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. © 2016 Elsevier Inc. All rights reserved.

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

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