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Research Article

Measuring the quality of life of people with dementia in nursing homes in Germany – the study protocol for the QoI-Dem Project

Die Erfassung der Lebensqualität von Menschen mit Demenz in stationären Altenpflegeeinrichtungen in Deutschland – Studienprotokoll des QoI-Dem Projektes

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Abstract

Background: QUALIDEM is a standardized dementia-specific quality of life (QoI) measurement, which was developed and validated in the Netherlands. A German version has been available since 2008. This study protocol describes the design and methodology for the quality of life of people with dementia (QoI-Dem) project.
Objective: This project aims to evaluate the reliability and validity of the German version of the QUALIDEM.
Method: Due to the lack of both a universal definition of QoI and of standards to verify the validity of QoI measurements, this study is divided into three phases. The aim of the first theoretical phase is the development of a dementia-specific QoI model as a result of a meta-synthesis of qualitative studies. The second empirical phase consists of the three following steps: (a) an investigation of the scalability and internal consistency of the measure, (b) an evaluation of the interrater and intrarater reliability, and (c) an extensive evaluation of the validity of the QUALIDEM. The resulting QoI model (phase 1) will be used for the selection of appropriate comparators for validity testing. In the third phase, the QUALIDEM will be adapted, if necessary, based on the knowledge generated in the first two phases.
Conclusion: The findings of the QoI-Dem project should deliver an accurate assessment of the psychometric properties of the German version of the QUALIDEM. The results will contribute to the further development of the instrument. Furthermore, the results will contribute to the theoretical development of the concept of QoI among people with dementia.

Keywords: quality of life, dementia, nursing homes, psychometrics, proxy-assessment, meta-synthesis, QUALIDEM

Zusammenfassung

Hintergrund: Das standardisierte demenzspezifische Lebensqualitätsinstrument QUALIDEM wurde in den Niederlanden entwickelt und validiert. Eine deutsche Übersetzung des Fragebogens liegt seit 2008 vor. Das vorliegende Studienprotokoll beschreibt Design und Methode des Quality of life of people with dementia (QoI-Dem) Projektes.
Zielsetzung: Ziel dieses Projektes ist die Untersuchung der Reliabilität und Validität der deutschsprachigen QUALIDEM-Version.
Methodik: Da eine allgemeingültige Definition der Lebensqualität von Menschen mit Demenz ebenso wie ein Standard zur Untersuchung der Validität von Lebensqualitätsinstrumenten fehlt, ist die Studie in drei Phasen unterteilt: Ziel der ersten theoretischen Phase ist die Entwicklung eines Modells zur Lebensqualität von Menschen mit Demenz als Ergebnis einer Meta-Synthese qualitativer Studien. Die zweite empirische Phase besteht aus drei Schritten: (a) einer Untersuchung der Skalier-

barkeit und Internen Konsistenz, (b) einer Evaluation der Interrater- und Intrarater-Reliabilität und (c) einer intensiven Überprüfung der Validität des QUALIDEM. Ausgehend von dem entwickelten Lebensqualitätsmodell aus Phase 1 erfolgt die Auswahl geeigneter Vergleichskonstrukte zur Untersuchung der Validität. Basierend auf den Ergebnissen der beiden ersten Phasen erfolgt bei Bedarf eine Überarbeitung des deutschsprachigen QUALIDEM.

Fazit: Insgesamt soll das QoI-Dem Projekt eine genaue Einschätzung der testtheoretischen Eigenschaften sowie einen Beitrag zur Weiterentwicklung des QUALIDEM liefern. Daneben werden die Ergebnisse zur theoretischen Weiterentwicklung des Konzeptes Lebensqualität von Menschen mit Demenz beitragen.

Schlüsselwörter: Lebensqualität, Demenz, stationäre Altenpflegeeinrichtung, psychometrische Eigenschaften, Fremdeinschätzung, Meta-Synthese, QUALIDEM

Introduction

The incidence and prevalence of dementia is increasing due to changes in demographics [1]. The most common type of dementia, Alzheimer's disease, is expected to increase from approximately 6 to 13 million affected people in Europe by 2040 [2]. In addition, estimates suggest an increase from the current prevalence of 1.2 million people in Germany to 2.5 million in the year 2060 [3]. Dementia is the primary reason why older adults are admitted to a nursing home [4]. In Germany, approximately 70% of care-dependent people with dementia live in nursing homes [3], [5]. For people with dementia, the disease results in a loss of significant roles, respect, autonomy, self-worth and competency [6]. Dementia is a progressive disease with an often insidious onset. This allows those who are affected with the disease to adapt to the situation and to manage the disease actively [7]. Because the disease is not curable, caring interventions provide support for patients who are trying to adapt to their new and changing life situation. The primary objective of care is the maintenance and promotion of quality of life (QoI) in this population [8]. Therefore, QoI has become a primary outcome in intervention studies and an indicator for the quality of care in this population [9], [10]. In addition, there is a need for dementia-specific QoI-measures [11], [12]. Thus, several dementia-specific QoI measures have been developed, which have used self-ratings, proxy ratings or observational data as information sources [12], [13]. QoI is a subjective, multi-dimensional and independent construct [14]. Therefore, self-reports from people with dementia are acknowledged as the gold standard for measuring QoI in this population [15], [16]. However, the cognitive decline among people with dementia is characterized by memory and concentration deficits and results in a decrease in decision-making and communicative abilities. Therefore, the reliability and validity of QoI self-reports has been questioned in later stages of the disease [12], and the use of proxy measures is preferred in advanced dementia and for longitudinal QoI evaluation [17]. However, proxy-rated QoI measures are associated with numerous methodological difficulties. Scores are systematically lower than self-rated QoI values [18], [19], [20], [21]. Proxy-rated QoI values from people with dementia are influenced by the burden [22], [23] and attitudes of proxy-raters [24]. Existing measurements can be distinguished based on their feasibility, psychometric properties, stage of dementia and care setting in which the application of the instrument is possible, as well as the underlying QoI definition and domains [12], [13]. These factors complicate the selection of an appropriate instrument.

The lack of theoretical clarity leads to a wide variance in the different strategies for the psychometric evaluation of these instruments, especially the evaluation of validity. Thus, different comparators and statistical methods have been used for the evaluation of the validity of dementia-specific QoI measures. These comparators include other standardized generic instruments, e.g. the EQ-5D [23], different dementia-specific measurements [25] and general ratings of the QoI of people with dementia that are made by relatives or head nurses. Mood and feelings [26], domains of challenging behavior [27], daily and social activities [27], [28], pain medication [29] as well as functional and cognitive ability are the commonly used comparators [25], [27], [28], [30]. The last two comparators might be questioned as long as there is no evidence for the assumption that a correlation, for example between cognitive impairment and QoI, is a reference for the validity of a dementia-specific QoI-measure. In contrast, pain is rarely used as a comparator, although pain is very likely to be associated with reduced QoI [31] and has a high prevalence in nursing home residents [32], [33]. Because a commonly accepted QoI definition does not exist, and standards to verify the validity of assessments as well as a validated set of comparators are lacking, it remains unclear how the validity of dementia-specific QoI-measures, either for self-rating or proxy-rating, should be appropriately investigated.

QUALIDEM

QUALIDEM is a fairly new dementia-specific QoL instrument [34]. It has been evaluated with respect to its psychometric properties with a focus on psychosocial domains [34]. The instrument is easy to administer [35] and was developed for proxy-rating of QoL throughout the entire course of dementia in nursing home residents [27]. Consequently, QUALIDEM is recommended for QoL assessment in the late stages of dementia [36] and to assess QoL longitudinally [11]. QUALIDEM was developed and validated between 2005 and 2007 by Dutch researchers. The instrument consists of two versions. QoL among people with mild to severe dementia is assessed using the 37 item-version covers the following nine domains of QoL: *care relationships, positive affect, negative affect, restless tense behavior, positive self-image, social relationships, social isolation, feeling at home* and *having something to do*. The domains *positive self-image, feeling at home* and *having something to do* cannot be assessed in people with very severe dementia. Thus, the second version consists of 18 items covering the following six domains of QoL: *care relationship, positive affect, negative affect, restless tense behavior, social relationships* and *social isolation*. The response options for all items are as follows: never, rarely, sometimes and frequently. The stages of dementia severity are classified according to the Global Deterioration Scale (GDS), which is a staging instrument indicating cognitive deterioration in dementia [37]. The scale score ranges from 1 to 7 (1: free of cognitive impairment, 2–6: very mild dementia to severe dementia, 7: very severe dementia) [37].
In 2008, the QUALIDEM was translated to German by a certified agency using forward-backward translation. The back-translated version has been verified by the questionnaire's first author, and the German version has been subsequently revised based on his comments. An initial exploratory study demonstrates the construct validity, as measured by factor analysis, and the moderate to high internal consistency of the German version [35].

Aim of the study

The study primarily aims to investigate the reliability and further validity of the QUALIDEM in Germany, using a theoretical framework for the evaluation of validity. To achieve this aim, a further goal is the development of a dementia-specific QoL model as a result of a meta-synthesis of qualitative studies. This is an important foundation for deriving appropriate strategies for the evaluation of the validity of dementia-specific QoL measurements among people with dementia.
The specific research questions are as follows:

- Which domains of QoL are described as relevant from the perspective of people with dementia?
- To what extent is the scalability of the German QUALIDEM?
- To what extent is the internal consistency of the German QUALIDEM?
- What is the interrater reliability of the German QUALIDEM?
- What is the intrarater reliability of the German QUALIDEM?
- To what extent is the validity of the German QUALIDEM?

Methods

The project consists of three methodological phases with different steps (Figure 1). The phases build on each other; thus, the results of the first phases will influence and guide the methods used in the following phases.

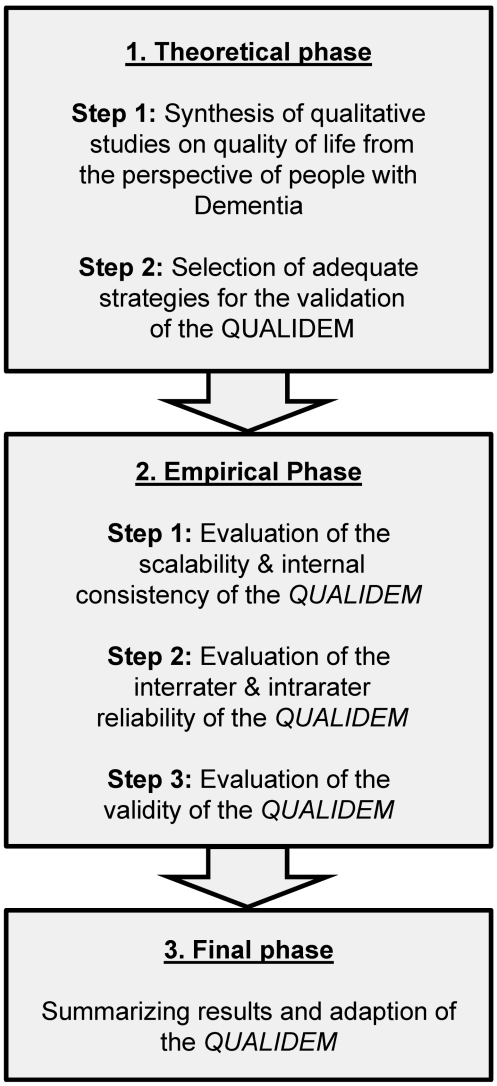


Figure 1: Phases of the evaluation of the QUALIDEM

Theoretical phase

Referring to the first research question, a meta-synthesis of qualitative studies on QoL from the perspective of people with dementia will be performed (Review registration: PROSPERO register CRD42013005014). This syn-

Table 1: Inclusion criteria for the study selection in the theoretical phase

Participants	Persons with dementia
Objective	Identification or description of QoI from the perspective of people with dementia (excluding studies based on a proxy-perspective, e.g. relatives, caregivers) Identification or description of influencing factors of QoI from the perspective of people with dementia (excluding studies based on a proxy-perspective, e.g. relatives, caregivers)
Design	Any qualitative method such as grounded theory, ethnographic and phenomenological studies
Language	English or German

thesis of perspectives on QoI will result in a dementia-specific QoI model and guide the selection of adequate strategies for the validation of the QUALIDEM as a further step.

Search strategy

To identify all relevant published studies addressing the research question, an extensive search strategy will be used covering the databases Medline, EMBASE, CINAHL, and PsychINFO without any time limit. Search terms for all relevant expressions of dementia and QoI will be combined using a sensitive strategy from the McMaster University, Canada [38] for the identification of qualitative studies. Reference lists of included publications will be checked. Web of Science or eligible databases will be used for forward citation tracking of selected papers.

Selection of the studies and quality appraisal

Both the selection of the relevant studies and the quality appraisal of the studies will be conducted by two independent reviewers. In the case of any discrepancy, a consensus will be reached by discussion or via consultation with a third reviewer. Table 1 provides the pre-defined inclusion criteria for the study selection.
The methodological quality of the selected studies and manuscripts will be assessed using the formal appraisal criteria from the Critical Appraisal Skills Programme [39].

Data extraction and synthesis

Data extraction will be conducted by two independent reviewers using the template form of the Qualitative Assessment Review Instrument [40]. Potential discrepancies will be discussed until a consensus is achieved, if necessary with the addition of a third reviewer. The principles and procedures of grounded theory will guide the analysis of the included publications [41]. In particular, the constant comparative method will be used for the coding, identification of categories and synthesis. The possible influence of culture and care setting as well as influences over time will be considered during the synthesis. The data will be analyzed using the MAXQDA software [42].

Selection of validation strategies

The results of the meta-synthesis will be used to determine the appropriate strategies for the validation of the QUALIDEM (see also empirical phase: validity).

Empirical phase: scalability and internal consistency

To evaluate scalability and internal consistency (research questions 2 and 3), a secondary data analysis of baseline data from the following three studies will be performed: Data collected in a pre-post-test design on the evaluation of quality instruments in nursing homes (InDemA: Interdisciplinary Implementation of Quality Instruments for the Care of residents with Dementia in Nursing Homes) [43], a cluster-randomized controlled trial on the evaluation of the Serial Trial Intervention (STI-D: Serial Trial Intervention-Germany) [44], and a cross-sectional study on Dementia Care Mapping use (Leben-QD I: Strengthening QoI among people with dementia) [45].

Setting and location

Data collection for the InDemA study occurred between October and December 2008, for the STI-D study between January and March 2009, and for the Leben-QD I study between September and November 2010. The total sample consisted of approximately 630 residents with dementia from 43 German nursing homes located in the area of Frankfurt/Main (STI-D study, n=19) and in North-Rhine Westphalia (InDemA study and Leben-QD I study, n=24).

Procedures

In the three primary studies, nurses with different qualifications (registered nurses and nursing assistants) completed the instrument based on a retrospective observation period of two weeks. Inclusion criteria for nurses were a close relationship to the assessed resident. A Functional Assessment Staging (FAST) [37] score ≥2 (Leben-QD I) or a Mini Mental Status Examination (MMSE) [46] score ≤24 (InDemA and STI-D) were the inclusion criteria for residents with dementia. In addition, the residents were required to have been living in the nursing home for at least 2 weeks (Leben-QD I and InDemA) or 4 weeks (STI-D). The Mini Mental Status Examination (MMSE) ranges from 1 to 30 points (≤ 24 points: mild dementia, ≤ 10 points: severe dementia) [46]. The interpretation of the FAST scale is similar to the GDS [37]. Exclusion criteria were a documented diagnosis of schizophrenia or other psychotic disorders (InDemA and STI-D). For the purpose of quality assurance, QUALIDEM administration was always initiated by external study as-

sistants who were registered nurses and students in nursing or health care study programs. They received prior training on data collection, and a comprehensive manual for data collection was available.

Statistical methods

To examine whether the adopted Dutch subscales are present in the German version of the QUALIDEM, Mokken's non-parametric latent trait model for uni-dimensional scaling will be used in a confirmatory manner. This non-parametric method is an improved version of the Guttman scale, which has a broad application in the social sciences [47]. Using this method, it is possible to identify homogeneous unidimensional (sub)scales based on a set of ordinal polytomous items, which allows for the reliable ranking of individuals. In addition, the choice of this technique provides the possibility of a direct comparison with the results from previous Dutch studies [11], [34]. To examine the internal consistency, Cronbach's Alpha will be calculated for all resulting subscales. If the presumption of double monotonicity will be fulfilled, the reliability coefficient Rho will also be calculated. This coefficient is not as prone to bias as Cronbach's alpha [48]. The Mokken scale analysis will be performed using the Mokken package for the software R [48], [49].

Empirical phase: interrater and intrarater reliability

This step aims to answer research questions 4 and 5, which result in an estimation of the interrater and intrarater reliability of QUALIDEM.

Setting and location

The data for interrater and intrarater reliability testing will be collected as a part of the baseline data collection of the Leben-QD II study (a quasi-experimental trial on Dementia Care Mapping use) [50]. This sample consists of residents of nursing homes distributed across the state North-Rhine Westphalia.

Sample size calculation

The sample size calculation is based on the recommendations of Bonett et al. [51]. They developed a method to estimate the number of subjects required for two or more raters to obtain a 95% confidence interval (CI) with desired width for any planning value of intraclass correlation coefficient (ICC). We aim to achieve ICCs similar to that obtained by Ettema et al. calculated for the different QUALIDEM subscales in their study [34]. We use the planning ICC values to obtain an interrater reliability range between 0.79 and 0.47 (37-item version) and between 0.79 and 0.55 (18-item version). With four independent raters (nurses) and a width of 0.2 for the resulting 95% (CIs), the sample size is, depending on the subscale, 34 to 106 residents with mild to severe dementia for the 37-item version and 34 to 93 residents with very severe dementia for the 18-item version of the QUALIDEM. To achieve precise results, we aimed to recruit 106 residents with mild to severe dementia and 93 residents with very severe dementia for the evaluation of interrater reliability. Based on previous findings [34] and on a defined CI width of 0.2, the sample size calculation for the investigation of the intrarater reliability resulted in a range between 18 and 85 (37-item version) and 39 to 75 (18-item version) residents depending on the subscale. To obtain precise results for intrarater reliability, we aim to recruit 85 (37-item version) and 75 (18-item version) residents for the evaluation of intrarater reliability.

Procedures

The evaluation of the interrater and intrarater reliability will also be based on proxy-ratings from nurses based on a retrospective observation period of 2 weeks. Inclusion criteria for residents with dementia will be a GDS score ≥2 and a length of stay of at least 2 weeks in the nursing home. The qualification level of the nurses (registered nurses and nursing assistants) will depend on organizational conditions and staffing levels at the time of the data collection. Inclusion criteria for nurses are as follows: a close relationship to the assessed resident and a working contract of at least 50% of the regular working hours. In addition, the nurses must be at work during most days within the last 2 weeks prior to the data collection to ensure the close relationship, which will facilitate the use of up-to-date information about the resident. For the examination of interrater reliability, four nurses from each nursing home will assess the QoI of 106 residents with mild to severe dementia and 93 residents with very severe dementia independently from each other. For intrarater reliability, one of these nurses will assess the QoI of 85 residents with mild to severe dementia and 75 residents with very severe dementia again after one week. The socio-demographic data for the nurses, e.g., age, professional qualification and work experience, will be recorded. To ensure standardized data collection, the QUALIDEM application will be initiated by external trained study assistants who are registered nurses.

Statistical methods

For the interrater and intrarater reliability, an ICC based on a two-way random effects model for absolute agreement will be calculated for each subscale of the QUALIDEM. This procedure allows the comparison of the results with previous findings from the Netherlands [34]. The interrater and intrarater reliability of every item of the QUALIDEM will be calculated using the mean of quadratic weighted Kappas. These additional analyses provide information about the reliability of the individual items within a subscale and, thus, can potentially be used to improve the reliability of a subscale.

Empirical phase: validity

In this step of the project, the sixth research question will be examined. The methods to be used are guided by the QoI model based on the previous meta-synthesis (theoretical phase).

Setting and location

The validity of the QUALIDEM will be examined in the nine nursing homes that are participating in the Leben-QD II project.

Procedures

Our meta-synthesis will identify domains of QoI. Consequently, relevant comparators and hypotheses can be derived for the investigation of the validity of the QUALIDEM. In addition to the identified constructs, further comparators will be assessed, allowing for a comparison of study results against other validation studies of QoI measurements. These comparators include *mood and feelings* [27], [28], [30], *domains of challenging behavior* [27], and *daily and social activities* [26], [28].
The commonly applied QoI measurements, the Quality of Life-Alzheimer Disease (QOL-AD) [52] (self- and proxy-assessment) and the Dementia Quality of Life Instrument (DQoI) [15] (self-assessment), will also be used as comparators for the evaluation of validity. Both instruments are recommended by a European consensus paper for the self-assessment of dementia-specific QoI [36].
Furthermore, possible pain of people with dementia will be assessed as comparator. There have been very few studies that have compared QoI among people with dementia and pain, as an expression of the validity of a QoI instrument. We identified only one study, which suggested the lack of a significant correlation between measured pain and QoI among people with dementia [53]. This result might be due to the lack of a sensitive assessment of pain among people with dementia. Therefore, a correlation between QoI and pain as an expression of the validity of a QoI instrument seems to be theoretically well justified.

Statistical methods

Descriptive statistics will be calculated for the sample characteristics. Bivariate statistics will be used to study the correlation between the scalable and reliable QUALIDEM subscales and the defined comparators.

Final phase: summarizing evaluation

In the final phase, all results from the previous project steps will be summarized to offer conclusions regarding the content and the psychometric quality of the German version of the QUALIDEM. Based on previous results, it may be necessary that adaptations of the content or the operationalization of individual items or subscales have to be performed.

Discussion

The psychometric properties of a standardized measurement are context-specific attributes. An instrument that has demonstrated satisfactory measurement properties in one population is not necessarily appropriate for use in other populations [54]. Moreover, the highly subjective construct of QoI underlies culture specific influences in the expression of QoI domains. The intensive psychometric evaluation of the German version of the QUALIDEM will result in a comprehensive statement of the reliability, validity and content quality of the use of the instrument during clinical trials in Germany. The samples for the different phases of the study are heterogeneous with respect to the course of dementia. This is the primary requirement for testing the instrument [11]. The results will be important for the comparison of QoI as a primary outcome in intervention studies for people with dementia.
The theoretical phase of the study is expected to provide an important contribution to the theoretical discussion of the QoI concept. The synthesis of qualitative studies on the perspectives of people with dementia about their QoI results in a new dementia-specific QoI model. The stepwise approach of the study allows for a theoretical justification of the methods in the validation step, and the summaries offer a broad and careful evaluation of the content and the psychometric properties of the German version of the QUALIDEM.

Notes

Ethics

The study protocol of the STI-D study was approved by the ethics committee of the Charité-Universitätsmedizin, Berlin. The ethics committee of the German Society of Nursing Science approved the study protocol of the InDemA study and the Leben-QD study (part I and II). Approval for the Leben-QD study covers the empirical steps of the QoI-Dem project.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

MND, MH, GM and SB designed the study. MND drafted the manuscript. MH, GM, OD and SB helped to draft the manuscript and supervise the study. All authors read and approved the final manuscript.

References

1. Wancata J, Musalek M, Alexandrowicz R, Krautgartner M. Number of dementia sufferers in Europe between the years 2000 and 2050. Eur Psychiatry. 2003 Oct;18(6):306-13. DOI: 10.1016/j.eurpsy.2003.03.003
2. Ferri CP, Prince M, Brayne C, Brodaty H, Fratiglioni L, Ganguli M, Hall K, Hasegawa K, Hendrie H, Huang Y, Jorm A, Mathers C, Menezes PR, Rimmer E, Scazufca M; Alzheimer's Disease International. Global prevalence of dementia: a Delphi consensus study. Lancet. 2005 Dec;366(9503):2112-7. DOI: 10.1016/S0140-6736(05)67889-0
3. Rothgang H, Iwansky S, Müller R, Sauer S, Unger R. BARMER GEK Pflegereport 2010. Schwerpunktthema: Demenz und Pflege [BARMER GEK Care Report 2010]. St. Augustin: Asgard; 2010. (Schriftenreihe zur Gesundheitsanalyse; 5).
4. Luppa M, Luck T, Brähler E, König HH, Riedel-Heller SG. Prediction of institutionalisation in dementia. A systematic review. Dement Geriatr Cogn Disord. 2008;26(1):65-78. DOI: 10.1159/000144027
5. Schneekloth U, Wahl HW, Hrsg. Pflegebedarf und Versorgungssituation bei älteren Menschen in Heimen. Demenz, Angehörige und Freiwillige, Beispiele für "Good Practice". Stuttgart: Kohlhammer; 2009.
6. Harris P, Sterin G. Insider's perspective: Defining and preserving the self in dementia. J Ment Health Aging. 1999;5(3):241-56.
7. de Boer ME, Hertogh CM, Dröes RM, Riphagen II, Jonker C, Eefsting JA. Suffering from dementia - the patient's perspective: a review of the literature. Int Psychogeriatr. 2007 Dec;19(6):1021-39. DOI: 10.1017/S1041610207005765
8. Moyle W, Mcallister M, Venturato L, Adams T. Quality of life and dementia. The voice of the person with dementia. Dementia. 2008 May;6(2):175-91. DOI: 10.1177/1471301207080362
9. Lawton MP. Assessing quality of life in Alzheimer disease research. Alzheimer Dis Assoc Disord. 1997;11 Suppl 6:91-9.
10. Logsdon RG, Albert SM. Assessing quality of life in Alzheimer's Disease: conceptual and methodological issues. J Ment Health Aging. 1999;5(1):3-6.
11. Bouman AI, Ettema TP, Wetzels RB, van Beek AP, de Lange J, Dröes RM. Evaluation of Qualidem: a dementia-specific quality of life instrument for persons with dementia in residential settings; scalability and reliability of subscales in four Dutch field surveys. Int J Geriatr Psychiatry. 2011 Jul;26(7):711-22. DOI: 10.1002/gps.2585
12. Ettema TP, Dröes RM, de Lange J, Mellenbergh GJ, Ribbe MW. A review of quality of life instruments used in dementia. Qual Life Res. 2005 Apr;14(3):675-86. DOI: 10.1007/s11136-004-1258-0
13. Ready RE, Ott BR. Quality of Life measures for dementia. Health Qual Life Outcomes. 2003;1:11. DOI: 10.1186/1477-7525-1-11
14. Rabins PV, Black BS. Measuring quality of life in dementia: purposes, goals, challenges and progress. Int Psychogeriatr. 2007 Jun;19(3):401-7. DOI: 10.1017/S1041610207004863
15. Brod M, Stewart AL, Sands L, Walton P. Conceptualization and measurement of quality of life in dementia: the dementia quality of life instrument (DQoL). Gerontologist. 1999 Feb;39(1):25-35. DOI: 10.1093/geront/39.1.25
16. Kane RA, Kling KC, Bershadsky B, Kane RL, Giles K, Degenholtz HB, Liu J, Cutler LJ. Quality of life measures for nursing home residents. J Gerontol A Biol Sci Med Sci. 2003 Mar;58(3):240-8. DOI: 10.1093/gerona/58.3.M240
17. Ettema TP, Dröes RM, de Lange J, Ooms ME, Mellenbergh GJ, Ribbe MW. The concept of quality of life in dementia in the different stages of the disease. Int Psychogeriatr. 2005 Sep;17(3):353-70. DOI: 10.1017/S1041610205002073
18. Gräske J, Fischer T, Kuhlmey A, Wolf-Ostermann K. Quality of life in dementia care – differences in quality of life measurements performed by residents with dementia and by nursing staff. Aging Ment Health. 2012;16(7):819-27. DOI: 10.1080/13607863.2012.667782
19. Addington-Hall J, Kalra L. Who should measure quality of life? BMJ. 2001 Jun;322(7299):1417-20. DOI: 10.1136/bmj.322.7299.1417
20. Novella JL, Jochum C, Jolly D, Morrone I, Ankri J, Bureau F, Blanchard F. Agreement between patients' and proxies' reports of quality of life in Alzheimer's disease. Qual Life Res. 2001;10(5):443-52. DOI: 10.1023/A:1012522013817
21. Huang HL, Chang MY, Tang JS, Chiu YC, Weng LC. Determinants of the discrepancy in patient- and caregiver-rated quality of life for persons with dementia. J Clin Nurs. 2009 Nov;18(22):3107-18. DOI: 10.1111/j.1365-2702.2008.02537.x
22. Sands LP, Ferreira P, Stewart AL, Brod M, Yaffe K. What explains differences between dementia patients' and their caregivers' ratings of patients' quality of life? Am J Geriatr Psychiatry. 2004 May-Jun;12(3):272-80.
23. Thorgrimsen L, Selwood A, Spector A, Royan L, de Madariaga Lopez M, Woods RT, Orrell M. Whose quality of life is it anyway? The validity and reliability of the Quality of Life-Alzheimer's Disease (QoL-AD) scale. Alzheimer Dis Assoc Disord. 2003 Oct-Dec;17(4):201-8. DOI: 10.1097/00002093-200310000-00002
24. Winzelberg GS, Williams CS, Preisser JS, Zimmerman S, Sloane PD. Factors associated with nursing assistant quality-of-life ratings for residents with dementia in long-term care facilities. Gerontologist. 2005 Oct;45 Spec No 1(1):106-14.
25. Smith SC, Lamping DL, Banerjee S, Harwood R, Foley B, Smith P, Cook JC, Murray J, Prince M, Levin E, Mann A, Knapp M. 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 Mar;9(10):1-93, iii-iv.
26. Albert SM, Del Castillo-Castaneda C, Sano M, Jacobs DM, Marder K, Bell K, Bylsma F, Lafleche G, Brandt J, Albert M, Stern Y. Quality of life in patients with Alzheimer's disease as reported by patient proxies. J Am Geriatr Soc. 1996 Nov;44(11):1342-7.
27. Ettema TP, Dröes RM, de Lange J, Mellenbergh GJ, Ribbe MW. QUALIDEM: development and evaluation of a dementia specific quality of life instrument--validation. Int J Geriatr Psychiatry. 2007 May;22(5):424-30. DOI: 10.1002/gps.1692
28. Logsdon RG, Gibbons LE, McCurry SM, Teri L. Quality of life in Alzheimer's Disease: Patient and caregiver reports. J Ment Health Aging. 1999;5(1):21-32.
29. Cordner Z, Blass DM, Rabins PV, Black BS. Quality of life in nursing home residents with advanced dementia. J Am Geriatr Soc. 2010 Dec;58(12):2394-400. DOI: 10.1111/j.1532-5415.2010.03170.x
30. González-Salvador T, Lyketsos CG, Baker A, Hovanec L, Roques C, Brandt J, Steele C. Quality of life in dementia patients in long-term care. Int J Geriatr Psychiatry. 2000 Feb;15(2):181-9. DOI: 10.1002/(SICI)1099-1166(200002)15:2<181::AID-GPS96>3.0.CO;2-I
31. Dichter M, Bartholomeyczik S, Halek M. Construct validity of quality of life instruments for people with dementia - a systematic review. Aging Clin Exp Res. 2011;23(Suppl. 1):79.

32. Takai Y, Yamamoto-Mitani N, Okamoto Y, Koyama K, Honda A. Literature review of pain prevalence among older residents of nursing homes. Pain Manag Nurs. 2010 Dec;11(4):209-23. DOI: 10.1016/j.pmn.2010.08.006

33. Achterberg WP, Gambassi G, Finne-Soveri H, Liperoti R, Noro A, Frijters DH, Cherubini A, Dell'aquila G, Ribbe MW. Pain in European long-term care facilities: cross-national study in Finland, Italy and The Netherlands. Pain. 2010 Jan;148(1):70-4. DOI: 10.1016/j.pain.2009.10.008

34. Ettema TP, Dröes RM, de Lange J, Mellenbergh GJ, Ribbe MW. QUALIDEM: development and evaluation of a dementia specific quality of life instrument. Scalability, reliability and internal structure. Int J Geriatr Psychiatry. 2007 Jun;22(6):549-56. DOI: 10.1002/gps.1713

35. Dichter M, Bartholomeyczik S, Nordheim J, Achterberg W, Halek M. Validity, reliability, and feasibility of a quality of life questionnaire for people with dementia. Z Gerontol Geriatr. 2011 Dec;44(6):405-10. DOI: 10.1007/s00391-011-0235-9

36. Moniz-Cook E, Vernooij-Dassen M, Woods R, Verhey F, Chattat R, De Vugt M, Mountain G, O'Connell M, Harrison J, Vasse E, Dröes RM, Orrell M; INTERDEM group. A European consensus on outcome measures for psychosocial intervention research in dementia care. Aging Ment Health. 2008 Jan;12(1):14-29. DOI: 10.1080/13607860801919850

37. Reisberg B. Global measures: utility in defining and measuring treatment response in dementia. Int Psychogeriatr. 2007 Jun;19(3):421-56. DOI: 10.1017/S1041610207005261

38. Search Filters for MEDLINE in Ovid Syntax and the PubMed translation [database on the Internet]. McMaster University. 23.07.2011 [cited 29.06.2012]. Available from: http://hiru.mcmaster.ca/hiru/HIRU_Hedges_MEDLINE_Strategies.aspx#Qualitative

39. Critical Appraisal Skills Programme (CASP). 10 questions to help you make sense of qualitative research. Public Health Resource Unit; 2006. Available from: http://www.civilservice.gov.uk/wp-content/uploads/2011/09/Qualitative-Appraisal-Tool_tcm6-7385.pdf

40. Pearson A. Balancing the evidence incorporating the synthesis of qualitative data into systematic reviews. JBI Reports. 2004;2(2):45-64. DOI: 10.1111/j.1479-6988.2004.00008.x

41. Glaser BG, Strauss AL. Grounded Theory. Strategien qualitativer Forschung. Bern: Hans Huber; 2005.

42. Kuckartz U. Einführung in die computergestützte Analyse qualitativer Daten [Introduction to computer-aided analysis of qualitative data]. Wiesbaden: VS Verlag für Sozialwissenschaften; 2005.

43. Holle D, Halek M, Mayer H, Bartholomeyczik S. Die Auswirkungen der Verstehenden Diagnostik auf das Belastungserleben Pflegender im Umgang mit Menschen mit Demenz in der stationären Altenhilfe [The influence of understanding diagnostics on perceived stress of nurses caring for nursing home residents with dementia]. Pflege. 2011 Oct;24(5):303-16. DOI: 10.1024/1012-5302/a000143

44. Fischer T, Kuhlmey A, Sibbel R, Nordheim J. Die deutsche Fassung der „Serial Trial Intervention“ (STI-D). Entwicklung und Testung eines pflegerischen Ansatzes zur Reduktion von herausforderndem Verhalten bei Menschen mit Demenz [The „Serial Trial Intervention“ German Version (STI-D) – Development and Testing of a Nursing Approach for Reducing Challenging Behaviours in People with Dementia]. Z Gerontopsychol Psychiatr. 2008;21(3):199-203. DOI: 10.1024/1011-6877.21.3.199

45. Halek M, Dortman O, Riesner C, Quasdorf T, Dichter M. The relationship between challenging behavior and quality of life of residents with dementia. 21st Alzheimer Europe Conference "European solidarity without borders"; 2011 Oct 6–7; Warsaw, Poland.

46. Folstein MF, Folstein SE, McHugh PR. "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. J Psychiatr Res. 1975 Nov;12(3):189-98. DOI: 10.1016/0022-3956(75)90026-6

47. Watson R, van der Ark LA, Lin LC, Fieo R, Deary IJ, Meijer RR. Item response theory: How Mokken scaling can be used in clinical practice. J Clin Nurs. 2012 Oct;21(19-20):2736-46. DOI: 10.1111/j.1365-2702.2011.03893.x

48. Van der Ark LA. Mokken Scale Analysis in R. J Stat Softw. 2007;20(11):1-19.

49. Van der Ark LA. New developments in Mokken Scale Analysis in R. J Stat Softw. 2012;48(5):1-27.

50. Halek M, Dichter MN, Quasdorf T, Riesner C, Bartholomeyczik S. The effects of dementia care mapping on nursing home residents' quality of life and staff attitudes: design of the quasi-experimental study Leben-QD II. BMC Geriatr. 2013;13:53. DOI: 10.1186/1471-2318-13-53

51. Bonett DG. Sample size requirements for estimating intraclass correlations with desired precision. Stat Med. 2002 May;21(9):1331-5. DOI: 10.1002/sim.1108

52. Logsdon RG, Gibbons LE, McCurry SM, Teri L. Assessing quality of life in older adults with cognitive impairment. Psychosom Med. 2002 May-Jun;64(3):510-9.

53. Wolak A, Novella JL, Drame M, Guillemin F, Di Pollina L, Ankri J, Aquino JP, Morrone I, Blanchard F, Jolly D. Transcultural adaptation and psychometric validation of a French-language version of the QoL-AD. Aging Ment Health. 2009 Jul;13(4):593-600. DOI: 10.1080/13607860902774386

54. Fitzpatrick R, Davey C, Buxton MJ, Jones DR. Evaluating patient-based outcome measures for use in clinical trials. Health Technol Assess. 1998;2(14):i-iv, 1-74.

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