.ca/download/documents/policy_forum_on_quality_of_life_report/trec_qol_policy_forum_report_17jan2020pdf.v1?attachment=1 [Accessed 08 Oct 2020].
- 45 Qatar Computing Research Institute. Rayyan QCRI. Available: <https://rayyan.qcri.org/welcome> [Accessed 04 Oct 2019].
- 46 Hoben M, Clarke A, Huynh KT, et al. Barriers and facilitators in providing oral care to nursing home residents, from the perspective of care aides: a systematic review and meta-analysis. *Int J Nurs Stud* 2017;73:34–51.
- 47 Hoben M, Kent A, Kobagi N, et al. Effective strategies to motivate nursing home residents in oral care and to prevent or reduce responsive behaviors to oral care: a systematic review. *PLoS One* 2017;12:e0178913.
- 48 Mokkink LB, de Vet HCW, Prinsen CAC, et al. COSMIN risk of bias checklist for systematic reviews of patient-reported outcome measures. *Qual Life Res* 2018;27:1171–9.
- 49 Shea BJ, Grimshaw JM, Wells GA, et al. Development of AMSTAR: a measurement tool to assess the methodological quality of systematic reviews. *BMC Med Res Methodol* 2007;7:10.
- 50 Shea BJ, Bouter LM, Peterson J, et al. External validation of a measurement tool to assess systematic reviews (AMSTAR). *PLoS One* 2007;2:e1350.
- 51 Shea BJ, Hamel C, Wells GA, et al. AMSTAR is a reliable and valid measurement tool to assess the methodological quality of systematic reviews. *J Clin Epidemiol* 2009;62:1013–20.
- 52 Kang D, Wu Y, Hu D, et al. Reliability and external validity of AMSTAR in assessing quality of TCM systematic reviews. *Evid Based Complement Alternat Med* 2012;2012:1–7.
- 53 Thomas BH, Ciliska D, Dobbins M, et al. A process for systematically reviewing the literature: providing the research evidence for public health nursing interventions. *Worldviews Evid Based Nurs* 2004;1:176–84.
- 54 Armijo-Olivo S, Stiles CR, Hagen NA, et al. Assessment of study quality for systematic reviews: a comparison of the Cochrane collaboration risk of bias tool and the effective public health practice



- project quality assessment tool: methodological research. *J Eval Clin Pract* 2012;18:12–18.
- 55 Clarke M, Oxman AD, eds. *Cochrane reviewer's handbook 4.1.4*. The Cochrane Library: Oxford, 2001.
- 56 Kmet L, Lee R, Cook L. Standard quality assessment criteria for evaluating primary research papers from a variety of fields, 2004. Available: <https://www.ihe.ca/publications/standard-quality-assessment-criteria-for-evaluating-primary-research-papers-from-a-variety-of-fields>
- 57 (CASP) CASP. CASP (Qualitative) checklists 2018 [Available from. Available: https://casp-uk.net/wp-content/uploads/2018/03/CASP-Qualitative-Checklist-2018_fillable_form.pdf [Accessed 24 June, 2019].
- 58 Kajermo KN, Boström A-M, Thompson DS, et al. The barriers scale—the barriers to research utilization scale: a systematic review. *Implement Sci* 2010;5:32.
- 59 Squires JE, Estabrooks CA, Gustavsson P, et al. Individual determinants of research utilization by nurses: a systematic review update. *Implement Sci* 2011;6:1.
- 60 Squires JE, Hutchinson AM, Boström A-M, et al. To what extent do nurses use research in clinical practice? A systematic review. *Implementation Sci* 2011;6.
- 61 Squires JE, Hoben M, Linklater S, et al. Job satisfaction among care aides in residential long-term care: a systematic review of contributing factors, both individual and organizational. *Nurs Res Pract* 2015;2015:1–24.
- 62 Hoben M, Berendonk C, Buscher I. Scoping review of nursing-related dissemination and implementation research in German-speaking countries: mapping the field/Scoping review. *Int J Health Prof* 2014;1:34–49.
- 63 de Vet HCW, de Bie RA, van der Heijden GJMG, et al. Systematic reviews on the basis of methodological criteria. *Physiotherapy* 1997;83:284–9.
- 64 Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Med Res Methodol* 2008;8:45.