Measuring Quality of Life in Intellectually Disabled Persons with Dementia with the Italian Version of the Quality of Life in Late-Stage Dementia (QUALID) Scale

De Vreese LP, Uberti M, Mantesso U, De Bastiani E, Weger E, Marangoni AC, Weiner MF and Gomiero T*

1Department of Primary Care, Psychogeriatric Service, Local Health District, Modena, Italy
2Sospiro Foundation, Cremona, Italy
3Department of Psychiatry, University of Texas, Southwestern Medical Center, Dallas, USA
4ANFFAS Onlus Trentino, Italy

Abstract

Purpose: The aim of this study is to verify a cross-cultural adaptation of an Italian version of the Quality of Life in Late-Stage Dementia (QUALID) scale in a sample of aging people with intellectual disabilities (ID).

Methods: The QUALID was translated according to standardized procedures. Internal consistency was analyzed using Cronbach’s alpha. A Principal Component Analysis verified its multidimensionality. Inter-rater and test-retest reliabilities were also assessed using the Intraclass Correlation Coefficient (ICC). Convergent validity was probed by Spearman’s correlations among the QUALID score and the six sub-scores of the Assessment for Adults with Development Disabilities (AADS), a proxy-based questionnaire rating behavioral excesses and deficits commonly found in people with intellectual disabilities and dementia. Clinical validity was assessed by comparing QUALID scores obtained by subjects with and without dementia using the Mann-Whitney U test.

Results: A total of 40 adults/older people with ID at five ID-specific centers in the province of Trento and Cremona participated in the study. Findings show optimal levels of internal consistency (α = 0.80) and confirm the factors identified in the Spanish validation study (symptoms of discomfort, positive social interaction and depression). The scale has high inter-rater (ICC = 0.95) and good test-retest reliabilities (ICC = 0.89). The total QUALID score correlates significantly with the AADS sub-scores for behavioral excesses, but does not differ between individuals with and without dementia, though two out of the three identified factor scores are significantly higher in the dementia subgroup.

Conclusions: The Italian version of the QUALID is a reliable and valid instrument for estimating quality of life in aging adults with ID and dementia.

Keywords: Intellectual disabilities; Dementia; Quality of life; Assessment; Psychometric properties; QUALID; Reliability; Validity

Abbreviations

QUALID: Quality of Life in Late-Stage Dementia Scale; AADS: Assessment for Adults with Developmental Disabilities; ANFFAS: Italian Parental Association of Intellectual and Relational Disabilities; QoL: Quality of Life; ID: Intellectual Disabilities; DS: Down Syndrome; Non-DS: Intellectual Disability other than Down Syndrome; DAD: Dementia due to Alzheimer’s Disease; PCA: Principal Component Analysis; ICC: Intraclass Correlation Coefficient; SPSS: Statistical Package for Social Sciences; CI: Confidence Interval; SD: Standard Deviation; df: Degree of freedom

Introduction

In recent years there has been a growing interest in research and clinical diagnosis of dementia in people with intellectual disabilities (ID) [1]. By contrast, there is scarce published research on the efficacy and effectiveness of daily management strategies of aging people with ID and dementia [2,3]. Proper care of these “new patients” could facilitate “aging in place”, avoiding or at least delaying relocation to long-term facilities [4] which may further decrease their quality of life (QoL) [5]. According to Kitwood [6], the relative well-being of people with dementia depends largely on the quality of their care [7]. The protection or enhancement of QoL is, in fact, the only realistic treatment outcome attainable in people with advanced irreversible dementing diseases [8]. For example, person-centered approaches according to the principles of Kitwood [9] can improve QoL of dementing individuals both in the general [10,11] and ID populations [12,13]. Obviously, QoL becomes at the same time both the objective and the parameter by which to verify the efficacy and effectiveness of these interventions. However, an area in which the definition of QoL presents considerable difficulties, both conceptual and practical, is precisely that of dementia either in the general [14,15] or in the ID population [16]. The progressive deterioration of cognitive functions and verbal communication, the inability to perform previously rewarding activities along with changes in perception, content of thought, mood and behavior, render troublesome the use of reliable and comparable criteria for evaluating QoL relative to the person and his social context during the course of dementia [17]. So the individual’s self-reporting on subjective experience of life comprising psychological well-being and perceived...
QoL is never reducible to a verbal response (when this is still possible), but should be understood on the basis of his/her behavior. This translates into the need for modes of assessment that integrate patients’ verbal expression with direct observation of their behavior [18].

In recent years, several tools have been developed to evaluate QoL in people with dementia due to Alzheimer’s disease (DAD) and other related disorders [14,15]. The basic premises for the development of these tools are: a) the emphasis on behavioral aspects, considered as the product of subjective perception of the environment and the socio-relational context, b) the possibility of objectively perceiving patients’ life experience; c) the completeness of the assessment, including items that suggest both high and low QoL [19].

The Quality of Life in Late-Stage Dementia (QUALID) developed by Weiner and co-workers [20] is a dementia-specific scale using some of the items of the Activity and Affect Indicators of Quality of Life scale Albert et al. [21] which borrowed from two previous QoL scales [8,22]. The QUALID provides information about advanced dementia sufferers’ QoL through assessments made by proxy informants, investigating 11 behavioral areas thought to be indicative of both positive and negative QoL [22,23]. Although there are several direct and proxy-based questionnaires evaluating QoL in the ID population with [24] or without concomitant chronic psychopathology and challenging behaviors [25], we do not know of a tool designed specifically to measure QoL in people with ID and dementia. Rather than developing a new QoL scale for this population, we chose the QUALID scale. The scale has excellent reliability and validity, both in the original and the Swedish [26] and Spanish versions [27]. It was also sensitive to positive and negative treatment effects of two atypical antipsychotics in persons with advanced dementia [28]. Further administration of the QUALID takes only at about five minutes. Finally, the QUALID does not rely on the ability to communicate feeling states in words [29], the purpose of this study was to evaluate the validity and reliability of an Italian version of the QUALID scale in a sample of older adults with ID.

Materials and Methods

Study sample

Three organizations in the ID field collaborated in this study: the non-profit Italian parental association of intellectual and relational disabilities of Trento (ANFFAS Trentino Onlus) that directs community housing and day centers scattered in the province of Trento, the cooperative “Social Laboratory” that manages sheltered employment centers and the Foundation Sospiro of Cremona that directs residential housing and day centers scattered in the province of Trento. All sites were involved in a multicenter multidisciplinary prospective project examining the effects on aging and development of dementia in ID, called the DAD project (http://www.validazione.eu/dad/). This longitudinal project [3] has been approved by the Directory Board of ANFFAS Trentino Onlus (Protocol No. 005932 of 15 September 2005).

Forty adults with ID aged over 45 years were examined. Typological diagnosis of ID was principally done by medical record review and examination of clinical phenotype. All participants were fully or partly able to speak and functionally sighted and hearing, without current clinically relevant chronic psychiatric or organic comorbidity as documented by medical records, and without a recent history of acute organic (e.g. hospitalization with or without (sub-)syndromal delirium) or socio-psychological (e.g. bereavement, removal, change in work activity) stressors. Diagnosis of dementia was done according to the guidelines produced by the international consensus panel established under the auspices of the Ageing Special Interest Group of the International Association for the Scientific Study of Intellectual Disabilities [30]. Explicit verbal, but not written, informed consent was obtained from those subjects who were able to consent. Where such consent was not possible, family members or guardians provided the subject’s willingness to participate in the study.

Study procedure

Raters with extensive first-hand knowledge about aging ID subjects (physician, professional educator, psychologist and education expert) went to each centre to administer the QUALID and one of the two returned after a two-week interval. Prior to the initiation of the study, all interviewers attended a three-hour briefing aimed at achieving a general consensus on scale administration and scoring by using practical examples. In order to be selected as proxy informants (respondents), professional ID caregivers needed to have a long-standing work experience with ID adults/elderly and to be well acquainted with the ID subjects’ general behavior and to have spent at least three of the past seven days with the subject before the QUALID assessment. To reduce transcription errors and counting, interviewees’ responses were entered directly in electronic format via a protected gateway to the website www.validazione.eu/dad, created for data gathering from all the sites involved in the DAD project and only accessible to the authors of this study.

Instruments

Quality of life in late-stage dementia

The 11 QUALID items are rated as to frequency of occurrence on a five-point Likert scale and total scores are summed to range from 11 (best QoL) to 55 (worst QoL). The respondent is given a white copy of the questionnaire so that he/she can see the items that are read aloud by the rater, along with instructions. The interviewer is asked at the end to judge the reliability of the respondent’s answers on a three-point Likert scale. One item (Q1) assesses the overall quality of the interview, which includes the ability to understand the 11 QUALID items and possible responses, and the effort he/she needs to reply to the questions. The other item (Q2) judges the proxy-informant’s level of knowledge with the patient. These two items are not included in the total score, but provide information about the reliability and usefulness of the assessment for that individual patient. The higher the score on these two items the worse the overall quality of the interview. For the current study, an iterative process of forward translations, back translations and evaluation of translation correspondence by a bilingual expert was conducted to achieve conceptual equivalence between the original and Italian translation of the QUALID, according to the procedures recommended for translation of psychometric scales [31].

Assessment for adults with development disabilities

A validated Italian version of the AADS [16,32] was also used. Briefly, the AADS is a proxy-based questionnaire that rates on a seven-point operationally defined Likert scale the Frequency, Management Difficulty and the Effect on the person of 11 behavioral excesses and 17 behavioral deficits commonly found in people with ID and dementia: Frequency (‘More than once a hour/continually’, score 6, to ‘Has not occurred’, score 0 in the preceding two weeks), Management Difficulty (‘no difficulty’, score 0, to ‘extremely difficult’, score 6) and Effect on the person showing the behavior (‘no effect’, score 0, to ‘extremely severe effect’, score 6). Maximum possible scores for each of the three subscales for behavioral Deficits and Excesses are 102 and 66, respectively. The method of data collection was the same as for the QUALID assessment.
Statistical analysis

Descriptive statistics were used to describe the demographic and general clinical data of the participants. The QUALID score distribution was examined in terms of skewness, kurtosis and proportions of participants scoring at maximum (ceiling) or minimum (floor) levels taking the criterion level equal to 15% of the study sample [33].

The dimensionality of the 11 items of the QUALID scale was evaluated using the Principal Component Analysis (PCA) with the Promax oblique rotation method in order to relax the assumption that factors should be uncorrelated with each other. Items were included if their factor loading was ≥ 0.4. Cattell’s scree plot, absorption of variance and face validity of potential dimensions were used as criteria for multidimensionality [34].

The internal consistency (homogeneity) of QUALID was measured with Cronbach’s α coefficient and item-scale correlations, corrected for overlap, taking as a criterion for acceptable reliability coefficients ≥ 0.7 and ≥ 0.4, respectively [30]. Inter-respondent reliability was examined by assessing the subjects’ QUALID twice on the same day by two independent proxy-informants. To assess test-retest reliability, the interviewer submitted one of the two informants again to the QUALID scale two weeks after the initial interview. A history of negative life events since the initial interview was obtained at the time of the second interview so as to identify possible factors contributing to any significant change that might have been observed in the QUALID scale. ICC based on a one-way random effect model was used [35]. The criterion level for acceptable inter-respondent and test-retest reliabilities were set at ICC ≥ 0.7.

Construct convergent validity was tested by calculating Spearman’s correlations for the QUALID with the AADS subcales. It was hypothesized that low scores on the QUALID scale (better QoL) would correlate with low AADS scores, and vice versa in particular Management Difficulty and Effect subscale scores of behavioral Deficits and Excesses [36].

Finally, to further investigate the clinical validity of the QUALID scale, adults/older people who had received a clinical diagnosis of DAD were compared with those who did not. It was hypothesized that persons with DAD would have lower levels of QoL. This comparison was performed using the Mann-Whitney U test.

Results are expressed as absolute numbers or percentages, means, standard deviations (SD) and 95% confidence interval (IC) where appropriate. Data processing and analysis were performed using SPSS statistical program version 15.0 for Windows. Level of statistical significance was set at 0.05.

Results

Participant’s demographic and clinical data

The mean age of the study sample was 56.6 years (SD = 4.9; range = 45–68 years). Eighteen (45%) were male and 22 (55%) were female. Twenty-four (60%) were diagnosed with Down syndrome (DS) and 16 (40%) with other types of ID. Twenty subjects, 17 with DS (85%), received a clinical diagnosis of DAD. There were no significant differences in age between male and female subjects and between ID subjects with and without DAD, whereas the non-DS subjects were significantly older (mean age 58.5 years; SD = 4.1) than the DS group (54.9 years; SD = 4.9) (Student t = -2.3; degrees of freedom [df] = 38; P = 0.024).

QUALID score distribution

No difficulty was encountered in the administration of the QUALID, and 100.0% of the proxy-informants responded to the questions. The overall quality of the interviews (Q1) and level of informants’ knowledge of the ID subjects (Q2) were judged by the raters excellent as evidenced by the low Q1 (mean = 0.1; SD = 0.4) and zero Q2 scores. The mean QUALID score was 19.6 points (SD 6.4; range 11 -39), the median score equal to 18.5 points was near the mean, suggesting a relatively normal distribution. The skewness and kurtosis coefficients were 1.01 and 0.93, respectively. The proportion of ID subjects rated at the ceiling and floor was 0.0% and 2.5%, respectively.

Dimensionality

Table I shows the results of the PCA with Promax rotation. Three factors were identified among the QUALID items, which accounted for a total of 62% of variance. The first factor comprised number 6, 5, 4 and 11 (symptoms of discomfort); the second factor included items number 9, 10 and 1 (positive social interaction); the third factor was composed of items number 2, 7 and 8 (depression). Cronbach’s α coefficients for factors 1 and 2 were higher than 0.70 indicating an acceptable level of internal consistency. The first factor correlated significantly with the third factor. The Spearman’s ρ correlation coefficient was 0.403 (P < 0.01).

Internal consistency, reliability and validity tests

Cronbach’s α for the total QUALID score was 0.80 (standardized). All items correlated with a total score above 0.2. Five items correlated with the total score at a value equal or above the criterion value of 0.4 (Table 1). The ICC of the QUALID scale between two different respondents was 0.954 (95% CI = 0.914 – 0.976). There were no significant differences in the QUALID scores between the two assessments (informant A = 19.33 vs. informant B = 19.95; Wilcoxon Rank Sum test = -1.786; P = 0.074). The ICC of the total QUALID scores obtained by the same rater at a two-week interval was 0.89 (95% CI = 0.795 – 0.941). Again, the difference between the two QUALID scores did not reach a level of statistical significance (first interview = 19.33 vs. second interview = 18.73; Wilcoxon Rank Sum test = -0.098; P = 0.922). The total QUALID score correlated significantly but weakly with the three AADS sub-scores of behavioral Excesses: Frequency (Spearman’s ρ = 0.30; P = 0.031); Management Difficulty (Spearman’s ρ = 0.34; P = 0.017) and Effect (Spearman’s ρ = 0.32; P = 0.023). However, these correlation coefficients increased respectively to 0.44 (P = 0.026), 0.46 (P = 0.019) and 0.40 (P = 0.041) in the DAD subgroup. In addition, among the three latent dimensions of QUALID only the factor of positive social interaction related significantly with the DAD subgroup’s Management Difficulty (Spearman’s ρ = 0.55; P = 0.007) Effect (Spearman’s ρ = 0.45; P = 0.025) sub-scores of behavioral Excesses but not of behavioral Deficits. The comparison of the total QUALID scores between ID subjects with and without DAD showed no significant difference (Mann-Whitney U = 145.1; P = 0.157). However, a post hoc analysis of the differences in factor scores showed that ID subjects with DAD scored significantly higher on the first factor, 9.65 points (SD = 4.40) vs. 6.90 points (SD = 2.42; Mann-Whitney U = 117.5; P = 0.024), and on the third factor, 6.6 points (SD = 2.23) vs. 4.65 points (SD = 2.13; Mann-Whitney U = 101; P = 0.006).

Discussion

The aim of this study was to ascertain the utility of an Italian version of the QUALID scale in ID adults, with and without a diagnosis of DAD.
All proxy informants responded to the 11 QUALID questions in a reliable and appropriate way as rated by the interviewers at the QUALID items Q1 and Q2. This confirms its feasibility of use, and suggests that potential biases of proxy ratings on subjective aspects of QoL can be minimized when the items target observable and concrete aspects of life [15,29] in persons with severe cognitive impairment (but see below). In this study, the proportion of ID subjects rated at the floor or ceiling was far below the 15% criterion [33], indicating that the scale adequately covered the possible range of QoL in the present sample. The internal consistency reliability as indexed by Cronbach’s α coefficient, was superior to the 0.70 criterion and even higher than both in the original [20] and the Swedish [26] and Spanish [27] validation studies. Notwithstanding substantial differences in the clinical status of the participants, the PCA performed in the present study confirmed the multidimensional structure of the QUALID. As in the Spanish validation study, three factors were identified reflecting three possible underlying dimensions of QoL, i.e. behavioral symptoms of discomfort (items 6,5,4,11 and 3), behavioral symptoms of positive social interaction (items 9,10 and 1) and behavioral symptoms frequently observed in geriatric depression (items 2, 7 and 8), and explained the 62% in score variance. The internal consistency reliability of each latent factor, according to Cronbach’s α coefficient, was superior (factors 1 and 2) or near (factor 3) 0.70, suggesting that the items of each factor were measuring the same latent dimension.

The Italian QUALID in this ID sample was found to have excellent inter-respondent (ICC = 0.95) and robust test-retest (ICC = 0.89) reliabilities. The evaluation of inter-informant reliability, as opposed to test-retest reliability, is important for proxy-based measures such as the QUALID that might be used prospectively when informants might change over time. The criterion convergent validity was tested under the hypothesis that QoL in aging ID should closely relate to the AADS since the scale provides a useful appraisal of specific behavioral negative and positive symptoms shown by adults with ID who have dementia, in terms of their frequency and their impact on caregivers and the individual showing the behaviors. No significant correlations among the behavioral Deficits subscales and the total QUALID score were found nor in the entire sample neither in the DAD subgroup. The 17 behavioral Deficits included in the AADS (e.g. inactivity, word finding difficulties, lack of interest, disinhibition, becoming lost, difficulties carrying out sequential acts, poor concentration) predominantly refer to symptoms that clearly derive from cognitive decline. The lack of a significant relationship between cognitive decline and QoL in DAD is in accordance with previous research in the general population [37,38]. By contrast, the total QUALID score correlated positively and weakly in the entire study sample and moderately in the DAD subgroup with the Excesses subscales. Interestingly, reduced opportunities for social engagement and for communicating feelings were associated in the DAD subgroup with the Management Difficulty and Effect on the individual of behavioral Excesses. Thus, QoL at least as regards positive social interaction appeared to be negatively influenced by the consequences of disruptive behaviors on the caregiver and the individual rather than by their frequency per se. This finding confirms the assumption that relative discomfort in ID people with dementia may be related to poor quality care which may be improved through caregiver training and person-centered psychosocial interventions [3,7]. The analysis of discriminative capacity of the QUALID involved a comparison between ID subjects with and without DAD. Though the mean total scores did not statistically differ between the two subgroups, a post hoc analysis using the three latent dimensions of the QUALID permitted us to detect worse discomfort and depression in the DAD subgroup. Both these factorial structures that correlated significantly with each other in the present study, are reported to compromise the QoL in the non-ID population with mild-to-moderate DAD [39]. There are some methodological limitations of this study. The participants were not randomly selected. However, the inclusion of four centres of the province of Trento and one centre in Cremona increased the generalizability of our findings, at least as regards aging ID subjects attending ID-specific services. Concurrent criterion validity was not assessed because there is no validated proxy-based QoL scale for aging ID people against which to compare the QUALID scale. Lastly, since attitudes of the proxy-informants towards the ID subjects and their self-perceived competence to cope with ID- or dementia-specific behavioral disorders were not addressed in this study, some errors of QoL measurement cannot be excluded [40]. Notwithstanding these shortcomings, our results indicate that the QUALID scale provides reliable and valid estimates of QoL in aging adults with ID and dementia. There are however a number of topics that might be pursued to extend research. Because many aging ID individuals continue to live with their family, QUALID’s reliability has also to be determined with family members as proxy informants. A larger scale study would allow the computation of cut-off values and/or the detection of more robust factorial structures confirming the multidimensionality of the QUALID that may be useful for the analysis of change in QoL over time. This would permit clinicians and caregivers to better appraise the effects of drug treatment, person-centered psychosocial interventions and

<table>
<thead>
<tr>
<th>Item 6. Verbalizations suggest discomfort</th>
<th>Factor 1</th>
<th>Factor 2</th>
<th>Factor 3</th>
<th>Correlationsa</th>
</tr>
</thead>
<tbody>
<tr>
<td>Item 5. Appears physically uncomfortable</td>
<td>0.837</td>
<td>0.124</td>
<td>0.124</td>
<td>0.550</td>
</tr>
<tr>
<td>Item 4. Facial expression of discomfort</td>
<td>0.767</td>
<td>0.084</td>
<td>0.084</td>
<td>0.502</td>
</tr>
<tr>
<td>Item 11. Appears calm and comfortable</td>
<td>0.252</td>
<td>0.025</td>
<td>0.025</td>
<td>0.513</td>
</tr>
<tr>
<td>Item 3. Cries</td>
<td>0.503</td>
<td>-0.225</td>
<td>0.183</td>
<td>0.316</td>
</tr>
<tr>
<td>Item 9. Enjoys touching/being touched</td>
<td>-0.163</td>
<td>0.891</td>
<td>0.302</td>
<td>0.375</td>
</tr>
<tr>
<td>Item 10. Enjoys interacting with others</td>
<td>0.209</td>
<td>0.886</td>
<td>-0.176</td>
<td>0.240</td>
</tr>
<tr>
<td>Item 1. Smiles</td>
<td>0.055</td>
<td>-0.187</td>
<td>0.768</td>
<td>0.299</td>
</tr>
<tr>
<td>Item 2. Appears sad</td>
<td>0.055</td>
<td>-0.098</td>
<td>0.683</td>
<td>0.358</td>
</tr>
<tr>
<td>Item 7. Is irritable or aggressive</td>
<td>0.126</td>
<td>0.385</td>
<td>0.672</td>
<td>0.485</td>
</tr>
<tr>
<td>Item 8. Enjoys eating</td>
<td>-0.036</td>
<td>0.297</td>
<td>0.503</td>
<td>0.626</td>
</tr>
<tr>
<td>Cronbach’s α coefficient</td>
<td>0.770</td>
<td>0.832</td>
<td>0.490</td>
<td></td>
</tr>
<tr>
<td>Explained variance (%)</td>
<td>30.4</td>
<td>22.3</td>
<td>9.6</td>
<td></td>
</tr>
</tbody>
</table>

Values in bold and cursive indicate that the QUALID item is included into factor

*Correlation coefficient between items and total score (corrected for overlap)
caregiver-training aimed at enhancing QoL in people with dementia, whatever the level of their premorbid intellectual status.

Acknowledgments

We thank the valuable cooperation of ANFFAS Trentino onlus, Fondazione Sospiro, the cooperative Laboratorio sociale, and Dr. John Maurizio Pradelli for the back translation of the scale.

References