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Quality of life in older people with dementia: A multilevel study of individual attributes and residential care center characteristics

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Aim: To analyze how the characteristics of institutionalized older people with dementia and residential care centers are associated with the individual's quality of life (QoL).

Methods: Data were collected from a survey carried out on 525 elderly people aged 60 years or older in 14 nursing care homes across Spain. Multilevel linear analysis to assess the differences in QoL level between centers and individuals was carried out.

Results: The characteristics of the individuals that were associated with a higher QoL were functional independence, health status and gathering with family, friends or neighbors. In contrast, higher levels of dementia, depression and the length of institutionalization had a negative effect on QoL. In relation to the residential care center characteristics, the availability of geriatricians was associated with higher QoL, compared with those centers with no geriatricians on staff. In addition, public centers (public ownership and publicly-funded residents) were also associated with higher QoL than private/mixed centers. The multilevel analysis showed that the 16.4% of the differences in QoL was related to residence factors.

Conclusion: These results reflect the importance of the functional, social, mental and residential dimensions in the QoL of older adults with dementia. Actions devoted to improving these key dimensions would contribute to promote the well-being of this vulnerable population. *Geriatr Gerontol Int* 2014; ●●: ●●–●●.

Keywords: dementia, multilevel analysis, older adults, quality of life, residential care centers.

Introduction

Living longer is not necessarily associated with well-being¹ and quality of life (QoL).² QoL is a multidimensional construct, dynamic and centered on the patient,³ which includes important dimensions such as health, psychological aspects of well-being, social relationships

and activities, autonomy, self-realization, freedom, and financial circumstances.⁴ Among the different factors that influence QoL, frailty syndrome, depression, disability or chronic health conditions, such as dementia, could have a significant negative effect at advanced ages.^{5–8}

Dementia is a progressive syndrome that affects cognitive function, such as memory, thinking, behavior and the ability to carry out everyday activities.⁹ The prevalence of dementia in Europe has been estimated to range from 5.7% to 7.3% among people aged 60 years and older, doubling with every 5-year increase in age¹⁰ and reaching 23.6% in adults aged older than 84 years.⁹

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Nowadays, roughly half of all nursing home residents suffer from some type of dementia in industrialized countries.¹¹ Moving to a care facility means to leave a known and familiar environment for an unfamiliar one,¹² and therefore the main challenge in residential care facilities is to create appropriate and supportive living environments that contribute to the QoL of older adults. It is known that many environmental interventions could improve the QoL in nursing home care, from the organization of indoor space¹³ to the development of activity programs (e.g. theater, occupational therapy).¹⁴

Previous research has shown the important role that cognitive performance¹⁵ and loss of independence¹⁶ has on the QoL of older adults with dementia, as well as the important negative effect of depression.¹⁷ Evidence also suggests that relationships with family and friends,¹⁸ and the residential care environment affect QoL of people with dementia.¹⁹ In addition, some studies investigated the difference in QoL between the care provided at home and in nursing homes.²⁰ However, there is a lack of research simultaneously analyzing how individual characteristics of the older adults with dementia and the characteristics of the residence where they live are associated with their QoL. In this direction, the aim of the present study was to contribute to the knowledge on QoL in institutionalized older adults with dementia, including the following questions: "How does QoL vary according to the characteristics of the individuals?", "To what extent are the differences in QoL related to the residential care centers?" and "Which specific characteristics of the centers help to understand these differences?". To answer these questions, a linear multilevel analysis will be applied.

Methods

Participants

Data were collected from a survey carried out on elderly people aged 60 years or older in 14 nursing care homes in 10 provinces of Spain during the year of 2010. Only people who fulfilled dementia criteria according to the Diagnostic and Statistical Manual of Mental Disorders-IV-Text Revision were included in the study, for a sample of 525 people. Because of missing data in several variables, a final sample of 429 was analyzed. Residents or legal guardians gave informed consent. The study was approved by the institutional review board of Carlos III Institute of Health, Madrid, Spain.

Data collection

This was a multicenter study that followed a cross-sectional design. The survey collected information on age, sex, level of education, marital status and social

relationships, as well as employment history and financial status. Furthermore, the following instruments were used:

The Clinical Dementia Rating (CDR) is a five-point scale in which CDR-0 connotes no cognitive impairment, and CDR-3 severe dementia.²¹ The CDR was completed by medical staff.

The Cornell Scale for Depression in Dementia (CSDD) focuses on depressive symptoms and signs occurring during the week preceding the interview. It consists of 19 items rated on a scale of 0–2 (0 = absent, 1 = mild or intermittent, 2 = severe). A total sum score below 6 is associated with the absence of depressive symptoms; scores above 10 indicate probable major depression, scores above 18 indicate definite major depression.²² CSDD was completed by medical staff.

The Quality of Life in Alzheimer's disease (QOL-AD) is a brief 13-item measure designed specifically to obtain a rating of the patient's QoL from both the patient and the caregiver.²³ It was developed for individuals with dementia, based on patients and caregivers to maximize construct validity. Domains are scored 1 (poor) to 4 (excellent). Higher scores indicate better QoL, and the possible range is from 13–52. The QoL-AD was completed by a caregiver.

The EQ-5D visual analog scale (EQ-VAS) records the current health state on a 100-point visual scale, from best imaginable to worst imaginable health.²⁴ The EQ-VAS was completed by proxies.

The Barthel Index measures patients' ability to carry out the activities of daily living (ADL) and mobility.²⁵ The score ranges between 0 and 100, where a higher score indicates a better ability to perform ADL. It was administrated by nurses or occupational therapist.

To assess the number of the chronic medical conditions, we used a modified version of the Cumulative Illness Rating Scale for Geriatrics (CIRS-G). Our questionnaire included 20 chronic medical conditions, and one open option, "others".^{26,27} It was completed by healthcare staff of the residential setting, based on chart review and the clinical condition of the resident.

Nursing care homes information was obtained by a questionnaire divided into four sections: localization, type of residence, structural information and services. The location includes data about rural or urban ($\geq 10\,000$ inhabitants) settings, the type of residence regards the ownership and the type of housing. All nursing care homes were classified as being public or private/mixed, according to the ownership and the funding of residents, even though all were managed by two private companies, of similar characteristics. In public institutions, the building is owned by a public organization, residents pay according to a sliding fee scale, and they have to go through a waiting list. In mixed institutions, some beds are public and others are private. The structural information of the questionnaire

gave details about the number of rooms and their subdivision in single or multiple rooms. The services section was used to assess the presence of professionals (geriatrician, physiotherapist, psychologist, physician), other non-pharmacological therapies (social work or occupational therapy), recreational activities (sociocultural entertainment), facilities (gym, solarium, library, TV, cafeteria) and other services, such as hairdresser or religious service. The questionnaire was completed by the directors of the nursing care homes.

Statistical analyses

In order to quantify the independent effect of the residence characteristics in the residents' QoL, two-level multivariate linear regression analyses were carried out. The first level grouped individuals and the second residences.

For the fixed-effects analysis, the association between QoL and individual and contextual-level variables was examined. Coefficient (Coef) and 95% confidence intervals (CI) were obtained from the beta coefficients (standard errors) in the fixed part of the model. Spearman's correlations were used to evaluate bivariate colinearity among independent variables. Next, we carried out a stepwise forward analysis. Models' fit to the data were compared using the log likelihood test.

In the random-effects analysis, we explored the differences of QoL between individuals living in the same residence and those in different residences. The intraclass correlation coefficient (ICC) and the proportion of variance explained (PVE) as a result of differences between residences were calculated in this way:

- $ICC = (V_m) / (V_m + V_i) \times 100$, where: V_m = variance between residences and V_i = individual variance.
- $PVE = (V_0 - V_1) / (V_0) \times 100$, where V_0 = second-level variance of the null model, and V_1 = second-level variance of the adjusted model.

A slope analysis was carried out with no random effects found. The parameters were estimated by maximum likelihood program.²⁸ We used the Stata software package, version 11.00 (StataCorp, College Station, TX, USA).

Results

Table 1 presents the characteristics of the 429 institutionalized older people with dementia. The mean age was 85.8 ± 6.7 years (range 60–102 years) and 82.05% were females. Most of the sample had incomplete primary education or lower (64.1%). The mean time living in the residence was 3.7 ± 3 years. Just 1.9% was totally independent. More than a half of the residents (59.4%) had severe dementia and 7% showed major depression according to the CSDD.

Table 1 Descriptive characteristics of the study sample

	Total sample (n = 429)
Sociodemographic characteristics	
Mean age, years (SD)	85.8 (6.7)
Sex, n (%)	
Female	352 (82.0)
Education, n (%)	
No education or incomplete primary	275 (64.1)
Primary	117 (27.3)
Secondary or higher	37 (8.6)
Marital status, n (%)	
Married	75 (17.5)
With partner in the nursing home, n (%)	33 (7.7)
With children alive, n (%)	295 (68.8)
Health and quality of life characteristics	
Barthel Index, mean (SD)	33.8 (29.3)
EQ-VAS, mean (SD)	52.2 (21.0)
QoL-AD, mean (SD)	27.6 (5.1)
CSDD	7.2 (6.3)
No. chronic medical conditions, mean (SD)	7.9 (2.8)
Clinical Dementia Rating, n (%)	
Mild	64 (14.9)
Moderate	110 (25.6)
Severe	255 (59.4)
Mean duration of institutional living, years (SD)	3.7 (3.0)
Social contacts	
Receiving visits from family, friends or neighbors, n (%)	
≥1 time a week	313 (73.0)
Gathering with family, friends or neighbors outside, n (%)	
≥1 time a week	106 (24.7)

CSDD, Cornell scale for depression in dementia; EQ-VAS, EQ-visual analogue scale; QoL-AD, quality of life in Alzheimer's disease; SD, standard deviation.

Regarding the residential care facilities characteristics (Table 2), more than half (64.3%) were public owned with private management. Skilled nursing assistance was provided by the 85.7% of the centers. More than 70% had all the categories of health professionals inquired about in the present study except for the geriatrician available only in three residences. The most common facility offered was TV room (92.9%), followed by a gym (64.3%).

Table 3 shows the results of the multilevel analysis. In relation to the multivariate individual-level analysis

Table 2 Characteristics of the residential care center

	Total sample (n = 14)
Type of center	
Ownership, n (%)	
Public (with private management)	9 (64.3)
Private	3 (21.4)
Mix	2 (14.3)
Assistance, n (%)	
Intermediate nursing	2 (14.3)
Skilled nursing	8 (57.1)
Mix	4 (28.6)
Mean no. rooms (SD)	62.9 (56.1)
Mean no. individual rooms (SD)	54.0 (28.5)
Mean no. residents per room (SD)	1.32 (0.3)
Location, n (%)	
Urban area	10 (71.4)
Facilities	
TV room, n (%)	13 (92.9)
Solarium, n (%)	7 (50)
Gym, n (%)	9 (64.3)
Cafeteria, n (%)	5 (35.7)
Library, n (%)	8 (57.1)
Professionals and services	
Physician, n (%)	11 (78.6)
Geriatrician, n (%)	3 (21.4)
Psychologist, n (%)	12 (85.7)
Physiotherapist, n (%)	11 (78.6)
Nurse, n (%)	14 (100)
Occupational therapist, n (%)	10 (71.4)
Social worker, n (%)	11 (78.6)
Religious services, n (%)	10 (71.4)
Sociocultural entertainment, n (%)	11 (78.6)

(model 2), QoL was inversely associated with depression, years living in the institution and was strongly associated with dementia disease severity (Coef = -1.45, 95% CI -2.32 to -0.59). A significant positive association was found with education and gathering with family, friends or neighbors ($P < 0.001$), the same as with current health status and ability to carry out activities of daily living ($P < 0.001$). In the saturated model (model 3), the important associations with QoL corresponded to dementia disease severity (Coef = -1.39, 95% CI -2.25 to -0.53) and gathering with family, friends or neighbors (Coef = 1.90, 95% CI 1.07-2.72), for the individual variables, and the presence of a geriatrician (Coef = 2.03, 95% CI 0.05-4.01) and ownership of the setting (Coef = 1.83, 95% CI 0.06-3.60) for the contextual variables.

Finally, the random effects showed the different contribution, in QoL, of the individual-level and contextual characteristics. In the empty multilevel model, the ICC

Table 3 Individual and center characteristics: Univariate, multivariate and multilevel analysis of quality of life

	Null model	Model 1 coef (95% CI)	Model 2 coef (95% CI)	Model 3 coef (95% CI)
Individual characteristics				
Age		0 (-0.07; 0.06)	0.03 (-0.02; 0.09)	0.09 (0.06; 0.11)
Sex (female vs male)		-1.18 (-2.36; 0.01)	-0.67 (-1.60; 0.27)	-0.58 (-1.51; 0.35)
Education (≥primary vs <primary)		1.56 (0.51; 2.61)*	0.84 (0.02; 1.67)*	0.87 (0.06; 1.68)*
Barthel Index		0.08 (0.07; 0.09)**	0.04 (0.02; 0.05)**	0.04 (0.02; 0.05)**
EQ-VAS		0.13 (0.11; 0.15)**	0.09 (0.06; 0.11)**	0.04 (-0.02; 0.09)**
Clinical Dementia Rating (Severe vs mild or moderate)		-3.94 (-4.81; -3.06)**	-1.45 (-2.32; -0.59)*	-1.39 (-2.25; -0.53)*
CSDD		-0.14 (-0.23; -0.06)*	-0.18 (-0.24; -0.11)**	-0.16 (-0.22; -0.09)**
Duration of institutional living		-0.34 (-0.50; -0.17)**	-0.21 (-0.34; -0.07)*	-0.21 (-0.35; -0.08)*
Gathering with family, friends or neighbors a week (≥1 vs 1)		1.53 (0.48; 2.59)*	1.89 (1.07; 2.72)**	1.90 (1.07; 2.72)**
Centers characteristics				
Ownership (public vs privately or mixed)		1.79 (-0.75; 4.33)		1.83 (0.06; 3.60)*
Geriatrician (yes vs no)		4.26 (2.75; 5.77)**		2.03 (0.05; 4.01)*
Individual rooms (≥50% vs <50%)		3.29 (-0.67; 7.24)		-0.84 (-2.39; 0.70)
First level variance and standard error	22.3	1.54	12.6	0.87
Second level variance and standard error	4.39	2.26	3.52	1.67
Intraclass correlation coefficient	16.4%		21.9%	8.12%
First level percentage of variance explained			43.6%	74.3%
Second level percentage of variance explained			18.8%	48.6%
Percentage of total variance explained			39.7%	48.6%

* $P < 0.05$; ** $P < 0.001$. CI, confidence interval; Coef, regression coefficient; CSDD, Cornell scale for depression in dementia; EQ-VAS, EQ-visual analog scale (current health status); model 1, univariate; model 2, multivariate with individual variables; model 3, multivariate with individual and context variables; QoL-AD, quality of life in Alzheimer's disease.

showed that 16.4% of the variance in QoL was related to contextual residence factors. Compared with the empty model, the individual-level variables (model 2) explained the 39.7% of the total variance found. In the final model (model 3), 48.6% of the total variance and 74.3% of the contextual variance were explained.

Discussion

In the present cross-sectional study of nursing home residents with dementia, we investigated how the individual and the residence characteristics influence residents' QoL using a multilevel design. The present study contributes to fill a gap regarding the complex relationship between older adults' characteristics and features of the nursing care homes. Regarding the individual characteristics and according to our multilevel analysis, the most important positive factor associated with a better QoL was gathering with family, friends or neighbors once or more times a week. The importance of social relationships in QoL might be due to the positive influence on behavioral and psychological symptoms of dementia. In particular, Minematsu showed that this effect was remarkable for subjects with moderate or severe dementia, which is the case for most of our sample.²⁹ A higher educational level was also associated with a better QoL. This positive association could be explained by several factors, such as higher income and better access to medical care.³⁰ However, other studies reported no correlation between education and QoL.^{31,32}

The role of age in QoL of people with dementia shows different findings. In the present study, age did not seem to be associated with QoL, as other studies have reported.^{31,32} In comparison, Banerjee *et al.* found a statistically significant association between older age and better QoL.³³ More important than age, in the present results, was the number of years living in residential care facilities. This variable showed a significant effect even after adjusting for age and severity of dementia. A longer stay in the residence would negatively impact QoL. We hypothesized that at the beginning, older adults with dementia conceive the move to the nursing care home as temporary and reversible, and sometimes voluntary and desirable.³⁴ Later on, they can experience loneliness and sadness,³⁵ which can reduce QoL.³⁶ In addition, residents might be in a better condition at admission than years after.

Current health status was associated with a higher QoL, as expected. The positive and complex relationship between health perception and QoL is explained by models such as the proposed by Wilson and Cleary.³⁷ The significant impact of functional limitations on QoL was more modest, but significant. It is known that loss of independence and physical function have important negative implications on QoL,²⁸ as well as depressive symptoms do.¹⁷ The presence of depressive symptoms,

such as loss of energy, multiple physical complaints and variation of mood, are common in older people with dementia,²² and the prevalence has been reported to be 20–60%.³⁸ According to the CSDD, in our sample, probable major depression and major depression was reported in 23.1% and 7.0%, respectively.

The severity of dementia, resulting from the cognitive and functional deterioration, presented the most important negative association with QoL, both in the multivariate and multilevel analysis. This finding is in agreement with a recent study where the CDR completed by the caregiver was a predictor of QoL.¹⁵

Regarding the residence characteristics, we found that in the empty model 16.4% of the variance was explained by the differences between the centers, whereas in the final model 74.3% of the variance was explained. Results suggest that residents in public care centers had better QoL than those in mixed or private ones. Also, the presence of a geriatrician seems to be associated with QoL.

Based on the present results, it is not possible to verify which specific factors of public or private centers mainly affect QoL. We could only specifically observe that public centers, regarding ownership and public funding of the residents, are positively associated with QoL in the Spanish context. This finding led to the following hypotheses.

We hypothesize that many different features between public and private structures in Spain can explain this difference in QoL of institutionalized older people. The literature suggests that in the private management, older people are seen more as customers, and care provided is centered on the old-customer with the counterproductive effect of undermining their independence.³⁹ This overprotectionism of the private structure has already been shown in other studies.⁴⁰ Instead, in the public context, this conception of old-customer is more nuanced, and it is preferred to maintain as much as possible the independence of older people, which has a double effect. First, older people feel better and more useful, and, second, their demand towards staff tends to decrease.³⁹ This goes in line with the importance of independence in ADL in QoL, observed earlier. Furthermore, public structures are subject to more restrictive legislation and controls, and a lower number of service staff than the private ones.³⁹ A Spanish investigation of 125 residences for older people found that the public structures had an average satisfaction score higher than the private facilities.⁴¹ However, these explanations might not be applied to the residences analyzed, as all but one were managed by the same company.

Another possible explanation is the different expectation of the subjects regarding their QoL in the nursing care homes. In Spain, residents of private structures pay a fee and consequently they might have higher expectations for the provided services, which would result in

a lower QoL assessment than residents of public structures. Finally, residents from public structures have to go through a waiting list, which might increase their expectations, and therefore a positive view of their stay, once they reach it.

Regarding the presence of professionals, only the geriatrician showed a significant positive role in QoL. The presence of a geriatrician in the facility is important for the specific and complex care needs of these frail persons. For example, the geriatrician approach can improve the well-being of older people by helping to maintain the health status, reducing the inappropriate drugs administration⁴² or the emergency hospital admissions.⁴³

Several limitations must be considered in the interpretation of the results. The study used a non-random, convenience sample, which makes it difficult to generalize the findings to the population of institutionalized older adults with dementia in Spain. However, the relevant sample size we used ($n = 429$) and the distribution of residences throughout Spain, including rural and urban settings, must be considered. In addition, the present results are based on cross-sectional data. To infer cause-effect relationships, longitudinal studies are required. Another limitation was the low number of facilities and the lack of information about other residential care characteristics, such as staff satisfaction or quality of care. Therefore, caution must be taken when interpreting the results related to the contextual residence factors. In addition, the inclusion of more individual variables in our analyses would possibly enhance the models; as for example, behavioral symptoms. This information was not assessed because of constraints on questionnaire length, in order to protect residents from fatigue and to avoid staff burden.

A significant proportion of persons with dementia cannot respond or provide responses to QoL questionnaires because of a lack of memory, inability to concentrate and other cognitive impairment linked to dementia.⁴⁴ To make up for the difficulty of completing questionnaires on QoL, they were answered by proxy. This could introduce a bias owing to the known underestimation of QoL rating by caregivers,⁴⁵ but other studies suggest that proxy response is a fair substitute for patient response.⁴⁶

Despite the limitations described, the present results contribute to a better understanding of the significant role that functional, social, mental and residential dimensions play in the QoL of older adults with dementia. Specifically, a greater frequency of family or friends visits should be encouraged, when possible, as they translate into a better QoL for the residents. In addition, interventions to prevent depression and to maintain independence as much as possible would benefit this population. To promote these kinds of interventions,

specialized professionals, such as geriatricians, are required.

The importance of a multidimensional approach to improve institutionalized older adults' QoL is clearly emphasized in this research, but more studies are required to investigate this complex relationship. To achieve a deeper understanding of QoL of institutionalized older people, it is important to move beyond individual characteristics and assess their importance along with those of the residence.

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References

- 1 WHO. World Health Report 1997. Geneva, 1997.
- 2 Netuveli G, Blane D. Quality of life in older ages. *Br Med Bull* 2008; **85**: 113–126.
- 3 Lawton MP. Background. A multidimensional view of quality of life in frail elders. In: Birren JE, Lubben J, Rowe J, Deutchman D, eds. *The Concept and Measurement of Quality of Life in the Frail Elderly*. San Diego, CA: Academic press, 1991; 4–27.
- 4 Bowling A. *Ageing Well: Quality of Life in Old Age*. Maidenhead: Open University Press, 2005.
- 5 Delgado-Sanz MC, Prieto-Flores ME, Forjaz MJ *et al.* [Influence of chronic health problems in dimensions of EQ-5D: study of institutionalized and non-institutionalized elderly]. *Rev Esp Salud Publica* 2011; **85**: 555–568.
- 6 Martín-García S, Rodríguez-Blázquez C, Martínez-Lopez I, Martínez-Martín P, Forjaz MJ. Comorbidity, health status and quality of life in institutionalized older people with and without dementia. *Int Psychogeriatr* 2013; **25**: 1077–1084.
- 7 Puts MT, Shekary N, Widdershoven G, Heldens J, Lips P, Deeg DJ. What does quality of life mean to older frail and

- non-frail community-dwelling adults in the Netherlands? *Qual Life Res* 2007; **16**: 263–277.
- 8 Zaninotto P, Falaschetti E, Sacker A. Age trajectories of quality of life among older adults: results from the English Longitudinal Study of Ageing. *Qual Life Res* 2009; **18**: 1301–1309.
 - 9 Knapp M, Prince M. *World Alzheimer Report 2009*. London: Alzheimer's Disease International, 2009.
 - 10 Knapp M, Prince M. *Demenzia UK*. London: Alzheimer's Society, 2007.
 - 11 Edvardsson D, Winblad B, Sandman PO. Person-centred care of people with severe Alzheimer's disease: current status and ways forward. *Lancet Neurol* 2008; **7**: 362–367.
 - 12 Grenade L, Boldy D. Social isolation and loneliness among older people: issues and future challenges in community and residential settings. *Aust Health Rev* 2008; **32**: 468–478.
 - 13 Crespo M, Hornillos C, de Quiros MB. Factors associated with quality of life in dementia patients in long-term care. *Int Psychogeriatr* 2013; **25**: 577–585.
 - 14 Graff MJ, Vernooij-Dassen MJ, Thijssen M, Dekker J, Hoefnagels WH, Olderikkert MG. Effects of community occupational therapy on quality of life, mood, and health status in dementia patients and their caregivers: a randomized controlled trial. *J Gerontol A Biol Sci Med Sci* 2007; **62**: 1002–1009.
 - 15 Buckley T, Fauth EB, Morrison A *et al*. Predictors of quality of life ratings for persons with dementia simultaneously reported by patients and their caregivers: the Cache County (Utah) Study. *Int Psychogeriatr* 2012; **24**: 1094–1102.
 - 16 Hoe J, Hancock G, Livingston G, Orrell M. Quality of life of people with dementia in residential care homes. *Br J Psychiatry* 2006; **188**: 460–464.
 - 17 Shin IS, Carter M, Masterman D, Fairbanks L, Cummings JL. Neuropsychiatric symptoms and quality of life in Alzheimer disease. *Am J Geriatr Psychiatry* 2005; **13**: 469–474.
 - 18 Livingston G, Cooper C, Woods J, Milne A, Katona C. Successful ageing in adversity: the LASER-AD longitudinal study. *J Neurol Neurosurg Psychiatry* 2008; **79**: 641–645.
 - 19 Garre-Olmo J, Lopez-Pousa S, Turon-Estrada A, Juvinya D, Ballester D, Vilalta-Franch J. Environmental determinants of quality of life in nursing home residents with severe dementia. *J Am Geriatr Soc* 2012; **60**: 1230–1236.
 - 20 te Boekhorst S, Depla MF, de Lange J, Pot AM, Eefsting JA. The effects of group living homes on older people with dementia: a comparison with traditional nursing home care. *Int J Geriatr Psychiatry* 2009; **24**: 970–978.
 - 21 Morris JC. The Clinical Dementia Rating (CDR): current version and scoring rules. *Neurology* 1993; **43**: 2412–2414.
 - 22 Alexopoulos GS, Abrams RC, Young RC, Shamoian CA. Cornell Scale for Depression in Dementia. *Biol Psychiatry* 1988; **23**: 271–284.
 - 23 Logsdon RG, Gibbons LE, McCurry SM, Teri L. Assessing quality of life in older adults with cognitive impairment. *Psychosom Med* 2002; **64**: 510–519.
 - 24 Group TE. EuroQol-a new facility for the measurement of health-related quality of life. The EuroQol Group. *Health Policy* 1990; **16**: 199–208.
 - 25 Mahoney FI, Barthel DW. Functional evaluation: the Barthel Index. *Md State Med J* 1965; **14**: 61–65.
 - 26 Martinez-Martin P, Fernandez-Mayoralas G, Frades-Payo B *et al*. [Validation of the functional independence scale]. *Gac Sanit* 2009; **23**: 49–54.
 - 27 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.
 - 28 Ferrans CE, Zerwic JJ, Wilbur JE, Larson JL. Conceptual model of health-related quality of life. *J Nurs Scholarsh* 2005; **37**: 336–342.
 - 29 Minematsu A. The frequency of family visits influences the behavioral and psychological symptoms of dementia (BPSD) of aged people with dementia in a nursing home. *J Phys Ther Sci* 2006; **18**: 123–126.
 - 30 Feinstein L, Sabates R, Anderson-Tashweka M, Hammond C. *The Effects of Education on Health: Concepts, Evidence and Policy Implications*. Paris: Organisation for Economic Co-operation and Development (OECD), 2006.
 - 31 Fuh JL, Wang SJ. Assessing quality of life in Taiwanese patients with Alzheimer's disease. *Int J Geriatr Psychiatry* 2006; **21**: 103–107.
 - 32 Hoe J, Katona C, Roch B, Livingston G. Use of the QOL-AD for measuring quality of life in people with severe dementia – the LASER-AD study. *Age Ageing* 2005; **34**: 130–135.
 - 33 Banerjee S, Smith SC, Lamping DL *et al*. Quality of life in dementia: more than just cognition. An analysis of associations with quality of life in dementia. *J Neurol Neurosurg Psychiatry* 2006; **77**: 146–148.
 - 34 Lee DT, Woo J, Mackenzie AE. A review of older people's experiences with residential care placement. *J Adv Nurs* 2002; **37**: 19–27.
 - 35 Wilson SA. The transition to nursing home life: a comparison of planned and unplanned admissions. *J Adv Nurs* 1997; **26**: 864–871.
 - 36 Prieto-Flores ME, Fernandez-Mayoralas G, Forjaz MJ, Rojo-Perez F, Martinez-Martin P. Residential satisfaction, sense of belonging and loneliness among older adults living in the community and in care facilities. *Health Place* 2011; **17**: 1183–1190.
 - 37 Wilson IB, Cleary PD. Linking clinical variables with health-related quality of life. A conceptual model of patient outcomes. *JAMA* 1995; **273**: 59–65.
 - 38 Tsuno N, Homma A. What is the association between depression and Alzheimer's disease? *Expert Rev Neurother* 2009; **9**: 1667–1776.
 - 39 Kaufmann AE, Frias R. Residencias: lo público y lo privado. *Rev Esp Invest Sociol* 1996; **73**: 105–126.
 - 40 Moyano de Grellet M. Bienestar subjetivo en adultos mayores residentes de centros geriátricos. *INTERPSIQUIS Congreso Virtual de Psiquiatria*. 2008; **2**.
 - 41 Eroski Consumers. Residencias para la tercera edad: analizadas 125 públicas, privadas y concertadas en 18 provincias. Vizcaya 2009 [Cited 11 Jun 2013]. Available from URL: http://revista.consumer.es/web/es/20090401/actualidad/tema_de_portada/
 - 42 Colloca G, Tosato M, Vetrano DL *et al*. Inappropriate drugs in elderly patients with severe cognitive impairment: results from the shelter study. *PLoS ONE* 2012; **7**: e46669.
 - 43 Lisk R, Yeong K, Nasim A *et al*. Geriatrician input into nursing homes reduces emergency hospital admissions. *Arch Gerontol Geriatr* 2012; **55**: 331–337.
 - 44 Kane RA, Kling KC, Bershadsky B *et al*. Quality of life measures for nursing home residents. *J Gerontol A Biol Sci Med Sci* 2003; **58**: 240–248.
 - 45 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.
 - 46 Kutner JS, Bryant LL, Beaty BL, Fairclough DL. Symptom distress and quality-of-life assessment at the end of life: the role of proxy response. *J Pain Symptom Manage* 2006; **32**: 300–310.