

ORIGINAL ARTICLE: EPIDEMIOLOGY,  
CLINICAL PRACTICE AND HEALTH**EQ-5D rated by proxy in institutionalized older adults with dementia: Psychometric pros and cons**

Alicia Diaz-Redondo,<sup>1</sup> Carmen Rodriguez-Blazquez,<sup>2,3</sup> Alba Ayala,<sup>1</sup> Pablo Martinez-Martin,<sup>2,4</sup> Maria João Forjaz,<sup>1,5</sup> on behalf of the Spanish Research Group on Quality of Life and Aging

<sup>1</sup>National School of Public Health, <sup>2</sup>Consortium for Biomedical Research in Neurodegenerative Diseases (CIBERNED), <sup>3</sup>National Center of Epidemiology, Carlos III Institute of Health, <sup>4</sup>Alzheimer Disease Research Unit, CIEN Foundation, Carlos III Institute of Health, Alzheimer Center Reina Sofia Foundation, and <sup>5</sup>Spanish Research Network on Social Services and Chronicity (REDISSEC), Madrid, Spain

**Aim:** Measurement of health-related quality of life in people with dementia is a challenge, because of their special characteristics and the difficulties that this term entails itself. The present study aimed at assessing the psychometric properties of the EQ-5D rated by a familiar or a professional caregiver of institutionalized older adults with dementia.

**Methods:** We analyzed the EQ-5D psychometric properties from 525 questionnaires rated by proxy, in a sample of institutionalized older adults with dementia.

**Results:** The mean EQ-5D index score was  $0.11 \pm 0.38$ , and  $51.54 \pm 21.47$  for the visual analog scale. The intraclass correlation coefficient was 0.72. Regarding internal consistency, Cronbach's alpha was 0.64, and the item-total correlation ranged from 0.33 to 0.53. Exploratory factor analysis identified a functional and a subjective factor, accounting for 67.35% of the variance. Convergent validity of EQ-5D with Quality of Life Alzheimer's Disease by proxy and Quality of Life in Late-stage Dementia scales was satisfactory ( $r = 0.36\text{--}0.58$ ). The EQ-5D showed appropriate discriminative validity among patients grouped into several categories. Multiple linear regression models, using EQ-index and visual analog scale as dependent variables, identified dependence level, proxy characteristics, leisure and comorbidity as determinants of quality of life.

**Conclusions:** Despite some limitations in the more subjective dimensions, the proxy-rated EQ-5D showed satisfactory psychometric properties in the present study, suggesting that it is a valid and alternative instrument to assess quality of life in institutionalized older people with dementia. *Geriatr Gerontol Int* 2013; ●●: ●●--●●.

**Keywords:** dementia, EQ-5D questionnaire, nursing homes, psychometric properties, quality of life.

## Introduction

In the Quality of Life (QoL) assessment, participants express the impact that the disease itself or the impact the interventions and treatments have on their lives. Assessing QoL in dementia is a challenge. There is not a widely accepted gold standard for QoL. In addition, subjective judgment is considered essential for measuring QoL and, apparently it is not possible to obtain reliable self-assessments in people with cognitive

impairment.<sup>1,2</sup> Loss of memory and insight, and lower ability for reasoning, elaborating judgment, and even for managing language are usually present in dementia. It is not clear at which point in the cognitive decline process patients are no longer able to provide accurate self-reports, and observational rating by proxy becomes necessary. Some studies have found a good correlation between self and proxy ratings, but, in contrast, they also have detected that caregivers systematically give lower ratings than patients themselves, with similar differences between patients and caregivers for all levels of impairment.<sup>1,3</sup> To measure QoL in dementia, we count on specific questionnaires, such as Quality of Life Alzheimer's Disease (QOL-AD)<sup>1</sup> and Quality of Life in Late-stage Dementia (QUALID),<sup>4</sup> and also on generic questionnaires, such as the EQ-5D.<sup>2,5,6</sup>

The EQ-5D is a standardized QoL and health status instrument that offers a simple generic measure for both

Accepted for publication 8 May 2013.

Correspondence: Dr Alicia Díaz-Redondo MD MPH, Escuela Nacional de Sanidad., Instituto de Salud Carlos III., Avda. Monforte de Lemos 5, Pab. 8, Despacho 1214., 28029 Madrid. España. Email: [adredondo@isciii.es](mailto:adredondo@isciii.es); [adredondo@salud.madrid.org](mailto:adredondo@salud.madrid.org)

clinical and economic appraisal. Its advantages are that it is an easy and quick to apply test, and it allows researchers to evaluate and compare essential aspects of health among groups and populations, and to determine the value of several health states. In addition, this information can be used for cost-utility studies of specific programs and interventions for different patient groups. The EQ-5D has been widely applied in the general population,<sup>7-9</sup> and is also suitable for patients with cognitive impairment.<sup>2,5,6</sup>

Some studies assessing QoL in dementia exclude patients with late-stage dementia, because it is difficult to measure in this population.<sup>1,2,5,10</sup> Besides, there is scarce information about using the proxy mode of administration of the EQ-5D instrument in patients living in nursing homes.

The objective of the present study was to estimate whether the EQ-5D rated by proxy is appropriate to measure QoL in the special population of older adults at any stage of dementia living in nursing homes. Specifically, the psychometric properties of the EQ-5D were analyzed. A secondary objective was to investigate the association between some sociodemographic and clinical characteristics of the patients, and their QoL, using the information provided by the EQ-5D by proxy.

## Methods

### Study design

The present cross-sectional study included 525 people living in 14 nursing homes located in 10 different provinces of Spain, and their usual caregivers. Patients had to be aged at least 60 years, with a diagnosis of dementia, according to the *Diagnostic and Statistical Manual of Mental Disorders*, Fourth revision, Task Force (DSM-IV-TR) classification,<sup>11</sup> at any stage of severity. Written informed consent was obtained from the patients themselves or their legal representative. Caregivers were a near relative with regular, close contact with the patient, familiar with his/her health status and behavior, or, in case a family member was not available, a staff member answered the questionnaire. All patients living in the nursing homes that fulfilled inclusion criteria were consecutively recruited. The study was approved by the institutional review board of the Carlos III Institute of Health.

### Assessments

Sociodemographic data of the patients were registered. The following QoL measures were completed by the caregiver: EQ-5D;<sup>7,9</sup> QOL-AD;<sup>1,4</sup> and QUALID.<sup>1,4</sup> The Barthel Index,<sup>12-14</sup> the Cornell Depression Scale,<sup>13,15</sup> the number of chronic medical conditions,<sup>16,17</sup>

“Mini-Examen Cognoscitivo” (MEC; the Spanish version of the MMSE)<sup>18,19</sup> and the Clinical Dementia Rating (CDR) scale<sup>20,21</sup> were clinician rated.

The EQ-5D is a generic QoL and health status instrument increasingly used in patients with neurological disorders.<sup>2,3</sup> It includes a section describing the current health state in five dimensions (mobility, self-care, usual activities, pain/discomfort, anxiety/depression), using three levels of severity (1 = no problems; 2 = some or moderate problems; 3 = unable or extreme problems). The five dimension scores can be combined and 243 possible health states are thus obtained. A utility index, ranging from -1 to +1, can be calculated and assigned to each health state through an algorithm. In the present study, the EQ-5D index based on the time trade-off method and validated for the Spanish population was used.<sup>8</sup> The second part of the EQ-5D consists of a visual analog scale (EQ-5D-VAS), where the respondent marks the perceived current health state from 0 (the worst imaginable state of health) to 100 (the best possible state of health). Alternative modes of administration for this instrument are available: self-completion form, asking participants to self-rate their health; and proxy, asking a caregiver to rate the participant’s health, used in the present study.<sup>9</sup> Although there is an extended version of the EQ-5D that includes a cognitive dimension (EQ-5D+C), the study of Wolfs *et al.* did not find differences with the EQ-5D in dementia patients.<sup>22</sup> The recently introduced EQ-5D-5L, which seems to improve sensitivity and to reduce the ceiling effects of the test in respect to EQ-5D, had not been validated for dementia patients, neither for the Spanish population when the data for the present study was collected.<sup>23,24</sup>

The QOL-AD is a specific instrument to measure QoL in people diagnosed with Alzheimer’s disease (AD).<sup>1,25</sup> It includes 13 items (physical health, energy, mood, living situation, memory, family, marriage, friends, self, ability to do chores, ability to do things for fun, money and life as a whole), rated from 1 (poor) to 4 (excellent). The sum score ranges from 13 to 52, with lower scores indicating worse QoL.

The QUALID is aimed at measuring QoL in people with severe dementia.<sup>1,4</sup> The QUALID<sup>4,26</sup> is composed of 11 items (smiles, appears sad, cries, has a facial expression of discomfort, appears physically uncomfortable, complaints, groans or screams, is irritable or aggressive, enjoys eating, touching or being touched, interacting or being with others, appears emotionally calm and comfortable), each one scoring from 1 to 5, with lower scores representing better QoL.

The Barthel Index measures the capacity to carry out activities of daily living.<sup>12-14</sup> The total score ranges from 0 (total dependence) to 100 (total independence). Ratings of 40 or less indicate severe dependence.<sup>14</sup>

The Cornell Depression Scale is a tool specifically developed to assess depression in dementia patients.<sup>13,15</sup> Scores  $\geq 6$  are indicative of a potential depressive disorder.

The number of chronic medical conditions was assessed through an adapted version of the Cumulative Illness Rating Scale for Geriatrics.<sup>16,17</sup> The questionnaire inquires about the presence (yes/no) of 20 medical conditions. The sum score of all positive responses was dichotomized according to the median (7 medical conditions in our sample).

Cognitive status was appraised using the “Mini-Examen Cognoscitivo”, which is the adapted and validated version for Spain of the Folstein Mini-Mental State Examination.<sup>18,19</sup> It consists of 23 questions scoring 35 as the maximum. In the present study, 23 out of 24 was used as the cut-off point for the geriatric population, and 14 as the cut-off point for severe cognitive impairment.

The Clinical Dementia Rating scale was used to evaluate the severity of dementia.<sup>20,21</sup> The scale ranges from 0 (no impairment) to 3 (severe dementia) in six domains. Scores are combined to obtain a composite score classifying dementia severity in stages: 1 (mild), 2 (moderate) or 3 (severe).<sup>20,21</sup>

### Data analysis

Descriptive statistics were applied to define sociodemographic characteristics of our sample. The following psychometric properties of the EQ-5D were explored.

Feasibility was assessed by means of the percentage of missing data (maximum acceptable 10%) and fully comparable data (minimum acceptable 95%).<sup>2,27</sup>

Acceptability was estimated through score ranges (observed *vs* possible), closeness of means to medians, floor and ceiling effects (less than 15% of responses accumulated at minimum or maximum values), and skewness (between  $-1$  and  $+1$ ).<sup>27</sup>

For reliability, we calculated the internal consistency through Cronbach’s alpha coefficient (standard criterion  $\geq 0.70$ ), and the item-total correlation corrected for overlap (ITCC; criterion  $\geq 30$ ).<sup>28</sup> For interrater reliability, we applied the EQ-5D to a subsample of 84 patients and calculated the intraclass correlation coefficient (ICC) with the caregiver’s responses (criterion  $> 0.70$ ).

To assess dimensionality and determine the factor structure of the EQ-5D descriptive system, an exploratory factor analysis using a principal components method with varimax rotation was carried out. Unidimensionality was also assessed with Rasch analysis,<sup>29</sup> carried out with RUMM2030 (Version 5.1 for Windows, Perth, WA, Australia).

Convergent validity was examined using Pearson’s or Spearman’s coefficients with specific scales for QoL in dementia. We hypothesized that the EQ-5D would cor-

relate at a moderate ( $r = 0.35-0.50$ ) or high ( $> 0.50$ ) level with QOL-AD and QUALID proxy scales.<sup>30</sup>

Known-groups validity was explored by determining the EQ-5D ability to distinguish among participants grouped by variables of interest, using Student’s *t*-test and ANOVA test. Answers to the EQ-5D dimensions were grouped into two categories (no problems, any problem) for this analysis.<sup>9</sup> We hypothesized that women would have significantly worse QoL than men, and that QoL would decrease with age. We also expected to find a lower QoL in people with lower education level, lower functional status (no leisure and lower Barthel Index), higher comorbidity, depression and CDR score, and those whose EQ-5D was completed by a family member instead of a professional caregiver.<sup>1,3,10,31</sup> As contradictory findings have been reported about the relationship between cognitive status and QoL, we explored how EQ-5D varied by different MEC levels.<sup>3,6,32,33</sup>

Two different multiple linear regression models were carried out, one for the EQ-5D index and one for the EQ-5D-VAS as dependent variables. The independent variables entered in the model were: age, sex, Barthel Index, Cornell Scale, CDR score, MEC, the number of medical conditions, leisure and if the respondent was a family member or a professional caregiver. Multiple linear regression assumptions were previously tested.

All calculations were carried out in SPSS 18 (SPSS, Chicago, IL, USA), except regression analyses, which were carried out with STATA 10 version for Windows (Statacorp, College Station, TX, USA). The significance level was set at 0.05.

## Results

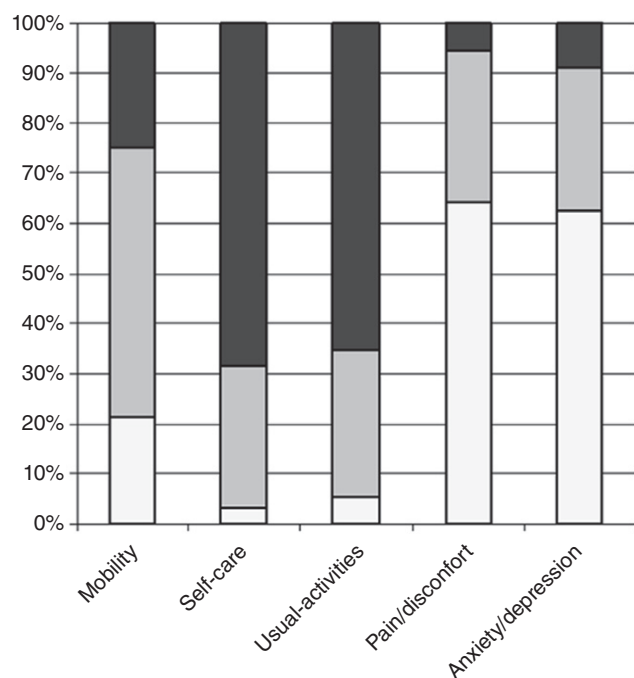
Descriptive statistics of sociodemographic characteristics and applied rating scales are shown in Table 1. The sample was composed mostly by women (82.70%), with a mean age of 85.57 years. Most of the patients were diagnosed with AD, 61.50% were classified as having severe dementia and almost 60% had severe dependence. Nearly 60% of the patients were classified as suffering from severe cognitive deterioration. Half of the people showed a high probability of depression.

The average EQ-5D index was 0.11 (standard deviation 0.38), and, the average EQ-5D-VAS was 51.54 (21.47). The distribution of responses by the three levels of each EQ-5D dimension is presented in Figure 1. There were less than 3% of lost values in EQ-5D dimensions, index and VAS. Some dimensions showed ceiling effects, whereas others had floor effects. However, the EQ-5D index and EQ-5D-VAS did not show floor or ceiling effects (Table 2).

**Table 1** Sociodemographic, clinical characteristics and applied rating scales

Sociodemographic characteristics	<i>n</i> (%) Mean ± SD	Clinical characteristics and rating scales	<i>n</i> (%) Mean ± SD
Sex (women)	434 (82.67)	Proxy	
Age (years)	85.57 ± 6.73	Family member	128 (24.43)
Marital status		Staff	396 (75.57)
Single	85 (16.28)	No. medical conditions	7.75 ± 2.80
Married	98 (18.77)	CDR	
Divorced	12 (2.30)	Mild	72 (13.71)
Widowed	327 (62.64)	Moderate	130 (24.76)
Education (less than primary)	343 (65.33)	Severe	323 (61.52)
Years in nursing home	3.59 (3.21)	MEC	13.24 ± 8.07
Leisure activities		Cornell scale	7.13 ± 6.17
Active	185 (35.51)	Barthel index	32.82 ± 29.54
Passive	233 (44.47)	EQ-5D index	0.11 ± 0.38
Cultural	95 (18.13)	EQ-5D-VAS	51.54 ± 21.47
Social	144 (27.53)	QOL-AD	27.26 ± 5.14
		QUALID	25.05 ± 9.17

CDR, Clinical Dementia Rating; EQ-5D-VAS, EQ-5D visual analog scale; MEC, "Mini-Examen Cognoscitivo" (Spanish version of the Mini-Mental State Examination); QOL-AD, Quality of Life in Alzheimer's disease Scale; QUALID, Quality of Life in Late-Stage Dementia Scale; SD, standard deviation.



**Figure 1** Proportions of EQ-5D dimensions responses. (■), Many problems, (▒) some problems, (□), no problems.

The Cronbach's alpha for the EQ-5D dimensions was 0.64 and it rose to 0.68 when anxiety/depression dimension was not considered, and to 0.75 when pain/discomfort was also removed (Table 2). The ITCC ranged from 0.21 to 0.53. The ICC was 0.72. The

exploratory factor analysis showed two different factors, which accounted for 67.35% of the variance. Factor 1 (functional area) was formed by mobility, self-care and usual activities dimensions (item loadings on this factor: 0.74, 0.85 and 0.85, respectively), and factor 2 (subjective area) by pain/discomfort and anxiety/depression (0.78 and 0.82). The lack of unidimensionality of the EQ-5D was also confirmed by Rasch analysis, showing a lack of fit to the Rasch model.

Convergent validity of the EQ-5D index and VAS with the QOL-AD and QUALID scales ranged from 0.36 to 0.58 in absolute values. Table 3 shows the mean scores by subject groups for EQ-5D index, EQ-VAS and each dimension of the instrument. Women and older people scored significantly lower in the EQ-5D index, whereas EQ-VAS presented lower values in those with a lower education level and more comorbidity. EQ-index and EQ-VAS scores were significantly lower for people with higher CDR and lower Barthel Index, and higher when the questionnaire was answered by a staff member and for those patients who were engaged in any kind of leisure.

In the multiple linear regression analysis (Table 4), the Barthel Index was a significant determinant for both EQ-5D index (standardized beta = 0.70) and EQ-5D-VAS (0.26), followed by the type of informant (0.10 and 0.13 for EQ-5D index and VAS, respectively). EQ-5D-VAS determinants were comorbidity (-0.23), and practising active or cultural leisure (0.12 and 0.17, respectively).



**Table 2** Feasibility, acceptability and reliability of EQ-5D

	EQ-5D index	EQ-5D-VAS	Mobility	EQ-5D Dimensions			
				Self-care	Usual activities	Pain/discomfort	Anxiety/depression
Missing (%)	11 (2.10)	15 (2.86)	10 (1.90)	8 (1.52)	8 (1.52)	7 (1.33)	8 (1.52)
Mean	0.11	51.54	–	–	–	–	–
Median	0.07	50.00	–	–	–	–	–
SD	0.39	21.47	–	–	–	–	–
Skewness	0.40	–0.09	–0.05	–1.26	–1.17	1.13	1.09
Minimum	–0.65	0	1.00	1.00	1.00	1.00	1.00
Maximum	1.00	100	3.00	3.00	3.00	3.00	3.00
Floor effect (%)	2.10	1.20	21.40	3.30	5.40	64.30	62.50
Ceiling effect (%)	1.40	2.20	25.00	68.70	65.20	5.40	8.90
Cronbach's alpha (ITCC)	0.64	–	(0.48)	(0.53)	(0.47)	(0.33)	(0.21)
Intraclass correlation coefficient (ICC)	0.72	–					

\*Significant at 0.01 level (bilateral). For convergent validity, Pearson's correlation coefficients for all but Quality of Life in Late-Stage Dementia Scale (QUALID; Spearman). ITCC, item-total corrected correlation; SD, standard deviation; VAS, visual analog scale. QOL-AD, Quality of Life in Alzheimer's Disease Scale.

## Discussion

The present study analyzed the psychometric properties of the EQ-5D rated by proxy, and, despite some limitations, it was found to be a valid and reliable tool to measure QoL in institutionalized patients with different stages of dementia. QoL was mainly related to patient's dependence level and comorbidity, the type of proxy and participation in leisure activities.

Proxy ratings might improve the EQ-5D feasibility, avoiding the loss of data of patients at advanced stages of dementia who are unable to answer by themselves. This finding is coincident with other studies that showed fewer missing values with EQ-5D than with QOL-AD in patient with severe cognitive impairment.<sup>2,3</sup> The EQ-5D index showed good acceptability, with no ceiling or floor effects, which is in line with other works.<sup>3,6,34</sup> Ceiling effects in functional dimensions (mobility, self-care and usual activities) can be explained by the high proportion of patients with severe dependency in our sample. One of the limitations of using proxy-rated scales is that the subjective component of QoL could be partially lost,<sup>2,3,34</sup> and this could explain the floor effects shown in the pain/discomfort and anxiety/depression dimensions.

Regarding the internal consistency, although ITCC was adequate, the Cronbach's alpha was moderate, although it was higher when analyzing only directly observable dimensions. This is consistent with the exploratory factor analysis results, and could reflect the multidimensional characteristic of the EQ-5D, measur-

ing complementary aspects of QoL. Besides, the ICC showed a satisfactory reliability between EQ-5D proxy and patient answers.<sup>1,3</sup>

Convergent validity of the EQ-5D index and EQ-5D-VAS, with QOL-AD and QUALID, was good, as hypothesized and in congruence with other works' results.<sup>2,3</sup> According to recognized criteria, we have found significant differences between EQ-5D scores by sociodemographics and clinical characteristics of the analyzed population. Contrary to other studies,<sup>1,25,35</sup> depression was not associated with the results of the EQ-5D index or the EQ-VAS. One explanation for this finding might be that proxies are less capable of rating patients' mood states than patients themselves.<sup>2,3</sup> Whether the questionnaire was completed by a professional instead of a family member showed a positive significant effect over QoL, in line with other studies.<sup>3,10</sup>

The most important determinant of EQ-5D value in the present study was the functional status of the patient, in agreement with the literature.<sup>6,10,31,36</sup> The relationship between QoL and the severity of the disease, as well as the cognitive function, was not maintained in the multivariate model. Other studies have found contradictory results regarding this.<sup>1,3,5,6,33</sup> In our study, leisure was a positive determinant of QoL. This finding corresponds with those reported by Longsdon *et al.* when using the QOL-AD; but less is known when it is assessed by the EQ-5D.

The present results lead us to believe that more efforts should be made to prevent functional dependence and to maintain the autonomy of this frail population. The

**Table 3** EQ-5D known-groups validity

	EQ-5D index		Reporting no (vs. any) problems in EQ-5D dimensions [n (%)]					Anxiety/ Depression
	M ± SD	M ± SD	EQ-5D-VAS M ± SD	Mobility	Self-Care	Usual Activities	Pain/ Discomfort	
Sex								
Men	0.2 ± 0.3	*	55.4 ± 20.1	23 (25.6)	1 (1.1)	3 (3.3)	63 (70.0)	56 (62.9)
Women	0.1 ± 0.4		50.7 ± 21.7	87 (20.5)	16 (3.7)	25 (5.9)	270 (63.1)	267 (62.4)
Age (years)								
60–85	0.2 ± 0.4		52.8 ± 21.6	64 (26.3)	8 (3.3)	15 (6.1)	160 (65.3)	157 (64.3)
86+	0.1 ± 0.4		50.4 ± 21.3	46 (16.9)	9 (3.3)	13 (4.8)	173 (63.4)	166 (60.8)
Education level								
Less than primary	0.1 ± 0.4		50.0 ± 21.3	66 (19.6)	12 (3.6)	16 (4.7)	212 (62.7)	218 (64.5)
Primary or higher	0.1 ± 0.4		54.3 ± 21.7	43 (24.6)	5 (2.8)	12 (6.8)	119 (67.6)	102 (58.3)
Proxy								
Family member	0.0 ± 0.3		47.5 ± 17.2	34 (26.8)	1 (0.8)	11 (8.7)	76 (59.8)	71 (55.9)
Staff	0.1 ± 0.4		53.0 ± 22.6	76 (19.6)	16 (4.1)	17 (4.4)	257 (65.9)	252 (64.8)
Active leisure								
No	0.0 ± 0.3		45.6 ± 20.6	36 (11.0)	5 (1.5)	5 (1.5)	198 (60.0)	204 (62.0)
Yes	0.3 ± 0.4		62.4 ± 18.7	72 (39.1)	12 (6.5)	22 (12.0)	133 (72.3)	117 (63.6)
Passive leisure								
No	0.0 ± 0.3		44.3 ± 20.0	39 (13.6)	4 (1.4)	5 (1.7)	180 (62.3)	178 (61.8)
Yes	0.3 ± 0.4		60.6 ± 19.8	70 (30.8)	13 (5.7)	22 (9.7)	152 (66.7)	144 (63.2)
Cultural leisure								
No	0.0 ± 0.4		47.2 ± 19.9	67 (15.9)	7 (1.7)	14 (3.3)	262 (61.9)	260 (61.6)
Yes	0.5 ± 0.3		70.8 ± 17.6	42 (45.2)	10 (10.8)	13 (14.0)	70 (74.5)	62 (66.0)
Social leisure								
No	0.0 ± 0.4		48.4 ± 21.2	54 (14.4)	7 (1.9)	7 (1.9)	239 (63.2)	232 (61.5)
Yes	0.3 ± 0.4		59.7 ± 20.1	54 (39.4)	10 (7.3)	20 (14.6)	92 (66.7)	90 (65.2)
Number of medical conditions								
≤7	0.1 ± 0.4		57.9 ± 22.3	64 (24.2)	8 (3.0)	15 (5.7)	178 (66.9)	163 (61.3)
>7	0.1 ± 0.4		45.4 ± 18.2	45 (18.6)	9 (3.7)	13 (5.3)	151 (62.1)	157 (64.9)
Barthel Index								
≤40 (severe)	-0.1 ± 0.3		43.2 ± 20.7	17 (5.7)	1 (0.3)	2 (0.7)	170 (56.3)	186 (61.8)
>40	0.4 ± 0.3		63.0 ± 17.0	90 (44.3)	16 (7.9)	26 (12.8)	154 (75.9)	128 (63.1)
Cornell scale								
<6	0.1 ± 0.4		53.5 ± 21.3	54 (22.2)	10 (4.1)	15 (6.1)	162 (66.1)	185 (75.5)
≥6 (probable depression)	0.1 ± 0.4		51.1 ± 20.4	54 (23.3)	6 (2.6)	13 (5.6)	146 (62.9)	112 (48.5)
MEC								
≤14 (severe)	0.1 ± 0.3		51.6 ± 19.3	33 (20.6)	2 (1.2)	9 (5.6)	108 (66.7)	95 (58.6)
>14	0.1 ± 0.4		50.9 ± 22.5	68 (20.0)	15 (4.4)	17 (5.0)	216 (63.5)	217 (64.0)
CDR								
Mild	0.5 ± 0.4		66.7 ± 17.1	28 (38.9)	11 (15.3)	11 (15.3)	50 (69.4)	44 (61.1)
Moderate	0.3 ± 0.4		61.4 ± 18	39 (30.5)	3 (2.3)	10 (7.8)	89 (69.0)	82 (63.6)
Severe	0.0 ± 0.3		43.9 ± 20.2	43 (13.7)	3 (0.9)	7 (2.2)	194 (61.2)	197 (62.3)

\* $P < 0.05$ ; \*\* $P < 0.01$ . Student's  $t$ -test was used to compare EQ-5D index and EQ-5D-visual analog scale (VAS) means, except for Clinical Dementia Rating (CDR) where an ANOVA test was used; proportion comparisons of five dimensions was carried out by  $\chi^2$ -tests. MEC, "Mini-Examen Cognoscitivo" (Spanish version of the Mini-Mental State Examination); SD, standard deviation.

**Table 4** Multiple lineal regression analysis with EQ-5D and visual analog scale as dependent variables

	EQ-5D Index Standardized coefficient	P-value	EQ-5D-VAS Standardized coefficient	P-value
Sex (men)	0.03	0.494	0.01	0.885
Age (years)	0.00	0.923	0.03	0.571
CDR (mild deterioration)				
Moderated deterioration	-0.02	0.671	-0.05	0.471
Severe deterioration	-0.10	0.153	-0.08	0.365
Proxy (professional)	0.10	0.030	0.13	0.029
Active leisure (yes)	0.05	0.244	0.12	0.039
Passive leisure (yes)	0.01	0.747	0.00	0.932
Cultural leisure (yes)	0.07	0.140	0.17	0.004
Social leisure (yes)	0.07	0.134	0.00	0.931
Cornell scale <sup>†</sup>	-0.04	0.326	-0.07	0.198
Comorbidity <sup>‡</sup>	0.03	0.415	-0.23	<0.001
Barthel Index <sup>§</sup>	0.70	<0.001	0.26	<0.001
MEC	-0.10	0.072	0.13	0.078
Constant (unstandardized coefficient)	(0.15)	0.500	(38.80)	0.006
Adjusted R <sup>2</sup>	0.61		0.37	

<sup>†</sup>Depression: score  $\geq 6$ ; <sup>‡</sup>>7 medical conditions; <sup>§</sup>moderate to mild dependence >40. CDR, Clinical Dementia Rating; EQ-5D-VAS, EQ-5D visual analog scale; MEC, "Mini-Examen Cognoscitivo" (Spanish version of the Mini-Mental State Examination).

present study suggests that the promotion of active and cultural leisure activities among these patients would increase their QoL. However, our findings about the factors associated to QoL should be verified with longitudinal studies.

Although some specific instruments for QoL in dementia, such as QOL-AD, had extensively shown their utility in this population,<sup>1,25</sup> the present study shows that the EQ-5D, a simple and quick generic QoL instrument, is a valid option to assess QoL in institutionalized patients at different stages of dementia. The use of a proxy rater contributed to increasing the feasibility and acceptability of this tool. Other psychometric advantages included a good interrater reliability, adequate convergent validity with EQ-5D-VAS, QOL-AD and QUALID, and good known-groups validity. However, the EQ-5D by proxy has some weaknesses that have to be taken into account when applied to institutionalized older adults with dementia: low internal consistency and lack of unidimensionality, and ceiling and floor effect for some dimensions (but not for the EQ-5D index).

## Acknowledgements

We thank Salome Martin Garcia and Iluminada Martinez Lopez (EULEN Social Care Services) for contributing to this study with the valuable information of institutionalized older adults with dementia. We also thank

Maria-Eugenia Prieto-Flores for her invaluable support in the manuscript drafting. Members of the Spanish Research Group on Quality of Life and Aging are: M João Forjaz and Carmen Rodríguez-Blázquez at the Carlos III Institute of Health; Gloria Fernández-Mayoralas and Fermina Rojo-Pérez at the Spanish National Research Council; Pablo Martínez-Martín, Belén Frades-Payo, Beatriz León-Salas and Marina Ávila at the Research Unit, CIEN Foundation, Carlos III Institute of Health, Alzheimer Center Reina Sofia Foundation; and María Eugenia Prieto-Flores at UNED University.

## Disclosure statement

The authors declare no conflict of interest.

## References

- 1 Logsdon RG, Gibbons LE, McCurry SM, Teri L. Assessing quality of life in older adults with cognitive impairment. *Psychosom Med* 2002; **64**: 510–519.
- 2 Naglie G, Tomlinson G, Tansey C *et al*. Utility-based Quality of Life measures in Alzheimer's disease. *Qual Life Res* 2006; **15**: 631–643.
- 3 Jonsson L, Andreasen N, Kilander L *et al*. Patient- and proxy-reported utility in Alzheimer disease using the EuroQoL. *Alzheimer Dis Assoc Disord* 2006; **20**: 49–55.
- 4 Weiner MF, Martin-Cook K, Svetlik DA, Saine K, Foster B, Fontaine CS. The quality of life in late-stage dementia (QUALID) scale. *J Am Med Dir Assoc* 2000; **1**: 114–116.

- 5 Coucill W, Bryan S, Bentham P, Buckley A, Laight A. EQ-5D in patients with dementia: an investigation of inter-rater agreement. *Med Care* 2001; **39**: 760–771.
- 6 Baquero M, Peset V, Burguera JA. Calidad de vida en enfermedad de Alzheimer [Quality of life in Alzheimer Disease]. *Rev Neurol* 2009; **49**: 337–342.
- 7 The EuroQol Group. EuroQol – a new facility for the measurement of health-related quality of life. The EuroQol Group. *Health Policy* 1990; **16**: 199–208.
- 8 Badia X, Roset M, Montserrat S, Herdman M, Segura A. [The Spanish version of EuroQol: a description and its applications. European Quality of Life scale]. *Med Clin (Barc)* 1999; **112** (Suppl 1): 79–85.
- 9 EuroQoL Group. EuroQol Group. User Guide. EQ-5D. Version 2.0. EuroQoL website 2009.
- 10 Bryan S, Hardyman W, Bentham P, Buckley A, Laight A. Proxy completion of EQ-5D in patients with dementia. *Qual Life Res* 2005; **14**: 107–118.
- 11 American Psychiatric Association. *Task Force on DSM-IV. Diagnostic and Statistical Manual of Mental Disorders: DSM-IV-TR*. Washington DC: American Psychiatric Publishing, Inc., 2000.
- 12 Barthel DW, Mahoney FI. Functional evaluation: the Barthel index. *Md State Med J* 1965; **14**: 61–65.
- 13 Collin C, Wade DT, Davies S, Horne V. The Barthel ADL Index: a reliability study. *Disabil Rehabil* 1988; **10** (2): 61–63.
- 14 Cid-Ruzafa J, Damian-Moreno J. [Disability evaluation: Barthel's index]. *Rev Esp Salud Publica* 1997; **71**: 127–137.
- 15 Alexopoulos GS, Abrams RC, Young RC, Shamoian CA. Cornell scale for depression in dementia. *Biol Psychiatry* 1988; **23**: 271–284.
- 16 Miller MD, Paradis CF, Houck PR *et al.* Rating chronic medical illness burden in geropsychiatric practice and research: application of the Cumulative Illness Rating Scale. *Psychiatry Res* 1992; **41**: 237–248.
- 17 Fernandez-Mayoralas G, Rojo-Perez F, Prieto Flores ME *et al.* *El significado de la salud en la Calidad de Vida de los Mayores [The Meaning of Health in the Quality of Life of Older People]*. Madrid: Portal Mayores, 2007.
- 18 Folstein MF, Folstein SE, McHugh PR. Mini-Mental State: a practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res* 1975; **12**: 189–198.
- 19 Lobo A, Saz P, Marcos G *et al.* [Revalidation and standardization of the cognition mini-exam (first Spanish version of the Mini-Mental Status Examination) in the general geriatric population]. *Med Clin (Barc)* 1999; **112** (20): 767–774.
- 20 Hughes CP, Berg L, Danziger WL, Coben LA, Martin RL. A new clinical scale for the staging of dementia. *Br J Psychiatry* 1982; **140**: 566–572.
- 21 Morris JC. The Clinical Dementia Rating (CDR): current version and scoring rules. *Neurology* 1993; **43**: 2412–2414.
- 22 Wolfs CA, Dirksen CD, Kessels A, Willems DC, Verhey FR, Severens JL. Performance of the EQ-5D and the EQ-5D+Q in elderly patients with cognitive impairments. *Health Qual Life Outcomes* 2007; **5**: 33.
- 23 Herdman M, Gudex C, Lloyd A *et al.* Development and preliminary testing of the new five-level version of EQ-5D (EQ-5D-5L). *Qual Life Res* 2011; **20**: 1727–1736.
- 24 Ramos-Goñi J, Errea M, Rivero-Arias O. QL1 EQ-5D-5L Valuation Project for the Spanish Population. A descriptive overview and preliminary results. *Value Health* 2012; **7**: 279.
- 25 Leon-Salas B, Logsdon RG, Olazaran J, Martinez-Martin P, The M. Psychometric properties of the Spanish QoL-AD with institutionalized dementia patients and their family caregivers in Spain. *Aging Ment Health* 2011; **15**: 775–783.
- 26 Garre-Olmo J, Planas-Pujol X, Lopez-Pousa S *et al.* Cross-cultural adaptation and psychometric validation of a Spanish version of the Quality of Life in Late-Stage Dementia Scale. *Qual Life Res* 2010; **19**: 445–453.
- 27 Martinez-Martin P, Fernandez-Mayoralas G, Frades-Payo B *et al.* [Validation of the functional independence scale]. *Gac Sanit* 2009; **23**: 49–54.
- 28 Martinez-Martin P, Prieto L, Forjaz MJ. Longitudinal metric properties of disability rating scales for Parkinson's disease. *Value Health* 2006; **9**: 386–393.
- 29 Rasch G. *Probabilistic Models for Some Intelligence and Attainment Tests*. Chicago, IL: University of Chicago Press, 1980.
- 30 Juniper EF, Guyatt GH, Jaeschke R. How to develop and validate a new health-related quality of life instrument. *Qual Life Pharmacoeconomics Clin Trials* 1996; **2**: 49–56.
- 31 Shiffczyk C, Romero B, Jonas C, Lahmeyer C, Muller F, Riepe M. Generic quality of life assessment in dementia patients: a prospective cohort study. *BMC Neurol* 2010; **10** (48): doi: 10.1186/1471-2377-10-48.
- 32 Beer C, Flicker L, Horner B *et al.* Factors associated with self and informant ratings of the quality of life of people with dementia living in care facilities: a cross sectional study. *PLoS One* 2010; **5** (12): e15621.
- 33 Lyketsos CG, Gonzales Salvador T, Chin JJ, Baker A, Black B, Rabins P. A follow up study of change in quality of life among persons with dementia residing in a long term care facility. *Int J Geriatr Psychiatry* 2003; **18**: 275–281.
- 34 Ankri J, Beaufils B, Novella JL *et al.* Use of the EQ-5D among patients suffering from dementia. *J Clin Epidemiol* 2003; **56**: 1055–1063.
- 35 Lopez mongil R, lopez Trigo JA. Prevalencia de demencia en pacientes institucionalizados: estudio RESYDEM. *Rev Esp Geriatr Gerontol* 2009; **44** (1): 5–11.
- 36 Hoe J, Hancock G, Livingston G, Woods B, Challis D, Orrell M. Changes in the quality of life of people with dementia living in care homes. *Alzheimer Dis Assoc Disord* 2009; **23**: 285–290.