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Use of the QOL-AD for measuring quality of life in people with severe dementia—the LASER-AD study

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Abstract

Background: health-related quality of life (HR-QOL) scales are particularly important in older people as global outcome measures for interventions. It is known that people with mild to moderate dementia can provide valid assessments of their own QOL, but it is unclear whether these instruments are useful in those with severe dementia.

Objective: we examined the usefulness of the QOL scale in Alzheimer's disease (QOL-AD) in people with severe dementia by considering the ability of older people with a Mini-Mental State Examination (MMSE) score of <12 and their caregivers to complete this scale, as well as its construct validity and internal consistency.

Methods: data were collected from people with Alzheimer's disease and their caregivers using a range of instruments measuring cognition, mood, behaviour, QOL and functional ability.

Results: of 79 participants and their caregivers, 41 (52%) could complete the QOL-AD. Cognition and functional abilities were significantly higher in the completers than in the non-completers (P < 0.001). The QOL-AD showed internal consistency and construct validity as it correlated with ability to look after self, fewer limitations due to physical health, positive mood status and low levels of apathy.

Conclusions: there is evidence for the validity and reliability of the QOL-AD in people with MMSE scores of 3–11, as well as the practicality of administering the scale in this population. The scale is unlikely to generate useful information for people with MMSE scores of <3. QOL does not decrease as cognition worsens. This throws into question most people's assumption that decreasing cognition worsens QOL. We consider that it may be important to inform the public of this, as living wills are used increasingly in our culture.

Keywords: quality of life, dementia, Alzheimer's disease, outcome measures, reliability and validity, elderly

Measuring quality of life in people with severe dementia

Background

Health-related quality of life (HR-QOL) scales that measure patients' perceptions of their global quality of life (rather than the number of symptoms they have) are particularly necessary in older people owing to the complex nature of their health status, for example, symptom alleviation in one domain may lead to deterioration within another [1, 2]. Consequently, HR-QOL instruments have been developed as outcome measures for interventions and as determinants of future care [3, 4]. These measures incorporate many relevant factors such as emotional, physical and social functioning and lifestyle [5]. In dementia, QOL also incorporates cognitive function and activities of daily living [6]. The use of QOL measures as outcome indicators for dementia has been given added impetus by the introduction of antidementia medication and the resultant need to measure the efficacy of specific treatment interventions [7, 8].

Measuring HR-QOL

HR-QOL can be measured using specific or generic rating scales. The latter are necessary to measure the range of disability but cannot indicate the specialist resources needed, as they reflect more general issues [3, 9]. Orley *et al.* [10] argued the need for disease-specific instruments so that the items relating to a particular illness were included. These ensure greater sensitivity to changes in health status and disease severity [5], but the concurrent use of generic scales would allow comparisons with other patient groups and the wider population [11].

Who should rate QOL in dementia?

A variety of methods for rating QOL are currently used for subjects with dementia, incorporating subjective, objective and observational methods. The accuracy of psychiatric patients' judgement in determining QOL has been questioned [10], but both carers and care recipients (CR) have been able to complete QOL assessments [7]. Professional caregivers have been able to rate the QOL of people with severe impairment using the Alzheimer's disease-related quality of life scale (QOL-AD) [12–14], but no instruments for QOL in dementia which involve CRs' rating have been validated in a group of the most severely ill. Although caregivers can reliably measure patients' global QOL [15], Brod et al. [16] suggested that the patient's subjective ratings should be the 'gold standard' for measuring QOL in dementia, but that observational ratings were of benefit for those patients with more severe dementia (Mini-Mental State Examination (MMSE) score <12).

QOL instruments for dementia

The 12-item Health Status Questionnaire (HSQ-12; [17]) provided a broad measure of perceptions of health and wellbeing in older people [18]. There were high completion rates in participants with dementia still living at home, and people with dementia provided valid assessments of their own QOL.

Logsdon et al. [19] devised the QOL-AD, which is completed by both CRs and caregivers. It includes assessment of physical health, mental health, social and financial domains

and an overall QOL rating. They considered differences in the ratings of QOL between the CR and caregiver to be due to varying perceptions, rather than a lack of reliability of the scale [20]. It had satisfactory validity and reliability, but had limited use for CRs with a MMSE score of <10. Other investigators have found that participants with a MMSE score of 12 or above provided reliable and valid data [16, 21]. Thorgrimsen et al. [22] used focus groups as well as administering the QOL-AD to 261 people with mild, moderate and severe dementia and their carers. They concluded the scale was a reliable and valid tool, which could be satisfactorily used to rate QOL in CR, some of whom had MMSE scores as low as 3. There were, however, very few people with a MMSE score of <12 in this study, and data from this subgroup were combined with the whole sample. It is therefore still unclear how useful the scale is for those with the most severe dementia.

Aims of the project

We investigated the ability of older people with severe dementia of Alzheimer's type to rate their QOL using the QOL-AD, and identified factors associated with QOL in this population.

Methods

This study forms part of a larger epidemiologically representative project involving people with AD and their caregivers recruited from the London and South East Region (LASER) of the UK: the LASER-AD study [23, 24]. Local ethical approval was obtained. Participants were from urban, suburban and semi-rural districts, and were selected to be representative of people with AD in terms of gender, dementia severity and living situations [25]. CRs and their caregivers were contacted through local psychiatric services, the voluntary sector and managers of care homes. Both caregivers and CRs were asked for their written informed consent. If the CRs were unable to give informed consent, they were asked for assent and the caregivers gave written agreement. The interview was stopped if the CR asked to withdraw or showed distress. Trained researchers from a range of disciplines (medicine, nursing and psychology) conducted all the interviews.

If possible, a family caregiver was interviewed. If there was no such caregiver, a statutory carer was interviewed instead. All caregivers had to spend at least 4 hours a week with the CR. Caregiver and CRs were interviewed at baseline and 6 months later. The diagnosis of AD was made using standardised criteria [26, 27]. We report here data concerning people who had a severe dementia as defined by a MMSE score of <12. We chose this cut-off point for two reasons: this is the group in which HR-QOL measures have not been validated [16, 21]; and this is a group in which cholinesterase inhibitors are not recommended, and outcome measures for future studies of treatment of AD are essential [28].

Instruments completed by CR and caregiver

The QOL-AD is a 13-item scale for measuring QOL in people with AD, through ratings from both the CR and

J. Hoe et al.

caregivers [19]. The CR's ratings are given twice the weight of the carer's and a weighted mean score calculated. Higher scores indicate better QOL. Possible totals range from 13 to 52.

The Cornell Scale for Depression in Dementia detects depression in people with dementia, through information from the person and their caregiver. The observer then gives an overall rating [29].

Instruments completed by CR

The HSQ-12 is a generic scale derived from the SF-36 [30]. It comprises eight domains. We judged three domains to be particularly likely to be impaired in severe dementia: mental health (mood state—calmness, sadness, happiness), role-physical (role limitation owing to physical health problems) and role-mental (role limitation owing to emotional health problems). The other domains such as pain, energy, fatigue, physical functioning and health perception are less related to AD.

The MMSE is a brief test of cognitive function, which we used to measure orientation, memory and attention [31].

Instruments completed by caregiver

The Neuropsychiatric Inventory (NPI) measures the severity and frequency of behavioural symptoms [32], with higher scores indicating increasing severity.

The Alzheimer's Disease Co-operative Study – Activities of Daily Living Inventory (ADCS-ADL) is a 23-item scale used to determine levels of functional ability, with higher scores indicating better functioning [33].

The Hospital Anxiety and Depression scale (HADS) is a self-assessment scale, which provides a valid measure of anxiety and depression [34]. In this study it was used for the caregiver.

Analysis

For the QOL-AD, cases with missing items were not included. We analysed descriptive data and used tests to explore differences in terms of age and MMSE between those CRs who were and were not able to complete the QOL-AD. We examined the scores on the MMSE at which participants were able to complete the QOL-AD. As there is no gold standard for criterion validity in measuring an individual's QOL, construct validity of the QOL-AD was assessed by correlating the scale with measures of cognition, mood, neuropsychiatric symptoms, activities of daily living and relevant domains in HR-QOL (MMSE, Cornell, NPI,

ACDS-ADL and HSQ-12, respectively). Analysis was undertaken as appropriate using Pearson's *r*, Spearman's Rho and Cronbach's alpha tests. Caregivers' HADS scores were correlated with CRs' QOL-AD scores to examine the relationship of caregiver mood to CR's QOL.

Results

Demographic data

Seventy-nine participants from the original study population of 224 participants had an MMSE score of <12. Of these, 58 were females (73.4%). Forty-three (54.4%) were widowed, 29 (36.7%) married, 4 (5.1%) single and 3 (3.8%) divorced. Forty-nine (62.0%) lived in 24-hour care settings. Of the remainder, 16 lived with a spouse or partner (19%), 9 lived with relatives (11.4%) and 5 were living alone (6.3%). Sixty-two were white British (78.5%), 5 were white Irish (6.3%), 7 white other (8.9%), 3 were black Caribbean (3.8%), 1 black other (1.3%) and 1 Indian (1.3%). Twenty-eight (35.4%) of the caregivers were children, 26 (32.9%) spouses, 4 (5.1%) other relatives, 2 (2.5%) friends and 19 (24.1%) paid caregivers.

Of the 79 CRs with a MMSE score of <12, 41 (52%) were able to complete the QOL-AD. They had a mean QOL-AD score of 32.8 (SD 6.2). Twenty-five (65.8%) of those who did not complete the QOL-AD did not answer any of its questions. Eight (21.0%) CRs partially completed the questionnaire; two had one item missing, three had three missing; one had six and two had 12 items missing. Five (13.2%) questionnaires were answered by the CRs but not by the caregiver and were excluded when characteristics of completers and non-completers of the QOL-AD were examined (Table 1). The MMSE and ACDS-ADL scores were significantly higher in the completers than in the non-completers (*P* < 0.001).

Figure 1 shows the MMSE scores for completers and non-completers of the QOL-AD. From Figure 1 it is clear that most completers (n= 41) had a MMSE score of \geq 3. As most people with a MMSE score of <3 could not complete the QOL-AD, we examined the QOL of people scoring 3–11 (n= 37 out of 52; 71.2% completed) to consider the validity and reliability of the measures.

Table 2 shows the QOL-AD scores and their correlation with the Cornell, NPI (total score and individual items),

Table 1. Characteristics of completers and non-completers of the QOL-AD

Variables	Able to complete Mean, SD, range (<i>n</i>)	Not able to complete	
		Mean, SD, range (n)	Significance
Age (years)	80.0, 8.8, 55–94 (41)	81.3, 7.6, 64–98 (33)	NS
MMSE score	7.0, 3.2, 0–11 (41)	2.2, 3.2, 0–10 (33)	P < 0.0001
Cornell score	5.6, 5.6, 0–21 (41)	4.0, 5.1, 0–24 (33)	NS
ACDS-ADL score	21.3, 14.1, 0–58 (41)	6.9, 8.5, 0–45 (33)	P < 0.0001
NPI score	24.9, 20.6, 0–79 (41)	20.8, 16.4, 0–69 (33)	NS
HSQ-Mental Health score	71.7, 17.9, 33–100 (37)	70.0, 42.4, 40–100 (2)	NS
HSQ-role-mental score	88.8, 22.8, 20–100 (38)	86.0, 19.2, 65–100 (5)	NS
HSQ-role-physical score	73.8, 36.9, 0–100 (39)	65.0, 48.7, 0–100 (5)	NS

NS = non-significant.

ACDS-ADL, HSQ-12 and the HADS. There was a significant correlation between the QOL-AD and the ACDS-ADL results (P < 0.001) and with the HSQ-role-physical (P < 0.01). In addition, higher levels of QOL were strongly associated with good mood status on the HSQ-mental health (P < 0.001), and negatively associated with the apathy item of the NPI (P < 0.05). These results were the same if all 41 completers of the QOL-AD were considered.

A reliability analysis examining internal consistency was undertaken using Cronbach's alpha test, which calculated the mean inter-item correlation (see Appendix 1 in the supplementary data on the journal website www.ageing.oup-journals.org). The item-total correlation between each QOL-AD item and the QOL-AD total score varied between 0.35 and 0.81, Cronbach alpha = 0.7829. Only 17 (54.8%) of the original participants were able to complete the QOL-AD at 6 months: six had died or refused follow-up. The others were interviewed but did not complete the QOL-AD. The mean QOL-AD score for these 17 had been 35.2 at baseline and was 35.6 at follow-up. Cronbach's alpha coefficient for test—retest reliability was 0.8930.

Discussion

This is the first study to report the ability of a group of people with severe dementia to rate their own QOL using standardised measures. The main findings are that there is evidence for the validity and reliability of the QOL-AD in people with MMSE scores of 3–11, and that it was possible for most individuals with a score of 3 or more on the MMSE to rate QOL using the QOL-AD. The scale could not be applied for most of those with a MMSE of <3. Most of the non-completers did not complete any of the items on the QOL-AD and we felt that the difficulty was in choosing from an abstract list to describe their feelings. In contrast they answered some cognitive questions and so had a degree of comprehension. Even those who answered were unable to retain the instructions to choose a rating from the list and this was repeated at every question. The QOL-AD showed construct validity in that it correlated with ability to

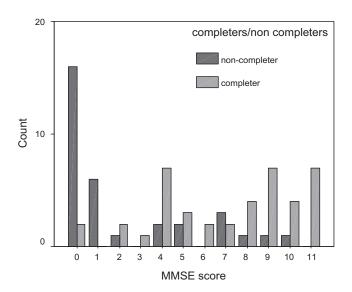


Figure 1. The MMSE <12 scores for completers and non-completers of the QOL-AD.

look after self, limitations owing to physical health, overall mood status and apathy. The highest correlation coefficient with other scales was with the HSQ mental health (mood state) and it is of interest that this seems to be such a large component of QOL even in severe dementia. The significant correlations with limitations owing to physical health and of activities of daily living are more modest but still of the degree which would be regarded as clinically significant [35]. It therefore successfully integrates information about mental and physical dimensions and their effects on health as is desirable from a QOL instrument. We did not expect that QOL would correlate with education or cognition and it did not as they are not measures of emotional state. Despite being strongly linked to QOL in general, depression (as measured by the Cornell scale) was not found to be associated with the QOL-AD ratings. This may be partly due to the fact that most of the participants were not clinically

Table 2. Correlations with the total QOL-AD score for people with a MMSE <12 and ≥3

Variable	n	Value	Significance
AGE	37	Pearson -0.081	NS
EDUCATION	33	Pearson -0.063	NS
MMSE	37	Pearson -0.020	NS
ACDS-ADL	37	Spearman 0.547	P < 0.001
Cornell	37	Spearman -0.272	NS
NPI-apathy	37	Spearman -0.395	P < 0.05
NPI-anxiety	37	Spearman -0.175	NS
NPI-agitation	37	Spearman 0.048	NS
NPI-aberrant motor activity	37	Spearman -0.207	NS
NPI-disinhibition	37	Spearman 0.264	NS
NPI total score	37	Pearson -0.114	NS
HSQ mental health	34	Pearson 0.582	P < 0.001
HSQ role-mental	35	Spearman 0.287	NS
HSQ role-physical	36	Spearman 0.481	P < 0.01
HADS anxiety	31	Pearson -0.050	NS
HADS depression	31	Pearson 0.092	NS

depressed. Their mood did however contribute to the QOL measurement. In addition, apathy was significantly correlated with the QOL-AD. We hoped and indeed found that it did not correlate with the caregivers' mental state as we were trying to measure the CR's QOL not the caregivers' emotions. The lack of correlation with other neuropsychiatric symptoms may be because, as is often observed in clinical practice, they distress the caregiver more than the CR. The test–retest reliability was highly correlated.

The scale showed reliability and lack of redundancy in its high item total correlation scores. Interestingly, the highest item—item correlations were between the items where participants rated relationships and overall QOL. The similarity of items regarding different relationships strongly suggests that the answers given were meaningful. The relationship to overall QOL again suggests that psychosocial items rather than health are important in this group. The results for those people scoring 3 and above on the MMSE can be considered generalisable to this population group, which was representative of people with severe AD in different geographical and institutional settings.

Our study is limited by the small sample size, as many could not complete the scale. There were, however, enough participants to show significant correlations. In addition, there is the lack of an accepted gold standard of QOL. This issue has been raised in other dementia studies and the use of patient subjective ratings was suggested [16, 18]. We have also defined severe dementia according to MMSE cutpoint, for the reasons explained above, as opposed to global rating. Thus, some of the participants in this part of our study may have been less severe and, conversely, some with higher MMSE may have had a global rating of severe. Our definition is, however, clinically useful and easy to understand.

For the population group able to complete the QOL-AD, QOL did not differ according to cognition. This finding is consistent with other studies of QOL in dementia [22, 36] and demonstrates how important it is to use the CR to rate their own QOL rather than relying solely on other raters' judgements. Our study suggests that in severe dementia, higher QOL was predicted by better functional ability, lack of disability, improved mood status and increased engagement with the environment.

Direct questioning does not impose the professional's opinion on the person. As the need for QOL measures within old-age psychiatric research becomes more important, it is essential that a range of reliable tools are available and that these can be used to consistently measure QOL across all levels of severity of the disease. It is also important that these tools are able to identify predictors of QOL relevant to the population group. In conclusion, this study has shown that QOL can be usefully measured in people with severe dementia, scoring >3 on the MMSE. It has also shown that (counter-intuitively) QOL does not decrease as cognition worsens. This throws into question most people's assumption that worsening dementia worsens QOL. We consider that it may be important to inform the public of this, as living wills become more part of our culture.

Key points

- People with MMSE scores of >2 can rate their own OOL.
- The QOL-AD is valid and reliable in people with an MMSE score of >2.
- Quality of life does not decrease as cognition worsens.
- This throws into question most people's assumption that decreasing cognition worsens quality of life.
- We consider that it may be important to inform the public of this, so that the knowledge can be used to inform the process of making living wills.

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