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*Published in:*

Age and Ageing

*DOI:*

[10.1093/ageing/afu089](https://doi.org/10.1093/ageing/afu089)

*Publication date:*

2014

*Citation for published version (APA):*

Aspden, T., Bradshaw, S. A., Playford, E. D., & Riazi, A. (2014). Quality-of-life measures for use within care homes: A systematic review of their measurement properties. *Age and Ageing*, 43(5), 596-603. Article afu089. <https://doi.org/10.1093/ageing/afu089>

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## SYSTEMATIC REVIEWS

# Quality-of-life measures for use within care homes: a systematic review of their measurement properties

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## Abstract

**Objective:** the aims of this review were (i) to identify quality-of-life (QoL) measures which have had their measurement properties validated in people residing in care homes or nursing homes, and to critically compare and summarise these instruments and (ii) to make recommendations for measurement instruments.

**Methods:** bibliographic databases PsycINFO, PubMed, Cochrane, CINAHL and Embase were searched for articles evaluating measurement properties of QoL instruments in people residing in care homes. Methodological quality of studies was assessed using the consensus-based standards for the selection of health measurement instruments checklist. Measurement properties of instruments were appraised using a systematic checklist.

**Results:** the search strategy resulted in 3252 unique citations, of which 15 articles were included in this review. These articles assessed 13 instruments, 8 of which were dementia or Alzheimer specific instruments. The QUALIDEM, a dementia-specific observational instrument, had the widest array of information available on its measurement properties, which were mostly satisfactory. Most measurement instruments lacked information on hypotheses testing and content validity. Information on responsiveness and measurement error was not available for any instrument.

**Conclusions:** for people with dementia living in care homes, the QUALIDEM is recommended for measuring QoL. For residents without dementia, we recommend Kane *et al.*'s Psychosocial Quality of Life Domains questionnaire. Studies of higher methodological quality, assessing a wider range of measurement properties are needed to allow a more fully informed choice of QoL instrument.

**Keywords:** systematic review, quality of life, care home, questionnaire, outcome, older people

## Introduction

Long-term care facilities such as care homes and nursing homes, hereafter referred to as care homes, are residential settings where a number of people live and have access to on-site care. There are an estimated 450,000 people living in care homes in the UK [1]. Between 51 and 74% of these individuals are estimated to have dementia [2], and depression affects an estimated 43% of residents [2].

Quality of life (QoL) can be defined as the individuals' perception of their situation in the context of their culture and values and in relation to their expectations and concerns [3]. Theoretical models of QoL (e.g. [4, 5]) suggest that it is multidimensional (i.e. composed of several statistically

distinct domains). General consensus suggests QoL encompasses at least the domains of psychological, social and physical well-being [6, 7, 8]. Predictors of QoL within older people living in care homes include perceived autonomy, frequency of available choices, ability to perform activities of daily living, risk of falling, social economic status, amount of time spent with family and perceived social support from and quality of interactions with care staff [9].

An increasing amount of interventional research is being conducted within care homes (e.g. [10]). QoL represents an important outcome for assessing impact and cost effectiveness of these interventions [11]. Previous reviews have evaluated QoL measures within similar populations, for example, within individuals with dementia [12, 13]. To our knowledge,

no systematic review has appraised QoL measures developed or evaluated within populations living in care homes. Such a review will be useful in choosing QoL measures for evaluating psychosocial interventions within care homes, and will be relevant to the goals of the INTERDEM (early and timely interventions in dementia) manifesto [14], which aims to conduct research to enhance the QoL of people with dementia.

To accurately assess QoL of residents living in care homes, instruments with good measurement properties are needed. These measurement properties demonstrate that an instrument measures the intended construct (validity), will reliably give a similar score if administered twice (reliability) and is responsive to change (responsiveness) [15]. The consensus-based standards for the selection of health measurement instruments (COSMIN) systematically evaluates the methodological quality of studies on measurement properties [16]. This allows for methodological quality of studies to be accounted for when forming conclusions about the measurement properties of an instrument.

## Aims

The aim of this review was to critically compare, contrast and summarise QoL instruments that have either been developed within or had measurement properties appraised within residents of care homes. Based on these findings, we also recommend appropriate QoL instruments.

## Method

### Search strategy

A search strategy was developed to locate articles that assessed measurement properties of a QoL instrument within a population residing in care homes. The search consisted of three components: (i) the term *QoL*, (ii) population (including *care homes*, *nursing homes* and *residential homes*) and (iii) type of study (including *questionnaire*, *self-report*, *self-assessment*, *outcome measure* and *outcome assessment*). Articles were retrieved from the databases PsycINFO, PubMed, Cochrane, CINAHL and Embase from the earliest records until 15 January 2014. Reference sections of articles included in the review and relevant review articles [6, 13] were also screened to identify relevant articles.

### Study selection

Inclusion criteria were: (i) assessment of at least one measurement property of a QoL instrument in a population residing in care homes and (ii) written in the English language. Exclusion criteria were: (i) the use of a mixed population that includes residents in care homes, *unless* measurement properties were appraised separately for the care home sample and (ii) purporting to appraise a QoL instrument but appraising an instrument measuring a different construct.

Study selection comprised two stages: (i) title and abstract screening and (ii) full text screening. The first and second authors independently selected studies.

### Measurement instrument appraisal

Each measurement instrument was appraised according to the following four criteria.

#### *Purpose of the instrument*

We established whether an instrument was developed to measure QoL in people with a specific disease, and whether the instrument's purpose was discriminative (e.g. distinguishing between groups), evaluative (e.g. evaluating change in QoL) and/or predictive [15].

#### *Content of instrument*

We appraised instruments according to breadth of content, and specifically whether they covered at least the domains of psychological, social and physical well-being [6, 7, 8].

#### *Measurement property appraisal*

Measurement properties of QoL instruments were appraised using published criteria [15; Table 1]. As there is no 'gold-standard' measure for QoL, criterion validity was not appraised. Measurement properties data were independently extracted by two reviewers. Any disagreements were resolved through consensus meetings.

#### *Methodological quality of studies*

Methodological quality of studies was assessed using the COSMIN checklist [16], which provides a standardised method of assessing quality of studies that assess measurement properties. The checklist consists of nine boxes rating different measurement properties, with 5–18 items per box. Items are rated as excellent, good, fair or poor. Methodological quality data were independently extracted by two reviewers, and any disagreements resolved through consensus meetings.

### Data synthesis: levels of evidence

Ratings of measurement properties were accompanied by the level of evidence supporting the rating [17]. Level of evidence for a measurement property was based on quantity, quality (rated using COSMIN) and concurrence of studies. Possible levels of evidence [18] were:

- *Strong*: consistent findings in multiple studies of good, or one study of excellent, methodological quality.
- *Moderate*: consistent findings in multiple studies of fair, or one study of good, methodological quality.
- *Limited*: evidence only from a single study of fair methodological quality.
- *Unknown*: only studies of poor methodological quality available.
- *Conflicting*: findings of different studies conflict.

Table 1. Quality criteria for measurement properties

Property	Rating	Criteria
Reliability		
Internal consistency	+	Cronbach's <i>a</i> of scale between 0.70 and 0.95.
	?	Chronbach's <i>a</i> not determined
	-	Cronbach's <i>a</i> (s) <0.70 or >0.95
Reliability	+	ICC or weighted Kappa $\geq 0.70$
	?	ICC or weighted Kappa not determined
	-	ICC or weighted Kappa <0.70
Validity		
Content validity	+	Clear description of measurement aim, target population, concepts being measured and item selection AND target population and (investigators OR experts) involved in item selection process
	?	A clear description of above aspects lacking OR only target population involved in item selection
	-	No involvement of target population in item selection
Hypothesis testing	+	At least 75% of results in accordance with hypotheses
	?	No hypotheses formulated in advance
	-	Less than 75% of results in accordance with hypotheses
Responsiveness	+	Smallest detectable change < minimal important change OR Minimal important change outside the limits of agreement OR responsiveness ratio >1.96 OR area under curve $\geq 0.70$
	?	Doubtful design or method
	-	Smallest detectable change $\geq$ minimal important change OR minimal important change equal or inside limits of agreement OR responsiveness ratio $\leq 1.96$ OR area under curve <0.70

## Results

### Search results and study selection

Results of the search and study selection procedure are displayed in Figure 1. Database searches resulted in 3252 unique citations. Screening by title and abstract resulted in the retention of 19 citations. Full text screening resulted in the exclusion of seven articles; four due to populations not exclusively from care homes [19, 20, 21, 22], two contained no information on measurement properties [23, 24] and one measured fear of falling [25]. Reference list screening led to the inclusion of 3 further citations, resulting in 15 articles [26–40] selected for data extraction (Supplementary data are available in *Age and Ageing* online, Table S1). One article provided a relatively large portion of data, a comparative study of 7 QoL measures used in Alzheimer's [33].

A total of 13 instruments were assessed in these studies (Supplementary data are available in *Age and Ageing* online, Table S1). One had a separate German translation, and two have separate proxy and resident versions. Proxy, resident and translated versions were evaluated individually, providing a total of 16 individual QoL instruments.

### Measurement instrument appraisal

Appraisals of methodological quality of studies and measurement properties of instruments are presented in Supplementary Tables S2 and S3, respectively. Synthesis of measurement properties and associated levels of evidence are summarised in Table 2.

*Alzheimer disease related quality of life* (ADRQL; [41]) is a proxy-completed questionnaire. This 47-item disease-specific questionnaire is multidimensional with scales covering: mood and emotions, social interaction, enjoyment of activities,

self-awareness and response to surroundings. Physical well-being is not assessed.

Internal consistency and (inter-observer) reliability were rated unknown [33] due to poor methodological quality [small sample size (<30), lack of factor analysis].

*Dementia care mapping* (DCM; [42]) is an observational instrument. This disease-specific instrument rates 24 activities, which are assigned behaviour category codes. Most BBCs fall into type I (positive) or type II (negative). A well-ill-being score is then assigned, possible scores being +5 (highest well-being), +3, +1, -1, -3 or -5. Three DCM indicators of QoL were assessed in the included studies: mean well-ill-being score, percent of values that were +3 or +5, and percentage of observations categorised as type I. In the present review, we evaluated mean well-ill-being score only.

As the DCM records behaviours, internal consistency and factor analysis were not relevant. Inter-observer reliability of the DCM was 0.70 based on limited evidence [33]. Limited evidence suggests test–retest reliability of the DCM is inadequate ( $r = 0.55$ ).

*Dementia quality of life* (DQoL; [43]) is a self-report questionnaire. This 27-item disease-specific questionnaire covers positive affect and humour, negative affect, self-esteem, feeling of belonging and sense of aesthetics. Physical well-being is not covered.

Confirmatory factor analysis showed limited evidence of the five-factor structure [28]. Based on limited evidence Cronbach's *a* for the 5 subscales were 0.65 (sense of aesthetics), 0.53 (feelings of belonging), 0.84 (negative affect), 0.62 (self-esteem) and 0.72 (positive affect) [28]. Test–retest reliability was inadequate ( $r = 0.60$  and  $0.64$ ) based on limited evidence. Inter-observer reliability was rated unknown due to poor methodological quality (no factor analysis).

*EQ-5D* [38] is a self- or proxy-completed questionnaire. It comprises five items measuring level of impairment in

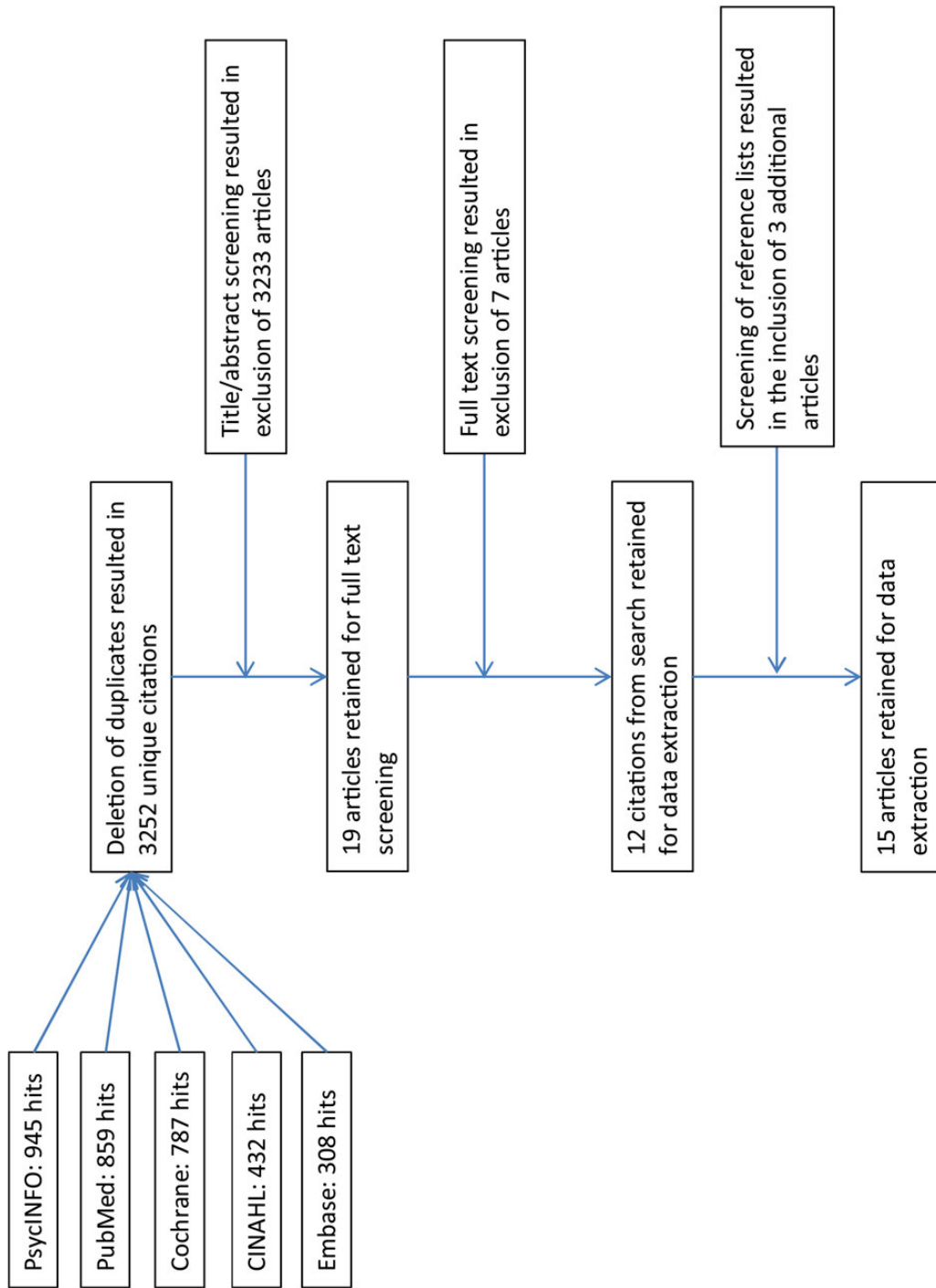


Figure 1. Flow diagram of search and study selection.

**Table 2.** Data synthesis of quality of measurement properties and level of evidence

Instrument	Number of studies	Internal consistency	Reliability (test–retest)	Reliability (inter-observer)	Content validity	Construct validity	Responsiveness
ADRQL	1	Unknown		Unknown			
DCM	2	n/a	? Limited	+ Moderate			
DQoL	3	– Limited	– Limited	Unknown			
EQ-5D	1	n/a		+ Limited		+ Limited	
PGC-ARS	1	n/a		+ Moderate			
QOL-AD (care-provider report)	2	Unknown		Unknown			
QOL-AD (resident report)	2	Unknown		Unknown			
QOL-D (care-provider report)	1	Unknown		Unknown			
QOL-D (resident report)	1	Unknown		Unknown			
QUALIDEM	2	? Strong	+ Moderate	– Moderate	+ Moderate	+ Limited	
QUALIDEM German translation		– Moderate					
RSOC-QoL	1	n/a		+ Moderate			
Byrne–MacLean QoL Index	1	Unknown			? Limited		
COOP/WONCA	1	n/a	– Limited	+ Limited		– Moderate	
PGCMS	1	Unknown				? Limited	
Psychosocial QoL domains measure	1	– Moderate			Unknown	+ Moderate	

? Strong/moderate/limited: intermediate result based on strong, moderate or limited level of evidence.

+ Strong/moderate/limited: positive result based on strong, moderate or limited level of evidence.

– Strong/moderate/limited: negative result based on strong, moderate or limited level of evidence.

Unknown: result not known due to poor methodological quality.

n/a, not applicable.

domains of mobility, self-care, usual activities, pain/discomfort and anxiety/depression, and a further item measuring perceived current health state. Social well-being is not covered. Inter-observer reliability was rated positive (ICC 0.72) based on limited evidence, and construct validity was demonstrated through expected group differences [38].

*Philadelphia Geriatric Centre Affect Rating Scale* (PGC-ARS; [44, 45]) is an observational measure. Whilst the PGC-ARS was developed to assess QoL [44], it is primarily a measure of affect. This dementia-specific measure codes body movements and facial expressions. It includes the affective states high pleasure, mild pleasure, anger, anxiety, sadness, alertness and sleeping/dozing. Physical and social well-being are not covered. Based on moderate evidence, inter-observer reliability is positive (ICC = 0.82) [33].

*Quality of life in Alzheimer’s disease* (QOL-AD; [46]) has both self-report and proxy (caregiver) versions. This disease-specific measure has been adapted for use with care home residents [47]. This 15-item adaptation evaluates mood, physical condition, relationships and ability to participate in activities, covering psychological, social and physical well-being. Internal consistency and inter-observer reliability were rated unknown for both resident and care-provider versions, due to poor methodological quality (no factor analysis [33] and small (<30) sample size [29, 33, 37]).

*Quality of life in dementia* (QOL-D [48]) has both self-report and proxy (caregiver) versions. The proxy (caregiver) version comprises 15 items and rates both activity and affect, the self-report version rates only activity. Social well-being is not represented. Internal consistency was rated unknown due to poor methodological quality (no factor analysis) [33]. Inter-observer reliability was rated unknown due to small (<30) sample size [33].

*QUALIDEM* [31, 32, 39] is an observational instrument. This evaluative, dementia-specific QoL instrument developed for use in care homes comprises 37 items rating behaviour in nine domains: care relationships, positive affect, negative affect, restless tense behaviour, positive self-image, social relations, social isolation, feeling at home and having something to do. Physical well-being is not covered.

Dimensionality was established using Mokken scale analysis. Internal consistency was rated intermediate based on strong evidence [39]. Test–retest reliability was rated positive (ICCs from 0.73 to 0.89) based on moderate evidence. Inter-observer reliability was rated negative (ICCs from 0.47 to 0.79, with 4 of the 9 scales demonstrating ICCs <0.70) based on moderate evidence. Content validity was rated positive (moderate evidence). Hypotheses testing showed that the scales correlated in expected directions with depression, behavioural problems and symptoms of dementia.

*QUALIDEM German translation* [40]. A German translation of the QUALIDEM showed good evidence of an eight-domain structure consisting of the domains satisfied behaviour, unapproachable unsatisfied behaviour, positive self-image, negative affect, social relations, feeling at home, tense behaviour and having something to do. Internal consistency rated negative (Cronbach’s  $\alpha$ s range from 0.64 to 0.87) based on moderate evidence.

*Resident and staff observation checklist—quality of life measure* (RSOC-QOL [49]) is an observational instrument. This dementia-specific instrument measures behaviours in agitation, physical contact and engagement. Physical well-being is not covered.

Inter-observer reliability was rated positive (ICCs for 3 scales range from 0.77 to 0.90) based on limited evidence [33].

*Byrne–MacLean QoL Index* [34] is a self-report questionnaire. This 56-item questionnaire covers environment, visitors, activities, comfort, nursing care, food and laundry, choice, attention, staff and worries. Physical well-being is not assessed.

Dimensionality of the Byrne–MacLean QoL Index was established using exploratory factor analysis, although methodological quality was poor (small sample size). Internal consistency is rated unknown due to poor methodological quality (small sample size). Content validity was rated as intermediate (limited evidence).

*Modified COOP/WONCA charts* [50] are a self-report QoL instrument. This instrument comprises five charts assessing physical fitness, health, feelings, daily activities, social activities and pain. Content of the COOP/WONCA charts covers psychological, social and physical well-being.

The ability of modified COOP/WONCA charts, which included a sixth card measuring overall QoL, to measure QoL of people with dementia living in nursing homes was assessed [30]. Test–retest reliability was rated negative based on limited evidence (linear weighted Kappas were 0.23, 0.27, 0.30, 0.46, 0.56, and 0.67), whilst inter-observer reliability was rated positive based on limited evidence (Kappas ranging from 0.90 to 0.97).

*Philadelphia Geriatric Centre Moral Scale* (PGCMS; [51]) is a self-report questionnaire. This 17-item questionnaire, which is primarily considered to be a life-satisfaction measure, covers agitation, attitude towards own ageing and lonely dissatisfaction. Physical well-being is not represented.

Internal consistency was rated unknown due to poor methodological quality (no factor analysis) [36]. Limited evidence showed that the PGCMS was inversely correlated with scales measuring depression and negative affect, but not with positive affect [36].

*Psychosocial QoL domains questionnaire* [27] is a self-report questionnaire. This 42-item questionnaire measures enjoyment, relationships, comfort, meaningful activities, security, functional competence, privacy, autonomy, spiritual well-being and dignity. These domains cover psychological, social and physical well-being.

Moderate evidence from confirmatory factor analysis supports the structure of the 10 domains, and internal consistency for the scales ranged from 0.53 to 0.77. Moderate evidence showed that all scales correlated in expected directions with measures of emotional well-being and satisfaction with care. Content validity was rated as unknown (insufficient information on domain and item development).

## Discussion

This systematic review identified 13 (16 counting unique resident, proxy and translated versions) QoL instruments that have had their measurement properties validated within care home residents. These were compared on their purpose, content and measurement properties, taking into account the associated level of evidence. The results

of this review can help guide clinicians and researchers within the care environment to select the most appropriate measure.

The purpose of the questionnaire was only stated for one instrument, the QUALIDEM, which was intended for evaluative purposes. Of the 13 instruments, 8 were disease-specific, whilst 5 were generic. Only three instruments (QOL-AD, COOP/WONCA charts and Kane *et al.*'s Psychosocial Quality-of-Life Domains questionnaire) measure the domains of psychological, social and physical well-being. However, other domains measured by these questionnaires, such as spiritual well-being (Psychosocial QoL Domains) and having something to do (QUALIDEM) may also make a significant contribution to residents QoL. Indeed, domains reflecting autonomy (Psychosocial QoL domains), choice (Byrne–MacLean QoL Questionnaire), comfort (Byrne–MacLean QoL Questionnaire) and privacy (Psychosocial QoL domains) may be particularly relevant to QoL of residents, as residents interviewed about their QoL have noted the importance of these domains [34].

This review highlights discrepancies in the frequency with which measurement properties are reported, and in the methodological quality used to assess these properties. Most studies appraised internal consistency reliability and test–retest reliability or inter-observer reliability. In contrast, hypotheses testing and content validity were rarely reported.

None of the studies assessed responsiveness, and none were longitudinal. This may be because QoL instruments are hardly used as outcome measures within the care home setting. However, given that there is now more interventional research conducted within the care home (e.g. [10]), studies on responsiveness within the care home setting are needed.

The instrument for which the broadest set of measurement properties has been reported is the QUALIDEM. Test–retest reliability was satisfactory based on moderate evidence, and inter-observer reliability was satisfactory for 5 of 9 scales. Content validity of the QUALIDEM was satisfactory, and hypotheses testing gave adequate evidence of construct validity. Contents are broad, although lacking items measuring physical well-being. On balance therefore, the QUALIDEM is a fairly comprehensive QoL instrument developed for the care home environment, has fairly comprehensive information on measurement properties and demonstrates adequate measurement properties overall. For measuring QoL in care home residents with dementia, in instances when an observational instrument is deemed appropriate, we therefore recommend the QUALIDEM.

In residents without dementia, or in instances where a self-reported instrument is required, the Psychosocial Quality of Life Domains questionnaire [27] is recommended. This questionnaire was developed for individuals living in nursing homes and covers a broad conceptualisation of QoL, including psychological, social and physical well-being. Whilst internal consistency was below satisfactory for 6 of 10 domains, hypotheses testing showed satisfactory evidence of construct validity.

However, the above recommendations need to be treated with caution. Future high-quality studies are needed to assess all important measurement properties of QoL instruments within samples of individuals residing in care homes. This review included only studies aiming to develop or evaluate a QoL instrument, similar to previous reviews (e.g. [52]). Studies which investigated QoL in care homes but did not directly aim to evaluate measurement properties were not included (such as intervention studies), and information on measurement properties of QoL instruments may have been available in these studies. Other limitations are that only articles published in English were included, and that use of COSMIN requires a degree of subjective judgement. To compensate for this, methodological quality for each study was independently rated by two reviewers. Other outcomes such as life satisfaction are also relevant to the well-being of residents, and future reviews of such outcome measures would be useful.

## Conclusion

In conclusion, those wishing to measure QoL of care home residents should select instruments that have known measurement properties assessed within populations of care home residents. Based on the information available, we have recommended the use of the QUALIDEM for measuring QoL in residents with dementia. For residents without dementia, we recommend the Psychosocial Quality-of-Life Domains questionnaire [27]. However, better quality studies, assessing a wider range of measurement properties are needed in order to make a fully informed choice of QoL measurement instrument for use within care homes.

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## Key points

- Systematic review of QoL measures used within care homes.
  - Systematic review of measurement properties.
  - Methodological quality of studies assessed using COSMIN.
  - Recommendations of QoL instruments are made.
- 

## Supplementary Data

Supplementary data mentioned in the text are available to subscribers in *Age and Ageing* online.

## Acknowledgement

We thank Miriam O'Driscoll for help in data extraction.

## Funding

This work was supported by the Multiple Sclerosis Society (Grant ref: 905/08).

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The very long list of references supporting this review has meant that only the most important references are listed here and are represented by bold type throughout the text. The full list of references is available on Supplementary data in *Age and Ageing* online, Appendix 1.

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**Received 20 September 2013; accepted in revised form 14 April 2014**