Instruments for assessing the quality of life of elderly people with alzheimer’s: integrative literature review

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ABSTRACT

The use of instruments to evaluate the quality of life of elderly people with Alzheimer’s is of great use for implementing adequate care for this population. The objective of this study is to seek in the literature evidence of the validity of the instruments that evaluate the quality of life of elderly people with Alzheimer’s, answered by the patients themselves. It is an integrative review of the literature. The search in the databases was performed in PubMed, Lilacs, and CINAHL. Ten articles were selected for comprehensive analysis. This review allowed a main evaluation tool to be identified (QoL-AD), validated for the different populations, as well as the proposal of two new instruments (DQI and BASQID). The analysis of the properties of validity and internal consistency (reliability) of the instruments found them to be satisfactory. It also reinforced the notion pointed out by the authors regarding the dependence among the dimensions of the quality of life of the elderly and Alzheimer’s disease.

Descriptors: Aged; Quality of Life; Validation Studies; Dementia; Alzheimer Disease.

INTRODUCTION

National and international studies have been recurrently discussing population aging. It is estimated that in the year 2050 there will be approximately two billion people aged 60 years or older in the world, reflecting the impact on political, socio-cultural, economic, and demographic matters that involve the rise in life expectancy and the decrease of birth rates. In addition to use of the term "Life Expectancy", we currently encounter frequent use of the term "Quality of Life", a very old concept, various meanings for which
have been created throughout history to better define it.

The WHO (World Health Organization) considers quality of life to be "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns". The multidimensionality of the concept of quality of life is related to biological, social, and psychological criteria found in the family circle and in social, environmental, and aesthetic relations, resulting in a group of factors that society considers its standard of comfort and well-being.

Paradoxically, we live in an era where life expectancy is growing very rapidly, and, with the same speed, non-transmittable chronic diseases arise, targeting the contemporary population.

Frequently affecting the elderly, Alzheimer’s disease (AD) leads to a neurodegenerative condition characterized by the deterioration of memory and other cognitive functions; progressive compromising of the activities of daily life; and a multiplicity of behavioral and psychological changes that even further impair quality of life in old age. AD is the main cause of dementia and leading cause of incapacitation among people over 60 years old, generating high direct and indirect costs. The prevalence of dementia in Brazil was estimated at 390,000 cases in 2000, around 50% of which were due to AD.

Thus, the development of technical instruments that allow the characteristics of the population to be evaluated must meet certain conditions and require standardized procedures. However, it is also necessary that their psychometric properties be evidenced and analyzed, given that an instrument that does not identify such properties is prevented from being scientifically recognized.

For the psychometric properties, we highlight precision (reliability) and validity. Precision can be understood as consistency or stability, defined as the extent to which measures are replicable, be it by the same examiner or by different examiners, making the same measurement of a construct. To do so, usually, two methods are used: the Pearson product-moment correlation coefficient and the Cronbach alpha coefficient, where the correlation of each item with the remaining items is calculated, indicating an average correlation among the variables.

It is important to note the evidences regarding validity, which can be classified into four ample categories: a) evidences of validity based on an analysis of the content or domain; b) evidences of validity based on the relationships with external variables; c) evidences based on the internal structure; d) evidences based on the response process. In light of this, according to, a good scale is one that allows easy application, scoring, and interpretation, as well as taking the least amount of time possible, both that of the examiner and of the person examined. It should also be relevant and appropriate for the sample of interest and, essentially, should have indications of precision and validity coherent with the objectives it intends to achieve.

For these reasons, and to guide future assessments, this study had the objective of searching the literature for evidence of the validity of the instruments developed to evaluate the quality of life of elderly people with Alzheimer’s.
METHOD

To develop this study, we opted for an integrative review of the literature. This method enables the systematic synthesis of knowledge on a certain subject, allowing the significant results of the studies to be implemented in the healthcare practice. Currently, we are faced with the need of guaranteeing a healthcare practice based on scientific evidence, and the integrative review has been marked as an essential tool in this area.\textsuperscript{(10)}

The Evidence-Based Practice (EBP) is a search for the latest, most reliable evidence on a problem, which can include, for example, healthcare, clinical context, and professional skill that contribute to the improvement of the clinical practice and decision making.\textsuperscript{(11)}

Thus, the methodology of the integrative literature review is an approach that allows diversified methodologies to be included, playing a larger role in the practice based on evidence, helping the researcher summarize theoretical and empirical literature on a specific topic.\textsuperscript{(12)}

In this study, we opted to adopt the elaboration of the guiding question, the PICO (Patient, Intervention, Comparison, Outcome) strategy.\textsuperscript{(13)} The terms used in this study were: "P" Elderly with Alzheimer’s; "I" Validation and Precision; "C" the authors did not have the goal of comparing interventions; "O" Quality of Life Tools. Thus, the guiding question was defined: “What is the evidence of validity and precision displayed by the tools that evaluate the quality of life of elderly people with Alzheimer’s?”

The study was developed at the Ribeirão Preto College of Nursing (EERP-SP) during the first quarter of 2016. The databases used were the National Library of Medicine, National Institutes of Health (PubMed), Cumulative Index to Nursing & Allied Health Literature (CINAHL), and Latin-American and Caribbean Literature on Health Sciences (Literatura Latino-americana e do Caribe em Ciências da Saúde – LILACS). The controlled descriptors were extracted from Medical Subject Headings (MeSH) and Health Sciences Descriptors (Descritores em Ciências da Saúde – DeCS), and we also included non-controlled descriptors with the intention of amplifying the findings in the literature. The Boolean operator "AND" was combined with the descriptors, resulting in the following search equations: 1) PubMed - (((Aged[Mesh]) AND "Validation Studies" [Publication Type]) AND "Quality of Life"[Mesh]) AND dementia) AND "Alzheimer Disease"[Mesh]; (((aged) AND validation studies) AND quality of life) AND dementia) AND Alzheimer’s disease; 2) CINAHL - aged AND validation studies AND quality of life AND dementia AND Alzheimer’s disease; 3) Lilacs - ("Idoso") AND "Qualidade de vida" [Palavras] and ("Estudos de validacao") AND "Demencia" [Palavras] and "Doenca de alzheimer" [Palavras].

The period from January 2006 to February 2016 (last ten years) was defined, given that the psychometric parameters of a test must be periodically reviewed, with a maximum time of 10 years between one study and another.\textsuperscript{(14)} For the analysis of the articles, we considered only those which were in Portuguese and English, available in full and online.

The articles were evaluated through a full reading of the texts, which should meet the following inclusion criteria: studies published within the last 10 years, written in Portuguese and English with themes...
related to the validity and precision presented by instruments that assess the quality of life of elderly people with Alzheimer’s, answered by the elderly individuals themselves.

The analysis was conducted through a synoptic table developed by the authors that considered the following categories: article title, periodical in which it was published, year of publication, name of the first author, affiliation of the first author, objective of the study, sample of participants, country of origin of the sample, degree of dementia of the participants, presentation of evidence of validity and precision of the instruments, and the database in which it was located. Next, they were grouped into two categories: new instruments and cultural adaptation.

Then, the results were presented and the data obtained were discussed descriptively, in a way that the reader could understand the depth and amplitude of the topic and provide new understanding of the phenomenon at hand(15).

Through the search strategies and criteria of eligibility, 30 articles were found by searching the databases. After reading the titles, abstracts, and whole articles, 10 articles were included to answer the research question, three of which were from CINAHL, six from PubMed, and one from LILACS.

Figure 1 illustrates the process of selecting the studies, as recommended by the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analysis) statement(16).
RESULTS

The synthesis of the results obtained is presented in Table 1, based on an instrument validated containing the following characteristics of the articles: reference number, country of origin, year of publication, databases, tool used to ascertain dementia, degree of dementia, objectives and characteristics of the study (validity/precision).\textsuperscript{17}
It can be stated that, for the most part, the publications found originated from European countries (n=8 – Spain, Germany, England, United Kingdom, France, and Holland). The articles analyzed were published between the years 2006 and 2012. Among the categories established in this study, all the articles mentioned the validity and precision of instruments that evaluate the quality of life of elderly people with Alzheimer’s. It can also be highlighted that most of the articles were in English (n=9). During the process of selecting the studies, 20 articles were excluded, which did not answer the guiding question and/or did not meet the inclusion criteria.

For the synthesis, the studies selected were classified into two categories, according to the type of development proposed: 1) new tools and 2) adaptation to the specific population.
<table>
<thead>
<tr>
<th>Authors / Periodical / Year of Publication / Country</th>
<th>Database</th>
<th>Instruments Used</th>
<th>Degree of Dementia</th>
<th>Objectives</th>
<th>Results of Validity and Precision</th>
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<tbody>
<tr>
<td>A1. Schölz-Dorenbos, Arons, Wammes, Rikkert, Krabbe / Health and Quality of Life Outcomes / 2012 / Holland</td>
<td>PubMed</td>
<td>DSM-IV-TR; Clinical Dementia Rating</td>
<td>Very Mild to Moderate</td>
<td>Develop and validate the prototype of a specific measurement of dementia index DQI.</td>
<td>Content validity: assessing judges. Concurrent validity done by correlation between the domains of the DQI and EQ-5D+C: statistically significant for patients and caregivers: memory, cognition, orientation, independence, self-care, daily activities, mood, depression/anxiety.</td>
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<tr>
<td>A3. Wolak, Novella, Drame, Guillemin, Di Pollina, Ankri, et al / Aging &amp; Mental Health / 2009 / France</td>
<td>PubMed</td>
<td>DSM IV; MEEM; Duke Profile</td>
<td>Mild to Moderate</td>
<td>Evaluate the psychometric properties and transcultural adaptation (QoL-AD) to French.</td>
<td>Internal consistency: patient and caregiver subscale α=0.70; Convergent validity QoL-AD x Duke Profile: 0.25&lt;r&lt;0.54 for patients and 0.25&lt;r&lt;0.39 for caregivers (p&lt;0.05).</td>
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<tr>
<td>A4. Matsui, Nakaaki, Murata, Sato, Shinagawa, Tatsumi, et al / Dementia and Geriatric Cognitive Disorders / 2006 / Japan</td>
<td>CINAHL</td>
<td>QOL-AD; NPI; HADL; SMQ</td>
<td>Mild to Moderate</td>
<td>Develop the Japanese version of the QOL-AD and verify its reliability and factors that alter the quality of life of patients with Alzheimer’s.</td>
<td>Internal consistency: patient subscale α=0.85 and caregiver subscale: α=0.82; Concurrent validity based on the scores of the patients and caregivers: r=0.60, p&lt;0.01.</td>
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<td>A5. Gómez-Gallego, Gómez-Amorb, Gómez-García / Neurologia / 2011 / Spain</td>
<td>PubMed</td>
<td>MEEM; HUI-3</td>
<td>Mild to Moderate</td>
<td>Determine the psychometric properties of the Spanish version of the QoL-AD scale in patients with Alzheimer’s, caregivers, and professionals.</td>
<td>Internal consistency: patient subscale α=0.85, caregiver subscale α=0.84, professional subscale α=0.9. Concurrent validity (total score): QoL-Ad x HUI-3: -0.47.</td>
</tr>
<tr>
<td>A6. Novelli, Nitrinia, Caramellia / Aging &amp; Mental Health / 2010 / Brazil</td>
<td>CINAHL</td>
<td>QV-AD / PQQL / CPQOL / WHOQOL BREF / CQOL</td>
<td>Mild or Moderate</td>
<td>Evaluate the reliability and validity of the construction of the Brazilian version of the (QoL-AD) scale.</td>
<td>Construct validity: QoL-AD x WHOQOL-BREF r&gt;0.70.</td>
</tr>
<tr>
<td>A7. Salas, Logsdon, Olazara’n, Martínez-Martin, Msu-Adru / Aging &amp; Mental Health / 2011 / Spain</td>
<td>PubMed</td>
<td>QOL-Adp / QOL-Adc / MMSE / GDS / CSDD / QUALID / EQ-VAS / LI / BI / AI / NPI</td>
<td>Mild or Moderate</td>
<td>Evaluate the psychometric attributes of the Spanish version of (QoL-AD) in institutionalized patients and family caregivers in Spain.</td>
<td>Internal consistency: patient subscale α=0.90, caregiver subscale α=0.86; convergent validity: QoL-AD x QUALID: 0.43 and QoL-AD x EQD-5: 0.65.</td>
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<tr>
<td><strong>A8. Hoe, Katona, Roch, Livingston / Age and Ageing / 2005 / England</strong></td>
<td>CINAHL</td>
<td>MMEE</td>
<td>Severe Dementia (MEEM&lt;12)</td>
<td>Examine the use of the (QoL-AD) scale in people with severe dementia and their caregivers, verifying the construct validity and internal consistency.</td>
<td>Internal consistency α=0.78 when considering the entire instrument.</td>
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<td><strong>A9. Voigt-Radloff, Leonhart, Schutzwohl, Jurjanz, Reuster, Gerner, et al / European Journal of Neurology / 2012 / Germany</strong></td>
<td>PubMed</td>
<td>MEEM / ADAS-cog / CSDD / IDDD</td>
<td>Mild to Moderate</td>
<td>Translate the (DQOL) instrument to German and evaluate its construction and concurrent validity in a community of people with dementia.</td>
<td>Internal consistency α=0.61 to 0.84 per factor. Concurrent validity DQoL x SF-12: r=&gt;0.43&gt;r-0.63.</td>
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<tr>
<td><strong>A10. Novelli, Rovere, Nitini, Caramelli / Arquivo Neuropsiquiatria / 2005 / Brazil</strong></td>
<td>LILACS</td>
<td>MEEM / DSM III-R-14</td>
<td>Mild to Moderate</td>
<td>Present the internal validation of the (QoL-AD) scale for patients with Alzheimer’s disease (AD) and their caregivers/family members.</td>
<td>Internal consistency: patient subscale α=0.81 and caregiver subscale α=0.85.</td>
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*Note: The internal consistency of the instruments was evaluated by calculating the Cronbach alpha. The process of validating the instruments included, for the most part, three distinct domains: content validity, criterion validity, and construct validity. These items are detailed throughout the text.*
New Instruments

A1 – Validation Study of the Prototype of a Disease-Specific Index Measure for Health-Related Quality of Life in Dementia

In this study performed in Holland\textsuperscript{[18]}, a structure was created to develop the instrument called the “Dementia Quality of Life Instrument” (DQI), based on: review of the literature, qualitative interviews with people with dementia and their caregivers, the opinion of specialists, and team discussion. The instrument was semantically validated through the assessment of 241 health professionals, who judged and classified the relevance of the items and the domains developed. After this step, a cross-sectional study was performed with individuals with very mild to moderate dementia and their caregivers (N=145) to evaluate the feasibility and concurrent validity with other generic health instruments. For the semantic analysis, the professionals judged all the domains and items relevant. The differences in the correlations simultaneously with the generic state of health instruments imply that the specific dementia domains of the DQI effectively provided different information, as expected.

A2 – How Can We Best Assess the Quality of Life of People With Dementia? The Bath Assessment of Subjective Quality of Life in Dementia (BASQID)\textsuperscript{[19]}

This article provides evidence on the psychometric properties of the BASQID self-report instrument, including the relationship with other clinical indicators, such as depression and cognition. The BASQID contains 14 items that evaluate a series of questions regarding quality of life from the perspective of the person with dementia. It includes the qualitative development of a conceptual table, generated based on in-depth interviews with 30 people with dementia in a mild to moderate state. The authors explored the conception of these people on quality of life and the way dementia affects this quality of life. The results showed that BASQID can be divided into two components: component 1 represented a subscale of Life Satisfaction and component 2 represented a subscale of Positive Feelings of Quality of Life. The BASQID score presented moderate correlation with GDS-15 (r=0.58) and low to moderate association with WHOQOL-BREF (r=0.32; \( \alpha = 0.59 \)). The internal consistency of the BASQID was calculated through the Cronbach alpha (\( \alpha = 0.89; n=143 \)), indicating good total internal consistency. It can be said that the instrument presents good indices of precision and validity.

Adaptation to the Specific Population

A3 – Transcultural Adaptation and Psychometric Validation of a French-Language Version of the QoL-AD\textsuperscript{[20]}

The general objective of the study was to conduct a cultural adaptation and psychometric validation of the Quality of Life in Alzheimer’s (QoL – AD) instrument. QoL-AD includes the caregivers’ evaluation of the patients and the patients’ evaluation of themselves. The procedure used was conducted with consent and
approval of the author of the original version of the instrument in English. A total of 102 patients and their caregivers, as well as over 25 health professionals participated in the study. The French version of the QoL-AD presented good internal consistency (α=0.70) and good reliability (r=0.80) in an interval of two weeks. Convergent validity between QoL-AD and the dimensions of the Duke Health Profile were also considered good.

A4 – Determinants of the Quality of Life in Alzheimer’s Disease Patients as Assessed by the Japanese Version of the Quality of Life – Alzheimer’s Disease Scale (21)

A cultural validation was performed and the psychometric properties of the Japanese version of the Quality of Life in Alzheimer’s (QoL-AD) tool were analyzed. The instrument was translated to Japanese using reverse translation standards, where the original version in English was translated to Japanese and then retranslated to English by people independent from the first version, and the original author participated in the semantic assessment so as to identify any discrepancies in the reverse translation. After the semantic assessment, the instrument was applied to the sample of elderly Japanese patients and their caregivers. The final sample of the study was composed of 140 elderly Japanese with mild to moderate Alzheimer’s and their respective caregivers. The reliability index for the patients was α=0.84 and the caregivers obtained α=0.82. The intra-class correlation coefficient was 0.84 for patients and 0.91 for the caregivers. The reliability test-retest (n=83) of the total score after one month was excellent (patients: α=0.84 and caregivers: α=0.91). The concurrent validity obtained a significant concordance index in the total score determined based on the answers of the patients and the caregivers (r = 0.60, p<0.01).

A5 – Validation of the Spanish Version of the QoL-AD Scale in Alzheimer’s Disease Patients, their Careers, and Health Professionals (22)

This study had the objective of ascertaining the psychometric validity of the Spanish version of the Quality of Life in Alzheimer’s (QoL-AD) instrument in patients, caregivers, and health professionals. The sample was composed of 102 patients and their caregivers, as well as 25 health professionals. The indices of reliability obtained were: patients α=0.85, caregivers α=0.84, professionals α=0.91. The construct validity was performed through the analysis of the main components and three factors were obtained with values higher than one (1), which explained 61.30% of the total variance. The factors obtained presented good internal consistency (α≥0.70) and were interpreted as follows: health factor (r²=29.57%), social relations and environmental factor (r²=17.27%) and functional capacity factor (r²=14.46%).

A6 – Validation of the Brazilian Version of the Quality of Life Scale for Patients with Alzheimer’s Disease and their Caregivers - QoL-AD (23)

The purpose of this article was to assess the reliability and validity of the Brazilian version of the quality of life scale for Alzheimer’s disease. The study was conducted at the Hospital das Clínicas de São Paulo

hospital with previous authorization by the author of the original version of the instrument. Sixty elderly people with mild to moderate Alzheimer’s participated, as well as their caretakers (N=120). The content validity was evaluated by specialists and researchers during the conception phase. The reliability for the version of the patients was 0.80, and that for the caretakers was 0.83. The total score of the Brazilian QoL-AD scale displayed significant correlations with the total score of the WHOQOL-BREF, a generic instrument for assessing quality of life. The correlation coefficients were higher than 0.70 in all three versions of the scale.

A7 – Psychometric Properties of the Spanish QoL–AD with Institutionalized Dementia Patients and their Family Caregivers in Spain(24)

The purpose of this study was to evaluate the psychometric attributes of the Spanish version of the Quality of Life Scale – AD in institutionalized patients and their family caregivers in Spain. The total sample was composed of 101 institutionalized patients diagnosed with Alzheimer’s disease (AD) and their caregivers (N=202), where 81.2% of the patients had Alzheimer’s dementia and 18.8% had mixed dementia (AD together with cerebrovascular diseases). The cognitive deterioration found was from moderate cognitive deterioration to severe cognitive deterioration. Of the 101 initial patients, 71 did not understand or did not want to collaborate to complete the patient version of the QoL-AD. The internal consistency determined through the Cronbach alpha index was 0.86 for the caretaker version of the QoL-AD and 0.90 for the patient version. The corrected item-total correlation varied between 0.11 (money) to 0.67 (life in general) in the QoL-AD caretaker version and in the QoL-AD patient version, it varied between 0.28 (memory) and 0.84 (energy).

A8 – Use of the QoL-AD for Measuring Quality of Life in People with Severe Dementia — the LASER-AD Study(25)

This was the first study to report evidence of validity and precision of the QoL-AD in people with a score between 3 and 11 evaluated through the Mini Mental State Examination. The authors justify this cutoff point for two reasons: this was the group in which there were no standardized measures validated for QoL-AD, and was also the group in which the use of cholinesterase inhibitors was not recommended. The construct validity of the instrument was evaluated by the correlation of the scale with measures of cognition, mood, neuropsychiatric symptoms, and daily life activities, among others. The item-total correlation between each QoL-AD item and the total score of the QoL-AD varied between 0.35 and 0.81. The Cronbach alpha for the instrument as a whole was 0.78. However, this scale is inappropriate for people with scores lower than three evaluated by the MMSE.

A9 – Dementia Quality of Life Instrument – Construct and Concurrent Validity in Patients with Mild to Moderate Dementia(26)

The main objective of this study was to translate the Dementia Quality of Life instrument – DQoL to
German and evaluate its construct and concurrent validity in a community of people with mild to moderate dementia. It was initially translated by a psychologist and an occupational therapist who translated the instructions, the items, and the answer formats based on a Dutch version to German, also considering the version in English. After the translations, pilot tests were performed with the target population. Next, the models were tested through a confirmatory factorial analysis and the internal consistency indices were verified. The authors found good internal consistency (α = 0.6 and 0.8) and moderate correlations between the instrument and the quality of life scales (Spearman coefficient between 0.3 and 0.6). The concurrent validity analysis revealed moderate correlations (r > 0.43) with the SF-12 Mental Scale and the QoL-AD score. Negative effect was moderately associated only with SF-12 on the Mental Scale (r > 0.63). Lastly, the confirmatory factorial analysis indicated a bad adjustment of the model in the sample used (n=286; χ²=888.6, g.l.=391, p<0.001).

A10 – Cross-Cultural Adaptation of the Quality of Life Assessment Scale on Alzheimer’s Disease(27)

The Brazilian authors present the internal validation data of the quality of life scale for patients with Alzheimer’s and their respective caretakers. The scale was adapted according to the method that involved the translation of the original instrument in English to Portuguese; then, after the necessary analyses, the instrument underwent a reverse translation (Portuguese-English), and equivalence assessments. The correlation indices found in the intra-examinational evaluation were 0.87/0.95/0.95 (p<0.001) for the versions for the patient, family member, and caretaker, respectively. To verify internal consistency, the instrument adapted was administered in 40 patients with mild to moderate Alzheimer’s disease. The reliability of the versions for the patient and family member were α = 0.81 e 0.85, respectively, and, for the QoL of the caretaker, α = 0.84.

DISCUSSION

This review allowed us to identify that the instruments that aim to assess quality of life in elderly patients with Alzheimer’s included the physical, emotional, social, and economic aspects, as well as the patients’ relationships with their families and the healthcare staff. It is evident that, for intervention measures to be adopted, these aspects must be understood and identified in a general manner, thereby implementing measures to improve quality of life. However, we highlight that only two of the 10 studies analyzed aimed to develop new assessment instruments (Dementia Quality of Life Instrument – DQI(18) and The Bath Assessment of Subjective Quality of Life in Dementia (BASQID)).(19)

The Dementia Quality of life Instrument (DQI)(18) represents an effort to contribute to the study of quality of life together with the elderly population affected by dementia and also help enrich the assessment area. It is worth noting that the process of developing the DQI was based on literature reviews, qualitative interviews with people with dementia and their caretakers, specialists’ opinions, and group discussion. The investigation of the evidence of content validity undertaken by specialists is important for the improvement

of the original version of an instrument. This is due to the fact that the judges offer suggestions that facilitate understanding of the items by the target population, avoiding possible misunderstandings by the participants. In addition, they can help select the best items to compose the scale.\(^{28-29}\) The authors state that the DQI prototype can be considered valid and viable for patients and caretakers, and is appropriate for mild to moderate dementia. However, they emphasize that further research is necessary to generate values for each of the possible dimensions that the DQI evaluates.

The University of Bath’s subjective quality of life assessment instrument for people with dementia provides great contributions by using in-depth interviews as a means of creating the items, obtaining good final indices of precision and validity. However, it still requires new studies to confirm the factorial infrastructure found.

As for the category of adaptation to the specific population, eight of the 10 studies aimed to transculturally adapt and psychometrically validate the Quality of Life – Alzheimer’s Disease instrument. It was observed that all the studies found were undertaken with consent of the original author, Rebecca Longsdon. The studies in this category, (A3, A4, A5, A6, A7, A8, A9, and A10) also followed the directives proposed by the International Test Commission\(^^{30}\), which has the objective of unifying different international practices so as to promote adequate practice in the adaptation of evaluation instruments in various cultural contexts. It also includes guides to streamline studies that aim to verify evidence of validity and instrument precision. In this regard, it can be stated that the articles with the objective of transcultural adaptation and psychometric validation presented similar collection methods and data analysis techniques amongst them. The internal consistency (precision) was verified by calculating the Cronbach alpha. The versions of the instruments developed based on the QoL – AD presented good internal consistency indices, given that they presented satisfactory Cronbach alpha rates in both versions, patient and caretaker (France \(\alpha=0.70\); Spain \(\alpha=0.84\) and 0.85; Japan \(\alpha=0.82\) and 0.84; Brazil \(\alpha=0.80\) and 0.83).\(^{18-26}\)

The A6 study (psychometric properties of the Spanish QoL-AD in institutionalized patients with dementia and their family caretakers in Spain) was inserted in the same category because it addresses the application of the instrument adapted in study A4 (validation of the Spanish version of the QoL scale in patients with Alzheimer’s, their caretakers, and health professionals) in institutionalized elderly people with Alzheimer’s. It was the only one in which the sample used was patients with a diagnosis of mixed dementia (AD together with cerebrovascular diseases) as well as moderate to severe cognitive deterioration, presenting different characteristics from that of the population used in the transcultural adaptation. The author reports that, of the 101 initial patients, 71 did not understand or did not want to collaborate to complete the patient version of the QoL-AD. This fact may have occurred due to the severity of dementia, demonstrating that the instruments which aim to evaluate quality of life in elderly people with Alzheimer’s must consider the degree/stage of pathology.\(^{31-32}\) In this regard, with the impossibility of the patient to answer the instrument because of their degree of dementia, instruments for measuring the quality of life of elderly people with Alzheimer’s must be used carefully. On the other hand, it is important and necessary to
study elderly people without advanced cognitive impairment, paying attention to the characteristics of the subjectivity in the construct of QL, which are multifactorial and complex, related to the economic and sociocultural aspects, personal experience, and lifestyles. The initial exploration of the quality of life of elderly people with Alzheimer’s through standardized instruments provides professionals with indicators and is justified by the possibility that patients will relate, from their perspective, what actually happens to them and what they feel.

It is important to highlight that another author approached the comparison of two questionnaires, making important contributions regarding the psychometric data of the two main questionnaires designed to measure quality of life in elderly people with Alzheimer’s, the DQoL and QoL-AD. The authors compared the psychometric properties in 123 patients aged 65 years or older who suffered from Alzheimer’s disease. They both presented good reproducibility based on interclass correlation indices with an interval of two weeks between the applications (r=0.80) and good internal consistency evaluated through the Cronbach alpha (α=0.70). In addition, the authors concluded that for faster assessments, such as, for example, QoL-Ad queries, it is preferable, as it is considerably shorter (13 items) and proven through the comparison using the Student t Test. On the other hand, when aiming to obtain more in-depth assessments, the DQoL is more highly recommended as it encompasses a greater number of dimensions.

This review study has limitations, such as the language restriction (Portuguese and English), where studies in other languages may have been excluded; the use of three databases; and the lack of a manual search – all of which may have restricted the findings in the literature.

CONCLUSION

According to the purpose of this study, the analysis of the properties of validity and internal consistency (reliability) of the instruments used to evaluate the quality of life of elderly people with Alzheimer’s can be considered satisfactory. The internal consistency of the instruments was evaluated by calculating the Cronbach alpha. The process of validating the instruments included, for the most part, three distinct domains: content validity (translation and reverse translation), criterion validity (concurrent and/or convergent), and construct validity. The result obtained in this study provided one more piece of evidence to strengthen the notion presented by the authors regarding the dependence among the dimensions of the quality of life of elderly people and Alzheimer’s disease. Greater scientific development in this area will henceforth allow interventions to be planned and evaluated together with elderly people, based on evidence that is constantly rooted in precise and valid measuring instruments with regard to Alzheimer’s disease.

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