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REVIEW ARTICLES

Linguistic validation and reliability properties are weak investigated of most dementia-specific quality of life measurements—a systematic review

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Abstract

Objective: For people with dementia, the concept of quality of life (Qol) reflects the disease's impact on the whole person. Thus, Qol is an increasingly used outcome measure in dementia research. This systematic review was performed to identify available dementia-specific Qol measurements and to assess the quality of linguistic validations and reliability studies of these measurements (PROSPERO 2013: CRD42014008725).

Study Design and Setting: The MEDLINE, CINAHL, EMBASE, PsycINFO, and Cochrane Methodology Register databases were systematically searched without any date restrictions. Forward and backward citation tracking were performed on the basis of selected articles.

Results: A total of 70 articles addressing 19 dementia-specific Qol measurements were identified; nine measurements were adapted to nonorigin countries. The quality of the linguistic validations varied from insufficient to good. Internal consistency was the most frequently tested reliability property. Most of the reliability studies lacked internal validity.

Conclusion: Qol measurements for dementia are insufficiently linguistic validated and not well tested for reliability. None of the identified measurements can be recommended without further research. The application of international guidelines and quality criteria is strongly recommended for the performance of linguistic validations and reliability studies of dementia-specific Qol measurements.

Keywords: Quality of life; Dementia; Psychometric properties; Reliability; Linguistic validation; Systematic review

1. Introduction

The estimated number of people with dementia worldwide was 44.4 million in 2013, and this number is estimated to increase to 135.5 million in 2050 [1]. Dementia as a syndrome results in progressive cognitive and functional declines that influence the affected individuals' performance of the activities of daily living and social behaviors. Quality of life (Qol) as a concept reflects the meaning that an individual attaches to the effects of the disease on him/her as a whole. Thus, it has become an important outcome in intervention studies, particularly psychosocial interventions, and an indicator of the quality of care of people with dementia [2,3]. Dementia-specific Qol was first defined by Lawton [4] as consisting of objective (e.g., behavioral competence and environment) and subjective (e.g., perceived Qol and psychological well being) components. Following Lawton's definition, other definitions have been suggested on the basis of various theoretical concepts. All the relevant theoretical concepts consider the subjectivity and multidimensionality of Qol [5,6]. The lack of the concepts' theoretical clarity has resulted in several dementia-specific Qol measurements with heterogeneous operationalizations of the concept [7,8]. Some measurements cover primarily functional and cognitive abilities, such as the Qol Alzheimer disease scale [9], which is used to measure the health status rather than the

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What is new?

Key findings

- Dementia-specific quality of life (Qol) measurements are often used in countries other than the origin; unfortunately, few measurements are linguistic validated, and their reliability properties are often unknown.
- Studies on psychometric properties often suffer from methodological shortcomings.

What this adds to what was known?

- This systematic review is the first to generate evidence on the lack of quality of linguistic validations and the reliability of dementia-specific Qol measurements.

What is the implication and what should change now?

- The application of international guidelines and quality criteria is strongly recommended for linguistic validations and reliability studies of dementia-specific Qol measurements.
- The application of these guidelines and quality criteria are recommended as prerequisites for publishing translated versions of Qol measurements and reliability studies.

Qol of people with dementia. By contrast, other measurements, such as the QUALIDEM [10], focus on the psychosocial domains of Qol. The self-rating of Qol by people with dementia is viewed as the gold standard method [3]. However, the reliability and validity of self-ratings are affected by deficits in memory, concentration, communication abilities, daily living capacity, and impaired decision making, which occur progressively through the stages of the disease [11]. Therefore, proxy measures are recommended for longitudinal ratings and in advanced stages of the disease [2]. However, proxy rating is also influenced by methodologic difficulties, and the results are systematically lower than those in self-rated Qol [12] and positively correlated with the raters' attitudes [13], burden [14,15], and general life satisfaction [15]. In addition, the reliability and validity of proxy ratings are affected throughout the entire course of dementia because the observation of behaviors, moods, gesturing, and facial expressions is challenging in the advanced stages of the disease. These theoretical and methodologic difficulties emphasize the challenge of selecting the best Qol measurement for research and for dementia practice. These difficulties underline the relevance of a comprehensive and careful psychometric examination of dementia-specific Qol measurements [16].

Since the late nineties, nine systematic reviews of dementia-specific Qol measurements have been published [7,8,17–23] (Table 1). The number of included measurements increased with the publication year. The reviews report the perspective, content (subscales, items, and response options), stage of dementia severity, and psychometric properties of the included measurements. Seven [7,8,17–19,22,23] of the nine reviews were based on a systematic literature search. Only one review included a detailed data extraction [8], and none reported the methodologic quality of the included studies (Table 1).

Most of the measurements that were included in previous systematic reviews were developed in native English-speaking countries [7,8,17–19,22,23]. Thus, the adaptation of the measurement in the context of increasing multinational research projects to gather comparable data on the Qol of people with dementia is crucial. Moreover, detailed analysis of the quality of linguistic validation processes in a review supports the selection of the most appropriate measurement in nonnative English-speaking countries.

None of the former reviews systematically investigated difference across national adapted versions of the Qol measurements.

Therefore, the objective of the present systematic review (PROSPERO 2013: CRD42014008725) was to assess the reliability of existing dementia-specific Qol measurements and to perform a critical appraisal of the quality of linguistic validations on the basis of the recommendations of the AMSTAR tool [40].

2. Methods

2.1. Search strategy

In January and February 2014, a systematic search of the MEDLINE (PubMed), CINAHL, EMBASE, PsycINFO (EMBASE), and Cochrane Methodology Register databases was performed without any date restrictions. In addition, potentially relevant publications known by the authors before the database search were considered. In a second step, forward and backward citation tracking of the included articles were performed using Web of Science and SCOPUS. The keywords used (and their combinations) are summarized in Appendix B at www.jclinepi.com. The studies selected for inclusion were restricted to English or German language studies that primarily focused on the development, linguistic validation, or reliability of dementia-specific Qol measurements. Studies and reviews that included people without any cognitive impairment were excluded. For the studies that reported further results, such as the predictors of Qol values or properties according to validity only, the study characteristics, methodologic

Table 1. Reviews on dementia-specific QoL measurements

Review/ measurements	Walker et al. 1998 [22]	Ready and Ott 2003 [19]	Ettema et al. 2005 [17]	Smith et al. 2005 [21]	Schölzel-Dorenbos et al. 2007 [20]	Oppikhofer 2008 [18]	Gräske et al. [23]	Perales et al. 2013 [7]	Bowling et al. 2014 [8]
Self-rated only									
BASQID							✓	✓	✓
DQoL	✓	✓	✓	✓	✓	✓	✓	✓	✓
MCQ									
Self-rating and proxy rating									
AAIQOL	✓	✓		✓		✓	✓	✓	✓
CBS QoL		✓	✓		✓	✓	✓	✓	✓
DEMQOL and DEMQOL proxy				✓	✓	✓	✓	✓	✓
H.I.L.DE.						✓	✓		
QoL-AD	✓	✓	✓	✓	✓	✓	✓	✓	✓
QoL-AD NH									
QOLAS		✓		✓		✓	✓	✓	✓
Proxy rating only									
ADRQL and AD-HRQL-J (QLDJ)		✓	✓	✓	✓	✓	✓	✓	✓
CDQLP	✓			✓			✓	✓	
DCM	✓	✓	✓			✓	✓	✓	✓
OQOLD and OQOLDA							✓		
PWP-CIP							✓		
QoL-D			✓	✓		✓	✓	✓	✓
QUALID		✓				✓	✓	✓	✓
QUALIDEM					✓		✓	✓	✓
Vienna List					✓		✓	✓	
Methodologic steps									
Literature search	✓	✓	✓			✓	✓	✓	✓
Data extraction									✓
Quality appraisal									
Data synthesis/ summary	✓	✓	✓	✓	✓	✓	✓	✓	✓

Abbreviations: QoL, quality of life; BASQID, Bath Assessment of Subjective Quality of Life in Dementia [24]; DQoL, Dementia Quality of life [11]; MCQ, Mild Cognitive Impairment Questionnaire [25]; AAIQOL, Activity and Affect Indicator Quality of life [26]; CBS QoL, Cornell-Brown Scale for Quality of Life in Dementia [27]; H.I.L.DE., Heidelberg instrument for the assessment of quality of life in dementia [28]; QoL-AD, Quality of Life in Alzheimer's Disease [9]; QoL-AD NH, Quality of Life in Alzheimer's Disease Nursing home version [29]; QOLAS, Quality of Life Assessment Schedule [30]; ADRQL, Alzheimer Disease–Related Quality of Life [31] (Japanese version called AD-HRQL-J or later QLDJ) [32]; CDQLP, Community Dementia Quality of Life Profile [33]; DCM, Dementia Care Mapping [34]; OQOLD, Observing Quality of Life in Dementia [35]; OQOLDA, Observed Quality of Life in Dementia Advanced [35]; PWP-CIP, Psychological Well-being in Cognitively Impaired Persons [36]; QoL-D, Quality of Life for Dementia [37]; QUALID, Quality of Life in Late-stage Dementia Scale [38]; QUALIDEM [10], Vienna List [39].

steps, and results relevant to the objective of the present review were included.

2.2. Data extraction

Each included study was categorized according to the study objective, sample inclusion and exclusion criteria, setting, proxy-rater inclusion and exclusion criteria, proxy training, sample size, and properties of the dementia-specific QoL measurements (i.e., dementia severity, perspective [self-rating or proxy rating], time frame, subscales, number of items, response options, and scoring procedure).

2.3. Quality assessment

Two independent reviewers conducted the literature search and screening, data extraction, and quality appraisal (M.N.D., C.G.G.S.). In cases of disagreement, a third person assessed the article, and the disagreements were discussed until a consensus was reached. To assess the quality of linguistic validation (called cross-cultural adaptation), each stage of the process recommended by Beaton et al. [41] was assessed. This process covers initial translation, synthesis, back translation, expert committee review, and pilot testing of the preliminary translation (See Appendix C at www.jclinepi.com). According to Acquadro et al. [42], we use the more precisely term of linguistic validation because cross-cultural adaptation includes the translation (linguistic validation) and evaluation of the psychometric properties of a measurement. As recommended by Beaton et al. [41], and in accordance with Uysal-Bozkir et al.'s [43] procedure, the overall quality of the linguistic validation was rated as follows: "good" if 4 to 5 of the steps of linguistic validation were

rated as positive, ‘‘moderate’’ if 2 to 3 of the steps were positively assessed, and ‘‘insufficient’’ if 0 to 1 of the steps were rated as positive. In cases in which no information of the linguistic validation was reported or the information was not available, no overall conclusion was reached. The quality of the internal consistency, interrater reliability, and test–retest reliability was assessed according to the criteria of the quality appraisal tool for studies of diagnostic reliability (QUAREL) by Lucas et al. [44] and the criteria for psychometric properties of Health Status Questionnaires by Terwee et al. [45] (See Appendix D at www.jclinepi.com).

3. Results

3.1. Search results

After the removal of 1,943 duplicate references, the comprehensive database search resulted in 3,659 references. Application of the inclusion and exclusion criteria led to the exclusion of an additional 3,552 references, and subsequent screening of the titles and abstracts revealed 107 eligible references for full-text screening. A total of 59 articles remained for the review. Forward and backward citation tracking based on the reference lists and citations of the included 59 articles resulted in an additional 1,319 publications after deleting 1,423 duplicates. Screening revealed 11 additional articles for inclusion, resulting in a total of 70 included articles (Fig. 1) addressing 19 dementia-specific Qol measurements (See Appendix A at www.jclinepi.com).

3.2. Measurements assessing quality of life

Of the 19 included dementia-specific Qol measurements, 3 were based on self-rating scores (Bath Assessment of Subjective Quality of Life in Dementia [BASQID] [24], Dementia Quality of life [DQol] [11], and Mild Cognitive Impairment Questionnaire [MCQ] [25]); 7 were based on self-rating and/or proxy rating (Activity and Affect Indicator Quality of life [AAIQOL] [26], Cornell-Brown Scale for Quality of Life in Dementia [CBS Qol] [27], DEMQOL [21], Heidelberg instrument for the assessment of quality of life in dementia [H.I.L.DE.] [28], Quality of Life in Alzheimer’s Disease [Qol-AD] [9], Qol-AD Nursing home (NH) version [29], Quality of Life Assessment Schedule [QOLAS] [30]); and 9 were based on proxy rating only (Alzheimer Disease–Related Quality of Life [ADRQL] [31], Community Dementia Quality of Life Profile [CDQLP] [33], Dementia Care Mapping [DCM] [34], Observing Quality of Life in Dementia [OQOLD] and Observing Quality of Life in Dementia Advanced OQOL-DA [35], Psychological Well-being in Cognitively Impaired Persons [PWP-CIP] [36], Quality of Life for Dementia [Qol-D] [37], Quality of Life in Late-stage Dementia Scale [QUALID] [38], QUALIDEM [10], and Vienna List [39]). The characteristics of the identified measurements (See Appendix A at www.jclinepi.com), their reliability properties and information about their linguistic validations are summarized in Table 2. Detailed results of the quality appraisal for each of the reliability studies and the linguistic validations are summarized in Appendices E and F at www.jclinepi.com.

3.3. Self-rated Qol measurements

3.3.1. BASQID

The BASQID is a self-rating measurement for people with mild-to-moderate dementia, and it is only available in its original British version [24,46].

The internal consistency was well investigated in one study, with sufficient results [46]. One study with methodologic weaknesses evaluated the test–retest reliability and demonstrated satisfactory results [24].

3.3.2. DQol

The DQol is a self-rating measurement for people with mild-to-moderate dementia. It was developed in the US [11] and has been used in Great Britain [47], Taiwan [48], France [49], Spain [50], and Germany [51]. For two versions, no linguistic validation was reported [21,49,52]; for the other versions, the quality of these validation processes was between insufficient [48,50] and good [51]. The internal consistency of the original US version was investigated six times in a US sample [11,29,53–56] and once each in an Australian [52] and a British [21] sample. Internal consistency results are available for the linguistic-validated British [47], Taiwanese [48,57], French [49,58], Spanish [50], and German [51] versions. In summary, the results varied between the subscales and country-specific versions of the DQol. Test–retest reliability was only assessed twice for the US [11,56] and French versions [49,58] and once for the British [47] and Spanish [50] versions, with heterogeneous results based on several methodologic weaknesses.

3.3.3. MCQ

The MCQ is a recently developed measurement for people with mild cognitive impairment, and it is only available in its original British version [25]. The internal consistency was tested in one methodologically strong study [25], with sufficient results; the test–retest reliability results are missing.

3.4. Self- and proxy-rated Qol measurements

3.4.1. AAIQOL

The AAIQOL allows for self-rating and proxy rating of Qol in people with mild-to-severe dementia [26]. Only the original US version exists; there are no linguistic-validated versions for other countries.

For the AAIQOL, which is also called Qol-D, internal consistency was evaluated once in one study [54], with

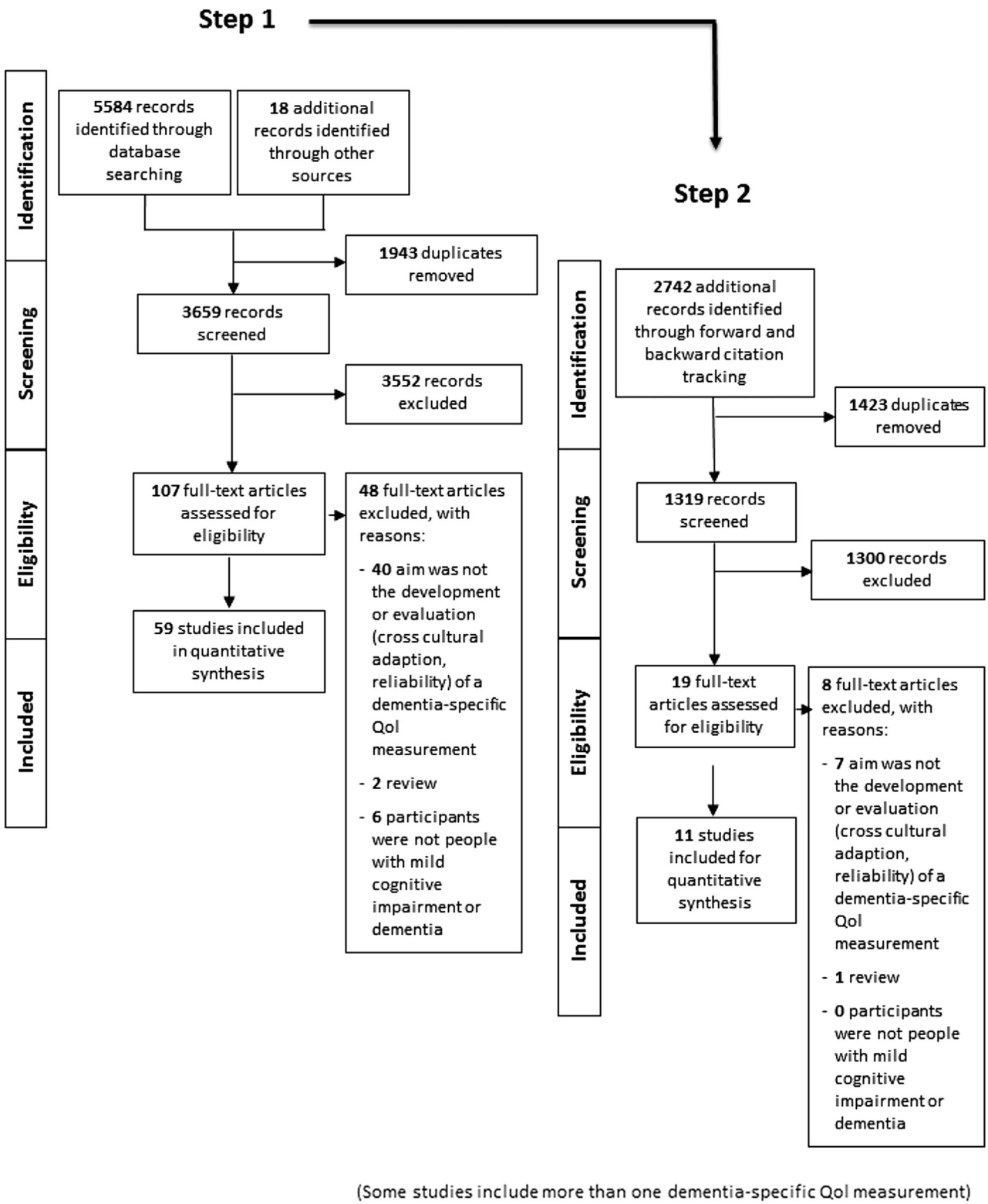

Fig. 1. A flow diagram of the literature search and study selection.

heterogeneous results depending on self-ratings or proxy ratings. Test–retest [26] and interrater reliability [54] were also assessed once. The test–retest reliability demonstrated varying results, depending on the items for both measurement versions [26]. The interrater reliability of the proxy-rating version showed nearly perfect results [54]. Both studies have methodologic limitations.

Table 2. Results of the linguistic validation and reliability evaluation of dementia-specific QoL measurements

Method of measurement/ measurements	Version—year of publication or validation	Quality of linguistic validation: Overall conclusion	Quality of reliability evaluation: IC	TRR	IRR
Self-rating only					
BASQID	(Original) GB—2007	NA	+	?	NA
DQoL	(Original) US—1999	NA	+	?	NA
	GB—2008	I	?	?	NA
	TW—2010	I	?	0	NA
	FR—2010	?	?	?	NA
	ES—2011	I	?	–	NA
	AU—2012	?	?	0	NA
	DE—2012	G	?	0	NA
MCQ	(Original) GB—2014	NA	+	0	NA
Self-rating and proxy rating					
AAIQOL (proxy)	(Original) US—1996	NA	? (?)	0 (?)	(?)
CBS QoL (proxy)	(Original) US—2002	NA	? (?)	0 (0)	(?)
	ES—2013	M	? (0)	0 (0)	(0)
DEMQOL (proxy)	(Original) GB—2005	NA	? (?)	? (?)	(0)
	DE—2009	?	? (?)	0 (0)	(0)
	ES—2010	I	? (?)	? (0)	(0)
H.I.L.DE.	(Original) DE—2005	NA	0 (0)	? (?)	?
QoL-AD (proxy)	(Original) US—1999	NA	? (?)	? (?)	(0)
	GB—2001	I	+ (?)	? (0)	(0)
	BR—2005	M	? (?)	? (?)	(0)
	TW—2006	?	? (?)	0 (0)	(0)
	JP—2006	I	? (?)	? (?)	(0)
	(Mandarin) CN—2008	M	? (?)	? (?)	(0)
	FR—2009	G	? (?)	? (?)	(0)
	(Cantonese) CN—2011	I	? (?)	? (?)	(0)
	TR—2012	M	? (?)	0 (0)	(0)
	PT—2013	M	? (?)	? (?)	(0)
	ES—2014	I	+ (?)	? (?)	(0)
	DE—2014	?	0 (+)	0 (0)	(0)
QoL-AD NH (proxy)	(Original) US—2005	NA	? (?)	0 (0)	(?)
	AU—2012	?	? (0)	0 (0)	(0)
QOLAS (proxy)	(Original) GB—2001	NA	? (?)	0 (0)	(0)
Proxy rated only					
ADRQL/Japanese version called AD-HRQL-J or later QLDJ	(Original) US—1999	NA	?	0	?
	JP—2000	I	?/+	?/?	?/?
	CH—2006	I	–	0	?
	DE—2013	?	?	0	0
CDQLP	(Original) US—1996	NA	0	0	0
DCM	(Original) GB—1992	NA	0	?	–
	DE—2004	I	0	0	–
	US—2005	I	0	0	?
OQOLD/OQOLDA	(Original) US—2007	NA	0/0	0/0	0/?
PWP-CIP	(Original) US—2005	NA	+	0	0
QoL-D	(Original) JP—2002	NA	+	0	?
QUALID	(Original) US—2000	NA	?	?	?
	SE—2007	I	+	?	–
	ES—2010	M	+	0	+
	NO—2014	?	+	0	0
QUALIDEM	(Original) NL—2007	NA	+	?	–
	DE—2011	I	+	+	–
Vienna List	(Original) AT—2004	NA	?	0	–

Abbreviations: QoL, quality of life; IC, internal consistency; TRR, test–retest reliability; IRR, interrater reliability; BASQID, Bath Assessment of Subjective Quality of Life in Dementia; DQoL, Dementia Quality of life; MCQ, Mild Cognitive Impairment Questionnaire; AAIQOL, Activity and Affect Indicator Quality of life; CBS QoL, Cornell-Brown Scale for Quality of Life in Dementia; H.I.L.DE., Heidelberg instrument for the assessment of quality of life in dementia; QoL-AD, Quality of Life in Alzheimer's Disease; QoL-AD NH, Quality of Life in Alzheimer's Disease Nursing home version; QOLAS, Quality of Life Assessment Schedule; ADRQL, Alzheimer Disease–Related Quality of Life (Japanese version called AD-HRQL-J or later QLDJ); CDQLP, Community Dementia Quality of Life Profile; DCM, Dementia Care Mapping; OQOLD, Observing Quality of Life in Dementia; OQOL-DA, Observed Quality of Life in Dementia Advanced; PWP-CIP, Psychological Well-being in Cognitively Impaired Persons; QoL-D, Quality of Life for Dementia; QUALID, Quality of Life in Late-stage Dementia Scale.

Linguistic validation overall conclusion: G = good; M = moderate; I = insufficient; ? = no information reported or cited source not available; NA = Not Applicable. Reliability evaluation overall rating: + = positive rating; – = negative rating; 0 = no information available; ? = unclear; NA = Not Applicable.

3.4.2. CBS Qol

The CBS Qol is a self- and proxy-rating measurement that was developed for people with mild-to-moderate dementia. It is available in its original US version [27] and in a linguistic-validated Spanish version; the quality of the linguistic validation process was moderate [59].

Internal consistency of the CBS Qol was determined twice for the original US version [27,60] and once for the Spanish version [59]. An evaluation of the test–retest reliability is missing, and only one assessment of interrater reliability for the proxy version of the CBS Qol exists [27]. The three reliability studies showed satisfying results. However, the specific weaknesses of internal validity must be considered in each reliability study.

3.4.3. DEMQOL (self-rated and proxy rated)

The dementia-specific measurements DEMQOL and DEMQOL proxy were originally developed in Britain [21] for people with mild-to-severe dementia. Both versions were linguistic-validated to a German [61] and a Spanish version [62]. The quality of the linguistic validation for the Spanish version [62] was judged to be insufficient. The quality could not be assessed for the German version because the conference abstract is not accessible [61,63].

Internal consistency of the British version was reported twice in one article [21] and that of the German [61] and Spanish versions [62] was reported once. The results were good for the British and Spanish versions and heterogeneous for the German version. The test–retest reliability was investigated for the British [21] and Spanish versions [62], with satisfying results. For all results, several methodologic limitations must be considered. An investigation of the interrater reliability of the DEMQOL proxy was not identified.

3.4.4. H.I.L.DE.

H.I.L.DE. is a Qol measurement for people with mild-to-severe dementia. It is mainly based on proxy rating; however, for some items, self-rating is required [28,64]. The original version is German, and no version for another country exists.

In one weak methodologic study, the test–retest and interrater reliability were investigated and demonstrated heterogeneous results depending on the particular item [64].

3.4.5. Qol-AD and Qol-AD proxy

The Qol-AD (proxy rating and self-rating) [9] is the most widely used dementia-specific Qol measurement for people with mild-to-severe dementia. For the Qol-AD, there are linguistic-validated versions for Great Britain [65], Brazil [66], Taiwan [67], Japan [68], Mandarin [69] and Cantonese China [70], France [71], Spain [72], Turkey [73], and Portugal [74]. The quality of these linguistic validations varied between good [71], moderate [66,69,73,74], and insufficient [65,68,70,72].

Internal consistency of the original US version was evaluated twice for the self- and proxy-rated versions [9,75] and once for a combined self- and proxy-rated version [76]. Internal consistency was assessed twice each for the British [21,77], Brazilian [66,78], Japanese [68,79], Chinese Mandarin [69,80], French [58,71], and Spanish versions [72,81]. For the Taiwanese [67], Chinese Cantonese [70], Turkish [73], and Portuguese versions [74], one study was available. One study was also available for the German proxy Qol-AD version; however, no information is available concerning its linguistic validation [82]. For all investigated Qol-AD versions, the internal consistency was sufficient. Test–retest reliability was investigated twice for the Chinese Mandarin [69,80], and French versions [49,58] and once for the US [76], British [77], Brazilian [66], Japanese [68], Chinese Cantonese [70], Spanish [81], and Portuguese versions [74]. The results showed satisfactory results for all versions, except for the Spanish Qol-AD proxy version [81]. However, the different methodologic weaknesses of the reliability studies (internal consistency and test–retest reliability) must be considered. Studies on the interrater reliability of the Qol-AD proxy version are missing.

3.4.6. Qol-AD NH (self and proxy)

The Qol-AD NH version is based on the original version, which is also used for people with mild-to-severe dementia [9]. For the adaption to the NH setting, 2 of the original 13 items were deleted, four items were added, and the wording of three items was changed [29]. In previous reviews, the two Qol-AD versions were described together. However, because of the substantial differences between the two versions, we treated them as single instruments. For the Qol-AD NH version, a self- and a proxy-rating version is available. In addition to the application in a US setting, the original version was applied to an Australian sample, without linguistic validation [52]. Currently, no version for another language is available.

The internal consistency of the self-rated and proxy-rated versions was studied in three US [29,53,54] studies and one Australian study [52], with sufficient results. No studies addressing test–retest reliability were identified. The interrater reliability of the proxy version was investigated in one US study [54], and it demonstrated nearly perfect agreement. To interpret the reliability properties, the methodologic limitations of each study must be considered.

3.4.7. QOLAS

The QOLAS is a dementia-specific measurement for the Qol rating of people with mild-to-moderate dementia [30]. Beyond the original British version, no other version is available.

The internal consistency of the self- and proxy-QOLAS version was investigated in one study that had methodologic weaknesses; this study showed a sufficient Cronbach alpha [30]. No studies on the test–retest and interrater reliability of the QOLAS were identified.

3.5. Self- and proxy-rated Qol measurements

3.5.1. ADRQL

The ADRQL is a proxy-rated Qol measurement for people with mild-to-severe dementia. In addition to the original US [31] version, linguistic-validated versions are available for Switzerland [83] and Japan [32]. The quality of both linguistic validation processes was assessed as insufficient.

The internal consistency of the original US version was investigated four times [29,53,54,84] and that of the German-Swiss version was investigated once [83]. The internal consistency was tested in Germany, whereas no information was reported about the applied version and a possible linguistic validation [82]. For the Japanese version, the internal consistency was also tested twice. In the first Japanese study, the ADRQL with 48 items and 5 subscales was tested and named AD-HRQL-J [32]. In the second study, the item number was reduced to 24 items that represented three subscales, "interacting with surroundings, expressing self, and experiencing minimum negative behaviors," and named QLDJ [85]. Depending on the subscales, heterogeneous results were found for internal consistency. All studies, except Yamamota et al. 2002 [85], had several methodologic limitations. The test–retest reliability was only assessed for the two Japanese versions of the measurement, with varying results. The study with the highest internal validity showed good test–retest reliability [85].

Interrater reliability was investigated for the original US version [54], the Swiss version [83], and twice for the Japanese version [32,85]. The results were good for the US and Japanese versions and weak for the Swiss version. The interrater reliability studies showed several methodologic limitations.

3.5.2. CDQLP

The CDQLP, which was developed in the US, is a proxy measurement for the assessment of Qol in people with mild-to-severe dementia [33]. Neither linguistic-validated versions for other languages nor reliability studies exist for this measure.

3.5.3. DCM

DCM is a dementia-specific Qol measurement that is based on proxy observations [34]. The original British version was developed in several steps. The identified studies applied the seventh DCM version. In addition to two British studies [86,87], we identified one German [88] and two US reliability studies [54,89]. A linguistic validation was not described for the application in Germany or the US.

No study investigated the internal consistency of DCM, and only one study tested the test–retest reliability. Test–retest reliability was evaluated for the British version, and it demonstrated unsatisfying results on the basis of a weak study design [86]. The interrater reliability was investigated once for the British [87] and German versions [88] and two times for the US version [54,89]. The studies show heterogeneous results, depending on the observed items. All interrater reliability studies lacked internal validity.

3.5.4. OQOLD and OQOLDA

The OQOLD version for mild to moderate and the OQOLDA version for severe dementia are observation-based proxy Qol measurements that were developed in the US [35]. No version for another language exists.

Only one methodologically weak reliability study investigated these measures' interrater reliability. This study suggested sufficient interrater reliability [35].

3.5.5. PWP-CIP

The PWP-CIP is a proxy-rating Qol measurement for people with mild-to-moderate dementia and was developed in the US [36]. No other linguistic-validated version is available.

Only one study evaluated the internal consistency of this measure [36]. The study was of sufficient methodologic quality and showed sufficient internal consistency.

3.5.6. Qol-D

Dementia-specific Qol measurement is a proxy-based Qol-D that was developed in Japan [37]. No version to any other language is available.

One well-designed study demonstrated the internal consistency of the original version and showed sufficient interrater reliability. The interrater reliability results are based on methodologic limitations [37]. Further reliability studies do not exist.

3.5.7. QUALID

The QUALID allows Qol assessments of people with moderate-to-severe dementia. In addition to the original US version [38], linguistic-validated versions are available for Sweden [90], Spain [91], and Norway [92]. The quality of the linguistic validation ranged between insufficient [90] and moderate [91]. For the Norwegian version, all information on the linguistic validation were reported in a conference abstract that is not available electronically [92].

For each QUALID version, one investigation of internal consistency exists, demonstrating satisfactory results. The Spanish [91] and Norwegian studies [92] showed high internal validity, whereas the original US [38] and Swedish studies [90] showed multiple methodologic weaknesses. Test–retest reliability was assessed for the latest two versions, demonstrating a high consistency of Qol ratings based on weak study designs [38,90]. Interrater reliability was evaluated once for the US [38], Swedish [90], and Spanish versions [91], demonstrating heterogeneous results. In addition, the methodologic quality of the studies was influenced by several weaknesses.

3.5.8. QUALIDEM

QUALIDEM is a proxy-based measurement that consists of one version for people with mild-to-severe dementia and one consecutive version for people with severe dementia [10]. In addition to the original Dutch version, one linguistic-validated German version is available. The quality of the used validation process was insufficient [93].

The internal consistency was assessed twice for the Dutch version [10,94] and three times for the German version [82,93,95]. For both versions, the studies demonstrated heterogeneous results depending on the subscales. The internal validity was high in one Dutch [94] and German study [95]. The other three studies showed multiple methodologic shortcomings [10,82,93]. Test–retest reliability was investigated once for the Dutch [10] and German versions [16], showing satisfactory results. The Dutch study had weak internal validity, whereas the German investigation showed high internal validity. The same two studies investigated interrater reliability, with unsatisfying results. The methodologic quality was equal, as mentioned for test–retest reliability.

3.5.9. Vienna List

The Vienna List allows Qol ratings for people with severe dementia [39]. The original version was developed in Austria, and no other is available.

The internal consistency of the Vienna List was studied once and demonstrated good consistency for nurse and physician ratings. In the same study, the interrater reliability was evaluated, demonstrating heterogeneous results, depending on the subscales. The investigation of both reliability properties had methodologic shortcomings [39]. No studies examined this measure's test–retest reliability.

4. Discussion

This systematic review follows the criteria of the AMSTAR tool [96] and is the first review of dementia-specific Qol measurements to report a detailed quality appraisal for each of the included studies. On the basis of the systematic literature search, 19 dementia-specific Qol measurements, which are heterogeneous according to their perspectives (i.e., self-rating or proxy rating) and operationalization of Qol in terms of subscales and items, were identified. Nine of these measurements are also used in countries other than the original country (i.e., DQol, CBS Qol, DEMQOL and DEMQOL proxy, Qol-AD, Qol-AD NH, ADRQL, DCM, QUALID, QUALIDEM). The quality of the conducted linguistic validation processes for these measurements varied between insufficient and good [51,71,73,91]. In six studies, dementia-specific Qol measurements were used in countries other than that of the original measurement version, but no information was available about the linguistic validation [21,49,52,54,67,82]; two studies cited conference abstracts that are not accessible as references for the linguistic validation process [61,92].

No linguistic validation followed all five steps recommended by Beaton et al. [41]. The steps synthesis, back translation, expert committee, and pilot testing were reported in less than half of the studies, and the quality rating of these steps varied. All adaptation processes were performed for the main language of the target country. Thus, no linguistic validation was performed for a minority group of immigrants in the target country. Beaton's linguistic validation approach was published 15 years ago, and only one study [32] that was included in the present review was published before that time. The large number of weak linguistic validation processes may hinder the development of equivalent measurements across countries, which are the basis for cross-national comparisons of Qol data. Moreover, the weak linguistic validations must be interpreted as a barrier to the application of dementia-specific Qol measurements in multinational research projects. On the basis of the increasing number of multinational research projects, this methodologic limitation must be solved in the future. Therefore, the performance of linguistic validation processes based on international guidelines is strongly recommended to ensure the development of equivalent scales across countries [43]. In addition, a clear description of the applied measurement version is recommended.

Internal consistency, which is certainly the weakest reliability property, is the most frequently tested reliability property. Of the 67 reliability studies, 58 investigated the internal consistency of 15 Qol measurements. Using the Terwee et al. criteria [45], the methodologic quality of only 14 internal consistency evaluations was rated as positive [25,36,37,46,56,72,77,82,85,90–92,94,95]. Methodologic weaknesses included small sample sizes [9,10,21,24,27,29,30,32,38,39,47–50,52–55,57–62,66,67,69,73,76,78–82,93], no analysis of the factor structure of the measurement [9,11,21,24,29,30,32,47–55,57–61,66–71,73–76,78–81,83,84], missing information on the characteristics of the study participants and missing information on the subsample for evaluation of internal consistency [10,54], missing information on characteristics of the proxy raters [27,29,32,38,39,53,54,59,84,85,92–95], and unreliable calculation of the statistical measurements [21,53,86].

A total of 31 studies reported test–retest reliability results for 10 measurements, and 20 studies reported interrater reliability for 11 measurements. The quality rating of these studies resulted in a positive rating for one test–retest reliability [16] and one interrater reliability study [91] that used the QUAREL tool [44]. The internal validity of test–retest and interrater reliability studies was threatened by small sample sizes [9,11,21,24,26,27,32,35,37–39,46,47,50,54,62,64,66,69,70,74,76,77,80,81,83,85–88,90], missing information on the characteristics of study participants [9,10,26,37–39,54,64,66,68–70,74,80,81,83,87,89,90] or proxy raters [9,10,26,27,32,35,37–39,54,64,66,68–70,74,80,81,83,85–87,89,90], inappropriate statistical

measurements [11,56,76], missing determination of statistical uncertainty [9,10,11,21,26,27,32,35,37,39,44,47,49,50,54,58,64,66,69−71,77,80,81,83,85−87,89,90], and missing information on blinding between the first and second observations or different proxy raters [9,10,11,21,26,27,32,35,37,39,46,47,49,50,54,56,58,62,64,66,68−71,74,77,80,81,83,85,86,90]. Because reliability is a necessary condition of the validity of a measurement, these results are surprising and highlight the need for methodologically well-designed reliability studies in the field of dementia-specific Qol measurements. An in-depth analysis of the test−retest and interrater reliabilities of different measurement items to gather a more detailed understanding of the properties of more or less reliable items was not feasible because of the missing information on the reported results at the item level.

The need for reliable dementia-specific Qol measurements is also illustrated by the need for effective psychosocial or nonpharmacological interventions in the field of dementia research and practice. The effectiveness of numerous interventions has been investigated in the past, and these studies demonstrated mostly unsatisfactory results [97]. One possible explanation for these results is insufficient knowledge about the reliability properties of applied dementia-specific Qol measurements, with negative consequences for the validity of the measures' Qol values.

On the basis of the linguistic validation and reliability results, the self-rated measurements DQol and Qol-AD and the proxy measurements QUALID and QUALIDEM seem to be the most widely studied measurements. However, the results of the present review demonstrate that these measurements also require further investigation. In general, before the application of a measurement in observational or experimental studies and in accordance with Schölzel-Dorenbos et al. [20], the researchers must select the most appropriate measurement on the basis of the measurement perspective, the recommended dementia severity stage and setting for the particular measurement, and the operationalization of the concept of Qol. In a second step, the investigation of the (likely) missing linguistic validation steps and reliability properties is recommended. To realize the needed linguistic validation steps and to evaluate the psychometric properties, financial funding must be increased for of these methodologic steps.

4.1. Strengths and limitations

This review is the first to consider the quality of the linguistic validation process. Thus, this review adds to the body of knowledge on dementia-specific Qol measurements and delivers a more detailed analysis compared to earlier reviews [7,8,17−22]. As a limitation, note that according to the inclusion and exclusion criteria, only the studies that addressed measurement development and psychometric testing were included. Other designs that may have provided information regarding the measurement properties were excluded. English and German language studies were considered for inclusion. Therefore, a possible language bias is not excluded. Because Qol is one major outcome in interventions, future studies on the psychometric properties of Qol measurements should be strengthened as a research priority. A financially independent international database that aims to register Qol measurement applications and that generates results on psychometric properties is desirable. Such a database will allow the estimation of possible language biases and decrease the possibility of publication biases in future reviews.

According to its objective, this review is limited to the linguistic validation and reliability of measurement scales. For a detailed evaluation of the validity of these measurements, a second review will be published elsewhere. As mentioned in the review by Bowling et al. (2015) [8], a rigorous appraisal scheme must be developed for a detailed validity review, which will allow the appraisal of the relationship of the conceptual framework of each Qol measurement and the applied validation strategies.

5. Conclusions

In summary, it has become clear that more research is needed to establish strong dementia-specific Qol measurements, which could be used for the evaluation of interventions in the context of dementia care or health care services. In addition to reliability studies, this review shows a need for rigorous linguistic-validated measurements. Without such measurements, the use of the same dementia-specific Qol measurements in different countries is questionable. For the performance of linguistic validations and reliability studies of dementia-specific Qol measurements, the application of international guidelines and quality criteria is strongly recommended. In addition, the analysis and reporting of reliability properties for each measurement item is recommended to allow an in-depth analysis of the properties of more or less reliable items.

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Supplementary data

Supplementary data related to this article can be found at http://dx.doi.org/10.1016/j.jclinepi.2015.08.002.

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