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RUNNING HEAD: Quality of life predictors in dementia

Change and predictors of quality of life in institutionalized older adults with dementia

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ABSTRACT

Purpose: This study aims to assess the change in and predictive factors of the quality of life (QoL) of institutionalized older adults with dementia over a 20-month period.

Methods: Information was used from a follow-up study conducted over an average period of 19.61 ± 1.93 months on a sample of 274 institutionalized older adults aged 60 or over, diagnosed with dementia. Two linear regression models were built to predict change in the EQ-5D index and the Quality of life in Alzheimer Disease (QOL-AD) scale, taking as independent variables: sociodemographic characteristics and measures of functional ability (Barthel Index), depression in dementia (Cornell Scale), number of chronic health problems, cognitive level (MEC, the Spanish Mini Mental State Examination) and severity of dementia (Clinical Dementia Rating) at baseline.

Results: The majority of the participants were women (81.75%) with an average age of 84.70 ± 6.51 years, single (78.15%), with severe dementia and moderate functional dependence. There was a significant decrease on the EQ-5D, EQ-VAS and QOL-AD between baseline and follow-up scores. The main predictors of QoL of the institutionalized older adults with dementia were the number of chronic problems and baseline scores of the QoL measures.

Conclusions: A significant decrease in the QoL of institutionalized older adults was observed over a 20-month period. Results suggest that interventions aimed at reducing the number of chronic medical conditions may have a beneficial effect on older adults' QoL.

Keywords: Dementia, quality of life, older adults, institutionalization, follow-up study.

INTRODUCTION

Dementia is defined as an acquired chronic brain syndrome, progressive in nature, which affects cognitive and behavioural functions and the ability to carry out daily activities [1,2]. Although the risk rises exponentially with age, dementia is not considered a natural ageing process [3]. The most frequent cause of dementia in the elderly population is Alzheimer's Disease [1].

The report "*Dementia: A Public Health Priority*" [4] indicates the need to implement, develop and strengthen health and social policies to promote social well-being and an improvement in the quality of life (QoL) of people with dementia and their carers. The WHO defines QoL as "the individuals' 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" [5]. QoL evaluation introduces a humanistic element in the assessment of the disease, providing patient-centred and patient-generated information.

In recent years, several dementia-specific instruments of QoL have been developed in older adults with dementia, such as QOL-AD [6], ADRQL [7] QUALID [8]. Generic measures such as the EQ-5D have also been used in samples with dementia [9,6,10]. While disease specific questionnaires provide particular information about the medical condition, generic measures allow for comparison with populations with other health conditions or the general population. Cross-sectional studies on QoL determinants in older adults with dementia have helped identify the most important associated aspects or determinants of their QoL, including mental state, health, functional abilities, level of activity and leisure activities, or social integration [7,11-13]. Longitudinal studies have also found similar results in terms of QoL predictors [14-19] and concur that baseline QoL is a significant predictor of QoL

during follow-up, while functional state and cognition measures were not significant in most of the studies [16-19].

The residential care environment is suitable for analyzing the QoL of people with dementia, because it has a very high prevalence (61.7% in Spain) [20] compared to the community (10.9%, estimated prevalence in Central and North-Eastern Spain using door-to-door surveys [21]). Moreover, there are few QoL assessment longitudinal studies in institutionalized elderly patients diagnosed with dementia. A previous study described a small decline in QoL ratings over two years in a cohort of 47 patients [18].

The aim of this study was to assess the change in the QoL of an institutionalized sample of older adults with dementia, and to assess the influence of various sociodemographic and clinical variables on QoL measured at follow-up.

METHODS

Study design and sample

A multicenter longitudinal study was carried out by surveying people aged 60 or over diagnosed with dementia, according to DSM-IV-TR criteria [2], cared for in 14 residential care facilities in 10 Spanish provinces, including 3 facilities located in a rural environment. The residential care facilities were managed by two private companies who participated in the research project. Although follow-up time had been planned for 18 months, the time between the first and the second assessment was actually 19.61 ± 1.93 months. The baseline study consisted of a convenience sample of 525 people. The follow-up sample amounted to 52.19% (274 people) of the initial sample, including all the participants who did not leave the study. The reasons for not participating were as follows: 3 residential care facilities

decided not to continue in the study (90 cases, 17.14% of the initial sample), change of residential care (23 individuals, 4.38%) and death (138 individuals, 26.29%). The residents (or their legal representatives) signed an informed consent. The study was approved by the Ethics Committee of the Carlos III Institute of Health.

Measurements

The baseline study included sociodemographic characteristics and variables describing the leisure activities, children alive, and frequency of contact with family members, friends or neighbors, all answered by proxy. The following instruments were applied to measure the QoL: the EQ-5D questionnaire [22], a generic health-related QoL measure previously validated in a sample with dementia [23]; and the Quality of Life scale in Alzheimer Disease (QOL-AD, proxy version), which measures QoL in Alzheimer Disease and is appropriate for dementia in general [24]. The Barthel Index [25] was used to assess functional ability and the Cornell Scale for Depression in Dementia [26] was used to evaluate the presence of depressive symptoms. The number of chronic health problems was recorded through a check-list based on the adapted version of the CIRS-G comorbidity scale [27]. To assess the cognitive level, the MEC [25], an adapted version of the Mini Mental State Examination (MMSE) validated in Spain, was used [28]. Information on the severity of dementia was collected through the Clinical Dementia Rating Scale (CDR) [29]. In the follow-up phase, the EQ-5D, QOL-AD and CDR questionnaires were administered.

The EQ-5D is a generic multidimensional instrument to measure the QoL and self-perceived state of health, validated in Spain [30]. It has the advantage of allowing to compare different populations. To overcome the difficulty of measuring QoL in our study population (older adults with dementia), the proxy version was used [31]. The EQ-5D can be expressed as an index value resulting from the

combination of responses in 5 dimensions, using the time trade-off method for the Spanish population [30]. The index ranges between 0 (worst state of health) and 1 (best state of health), although there are negative values for those states of health considered worse than death [32]. There was 11 (2.10%) and 1 (0.36%) missing cases, for basal line and follow-up, respectively. The second part of the EQ-5D measures today's state of health using a Visual Analogue Scale (EQ-VAS), and ranges between 0 (worst state of health imaginable) and 100 (best state of health imaginable). The QOL-AD scale measures the QoL in the geriatric population with dementia, bearing in mind the four most important areas of QoL: psychological well-being, self-perceived QoL, level of ability and environmental factors [24,33]. It consists of 13 items, assessed on a scale with four response options, from 1 (poor) to 4 (excellent). The total sumscore ranges from 13 to 52.

The paper-and-pencil questionnaires were applied face-to-face by trained staff. The EQ-5D and QOL-AD scales were answered by proxy by a family member or friend or, in their absence, the worker at the nursing home in closest contact with the resident. The proxies were identical at baseline and follow-up in 97.70% of all cases. The Barthel Index, the Cornell Scale, the MEC and the comorbidity scale were completed by the medical staff at the nursing home.

Statistical analysis

After checking whether the continuous variables followed a normal distribution, a descriptive analysis of the sample baseline characteristics was performed. The Pearson's chi-squared test (χ^2) was used to compare the proportions of the categorical variables between the groups of older adults, that remained in the study, were deceased or lost at follow-up. For continuous variables (age, number of chronic health problems, the EQ-5D index, EQ-VAS and the QOL-AD scale), the ANOVA parametric test was

used, while for the Barthel Index and the Cornell Scale, the Kruskal-Wallis non-parametric test was applied.

The Student t-test for related samples was used to analyze the changes in the QoL and health status (EQ-VAS) scores between the baseline and follow-up. The McNemar test was used to assess the changes in the CDR, categorized into two groups in order to achieve similar proportions: mild/moderate and severe dementia. The QoL and health status difference between the baseline and follow-up, relative change ($[(\text{Mean}_{T2} - \text{Mean}_{T1}) * 100 / \text{Mean}_{T1}]$), effect size ($[(\text{Mean}_{T2} - \text{Mean}_{T1}) / \text{SD}_{T1}]$, SD=Standard deviation) and the cumulative distribution function of responses (CDF) was also calculated [34].

Three multiple linear regression models were built with the same independent variables to analyze the factors associated with the QoL and health status in the follow-up, using as dependent variables the EQ-5D index, EQ-VAS and QOL-AD. A three block nested design was used for each regression model. The first block included sex, age, marital status and the type of person who answered the questionnaire as independent variables. The second block included, jointly with the first block variables, the health-related variables (Barthel Index, Cornell Scale, number of chronic problems, MEC and CDR in two categories), the variables on participation in passive, active, cultural and social leisure, children alive, and the frequency of contact with family members, friends or neighbors. The third block included, together with the first and second block variables, the follow-up time in months, and the dependent variable at baseline.

The basic assumptions of the multiple linear regression models (independence, normality, linearity and homoscedasticity) were confirmed by visual inspection of the residual plots. In addition, all models obtained met the assumption of non-collinearity. We used a Bonferroni adjustment, with an alpha level

of 0.05/18=0.003. The statistical analyses were performed with the IBM SPSS 19 program (IBM/SPSS, Armonk, NY, USA).

RESULTS

The baseline sample was formed by 525 residents with a mean age \pm standard deviation of 85.59 ± 6.74 years, 82.67% were women, 18.8% were married, and 71.6% had contact with families once a week or more often. The means of EQ-5D index, EQ-VAS and QOL-AD were 0.11 ± 0.38 , 51.54 ± 21.47 and 27.26 ± 5.14 , respectively. The mean values of the other scales showed a population with severe dependence, depressive disorders and severe cognitive impairment (Barthel Index of 32.82 ± 29.54 , Cornell scale of 7.13 ± 6.17 , and MEC of 13.24 ± 8.07). Table 1 shows the sociodemographic characteristics and the QoL scores of the study subjects. Compared to the groups of deceased and cases lost at follow-up, the study sample showed significantly better initial scores for the EQ-5D index (0.18 ± 0.38), EQ-VAS (54.67 ± 20.36) and QOL-AD scale (28.47 ± 5.12), expressing a better QoL and health status at the beginning.

The follow-up revealed a significant decline in the EQ-5D, EQ-VAS and QOL-AD scores compared to the initial scores, with small effect sizes (Table 2). An increase in the number of people diagnosed with severe dementia (CDR) was also observed. The results of CDF for the three scales show that the QoL and health status ratings worsened for more than half of residents (58.76% for the EQ-5D index, 50.18% for the EQ-VAS and 57.35% for the QOL-AD). The percentage of older adults with no change (zero value) was 12.04%, 15.15% and 12.72%, respectively; and of those who improved 29.20%, 34.67% and 29.93%, respectively. The residents whose QoL worsened presented a significantly higher QoL and health status values at baseline than the residents whose QoL or health status remained stable

or improved ($t(269)=5.753$, $t(269)=8.928$, $t(279)=6.966$ for EQ-5D, EQ-VAS and QOL-AD respectively; $p < 0.001$ for all).

Using the EQ-5D index as a dependent variable (Table 3), the first linear regression block showed that the professionals valued the QoL of the resident as significantly higher than the family members (standardized beta, $\beta=0.28$; $p=0.001$). In the second block, a significant positive association was observed with the Barthel Index ($\beta =0.35$; $p<0.001$). In the third block, there were no significant variables at the Bonferroni corrected alpha level. The variance explained by the final model was 29.22%. The regression with EQ-VAS as dependent variable showed in the first block no significant association with any of the independent variables. In the second block a higher EQ-VAS was significantly associated with lower number of chronic problems ($\beta = -0.29$, $p = 0.001$). In the third block, no statistically significant variables remained and final model explained a very small proportion of variance, only 8.91%.

Adopting the QOL-AD scale as a dependent variable (Table 3), there were no significant variables in the first block. In the second block, a higher significant QoL was observed when answered by family members or friends ($\beta =-0.35$; $p=0.001$), and for residents with fewer chronic problems ($\beta =-0.26$; $p=0.001$). With an explained variance of 26.02%, the third block showed a significant association between a better QoL and a lower number of chronic problems ($\beta =-0.27$; $p=0.001$) and a significant positive association with the initial QOL-AD ($\beta = 0.47$; $p<0.001$).

DISCUSSION

The aim of our study was to assess the change of QoL and determine predictive factors in institutionalized older adults diagnosed with dementia. The profile of older adults in our study was very similar to that found in another work with similar inclusion criteria [24,20,35].

When comparing the follow-up sample with the deceased and lost cases, the deceased were significantly older and had poorer health results in the first phase of the study (“survivorship bias”), as expected [36]. A significant deterioration of the QoL was also observed after an average period of 20 months follow-up in more than half of the older adults, albeit of low magnitude. Similar results were found in other studies [17,18]. Less than half of the sample showed an improvement in the QoL and health status ratings, which is similar to another study [18]. This could reflect that the residents who are in a worse state also receive special attention and care, which makes them improve. Further studies are needed to specifically address this issue.

The QoL determinants varied according to the QoL measurement scale analyzed, justified by the different items of each measurement. The professional carer valued the health-related QoL (EQ-5D) as higher than family members, in contrast to what happened with QoL measured by the QOL-AD. A possible explanation would be that family members or friends, having lived with the resident in life phases prior to the beginning of dementia, might compare more basic aspects of the resident’s health with the previous situation; however, in the QOL-AD, questions are asked about relationships with family and friends which could be viewed more negatively when they enter the residential care.

Although not as relevant as other predictors, the number of chronic problems was significantly associated with the QoL as measured by the QoL-AD: fewer chronic problems at baseline were associated with better subsequent QoL. Comorbidity was another significant determinant of QoL in other studies of older adults with dementia [37], Parkinson's disease [38] and those without dementia

who live in the community [39]. The clinical recognition of chronic problems that most affect older adults may offer the opportunity to take proactive clinical decisions and thereby minimize the effect of comorbidity on the QoL [40]. The comorbidity index for the CIRS-G would have provided more information, but we used a modified version that did not allow the calculation of this index.

The initial QoL scores in QOL-AD were the most important determinants of QoL in the follow-up, as found in other studies [14,18,19]. This suggests that it is very important to bear in mind the assessment of QoL of older adults when diagnosing dementia, as it helps identify the most affected aspects and to act accordingly to help maintain or improve the QoL of these individuals.

Our study has certain limitations. Since our sample was obtained by convenience, and it is not a random sample, we cannot generalize the results to the population of institutionalized older adults with dementia in Spain [20,24,35]. More than half of the older adults (55.84%) were diagnosed with severe dementia, which led us to analyze the questionnaires answered by proxy of all the older adults. It is therefore important to bear in mind this aspect when comparing results with those of other studies based on self-perceived QoL. However, a previous study showed a good inter-rater reliability between proxy and self-ratings of the EQ-5D (intraclass correlation coefficient = 0.72) [23]. Another of the limitations of this study is the considerable loss of cases in the follow-up, although the scope of the loss due to deaths (26.29%) is similar to that observed in other studies [36]. Although similar to the one found in other studies, the explained variance of our models was not very high [14-18], which suggests the presence of other possible influencing factors affecting the QoL of older adults with dementia, such as contextual factors [41].

One of the strengths of our study is that, compared to other similar studies which excluded severe dementia [14,17,18], our results were obtained from a sample of older adults with mostly severe

dementia different levels of severity of dementia, and high proportion presented severe dementia. In addition, the QoL was assessed through various standardized measures, with a sufficiently long follow-up period to observe changes, which were captured by the measures used.

CONCLUSION

The number of chronic medical problems and QoL at baseline were predictors for QoL at follow-up. Knowing the original level of QoL of a person, we can predict how it will evolve and also identify vulnerable groups which can be the target of interventions. The relationship observed between the number of chronic problems and the worst QoL in the follow-up suggests that the early promotion of a healthy lifestyle and the introduction of preventive methods could indirectly help maintain or even improve the QoL of older adults.

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Table 1. Comparison between the baseline variables of participants in the follow-up study and deceased and lost participants.

	Follow-up sample (n=274)	Deceased (n=138)	Lost to follow-up (n=113)	
	n (%)	n (%)	n (%)	p-value*
	M ± SD	M ± SD	M ± SD	
Sex (Woman)	224 (81.75)	113 (81.88)	97 (85.84)	0.602
Age	84.70±6.51	87.49± 6.96	85.43 ± 6.60	0.001
Marital status (single)	214 (78.10)	114 (83.82)	96 (85.71)	0.147
Children (children alive)	187 (68.25)	98 (71.01)	75 (66.37)	0.723
Passive leisure (practices)	105 (38.46)	37 (27.41)	43 (38.05)	<0.001
Active leisure (practices)	140 (51.28)	44 (31.88)	49 (43.36)	0.073
Cultural leisure (practices)	56 (20.51)	23 (16.67)	16 (14.16)	0.295
Social leisure (practices)	88 (32.23)	20 (14.60)	36 (31.86)	<0.001
Who answered the questionnaire? (professional)	212 (77.37)	123 (89.78)	61 (53.98)	<0.001
CDR				<0.001
Mild Dementia	50 (18.25)	14 (10.14)	8 (7.08)	

Moderate Dementia	71 (25.91)	40 (28.99)	19 (16.81)	
Severe Dementia	153 (55.84)	84 (60.87)	86 (76.11)	
Contact with families (once a week or more)	190 (70.37)	98 (72.59)	82 (73.21)	0.815
Number of chronic problems	7.33±2.84	8.03 ± 2.91	8.49 ± 2.32	0.001
Barthel Index	38.14±29.89	24.96 ± 28.40	29.60 ± 27.70	0.001
Cornell Scale	5.53±5.25	6.28 ± 5.87	12.09 ± 6.09	0.001
MEC	12.96±8.51	12.65 ± 7.63	14.93 ± 7.18	0.235
EQ-5D Index	0.18±0.38	0.03 ± 0.37	0.04 ± 0.37	0.001
EQ-VAS	54.67±20.36	48.84 ± 23.68	46.88 ± 20.26	0.003
QOL-AD (by proxy)	28.47±5.12	26.30 ± 4.74	25.45 ± 4.90	0.001

CDR: Clinical Dementia Rating; MEC: Mini Mental State Examination; EQ-VAS: Visual Analogue Scale of EQ-5D; QOL-AD: Quality of Life in Alzheimer Disease, proxy version.

* To calculate the P-Value, χ^2 was used for sex, mental state, children, leisure and CDR; ANOVA was used for frequency of contact with family members, age, comorbidity, MEC, EQ-5D Index, EQ-VAS, QOL-AD (proxy); and the K-Wallis for the Barthel Index and Cornell Scale.

Table 2. Changes in the scores of the scales between the baseline and follow-up (n=274).

	Baseline	Follow-up	p-value*	Follow-up	Relative	Effect size
	n (%)	n (%)		baseline	change	
	M ± SD	M ± SD		difference	(%)	
EQ-5D index	0.18±0.38	0.06±0.38	<0.001	-0.12	-66.67	-0.32
EQ-VAS	54.67±20.36	49.48±18.29	<0.001	-5.19	-9.49	-0.25
QOL-AD	28.47±5.12	26.98±5.15	<0.001	-1.49	-5.23	-0.29
CDR			<0.001			
Mild/Moderate	121 (44.16)	84 (32.55)				
Severe	153 (55.84)	174 (67.44)				

EQ-VAS: EQ-5D Visual Analogue Scale; QOL-AD: Quality of Life in Alzheimer Disease, carer version; CDR: Clinical Dementia Rating. *Note: to calculate the p-value, the matched sample Student t-test was used in the EQ-5D, EQ-VAS, QOL-AD variables; and McNemar in the CDR.

Table 3. Multiple linear regression analysis of the EQ-5D index and the QOL-AD in the follow-up.

	Follow-up EQ-5D index			Follow-up QOL-AD		
	Standardized			Standardized		
	R ²	β	p-value	R ²	β	p-value
Block 1	0.070			0.032		
Constant (unstandardized coefficient)		0.43	0.265	27.38	<0.001	
Who answered the questionnaire? (1=professional)		0.28	0.001	-0.23	0.004	
Block 2	0.272			0.131		
Constant (unstandardized coefficient)		0.77	0.058	27.59	<0.001	
Children (1 = has living children)		-0.16	0.047	-	-	
Who answered the questionnaire?				-0.35	0.001	
Social Leisure (1=Yes)				-0.18	0.043	
Barthel Index		0.35	<0.001	0.20	0.048	
Number of chronic problems				-0.26	0.001	
Block 3	0.292			0.260		
Constant (unstandardized coefficient)		1.61	0.045	16.24	0.148	

Social Leisure	-	-	-0.22	0.007
Number of chronic problems	-0.15	0.046	-0.27	0.001
EQ-5D index baseline / QOL-AD baseline	0.23	0.039	0.47	< 0.001

Block 1 controlled for sex, age and marital status; *Block 2* for the MEC (Mini Mental State Examination), the Cornell Depression Scale, number of chronic problems, CDR (Clinical Dementia Rating), participation in leisure activities, children and frequency of contact with family members, friends or neighbours; and *block 3* controlled for follow-up time and the measure at baseline.