

# Profile and Risk of Mental Illness in Caregivers for Home Care Patients

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**Objectives.** To determine the profile of caregivers for patients in home hospitalization, and to investigate morbidity and strain in caregivers.

**Design.** Descriptive, cross-sectional study based on personal interviews.

**Setting.** Health area in the community (autonomous region) of Valencia (Eastern Spain).

**Participants.** Systematic sampling was used to select 215 caregivers who took care of home-hospitalized patients during the year 2001.

**Measures.** Personal interview at home with a questionnaire that contained items on descriptive variables, psychological well-being (Goldberg Anxiety and Depression scale), social support (Duke-UNC Functional Social Support Questionnaire), caregiver strain index and profile of the care receiver.

**Results.** The typical caregiver was a 55-year-old woman who was a first-degree relative of the patient, with primary level education, who formed part of a normally functional family and who received good social support. Anxiety was found in 32%, depression in 22% and a high strain index in 11%. The patient was typically a 70-year-old man with chronic disease, a high degree of dependence and good mental status. Correlation analysis showed that the risk of anxiety, depression and strain in caretakers increased with the patient's degree of physical dependence and mental deterioration, and with lower degrees of social support and longer periods devoted to caregiving. The risk of anxiety and depression increased as the strain index and familial dysfunction increased. Strain index was the factor that explained most of the variability in anxiety and depression.

**Conclusions.** Feelings of psychological distress (anxiety and depression) and strain were common among caregivers. Care for caregivers should form part of the measures to provide care to patients.

**Key words:** Home care. Caregiver. Social support.

PERFIL Y RIESGO DE MORBILIDAD PSÍQUICA EN CUIDADORES DE PACIENTES INGRESADOS EN SU DOMICILIO

**Objetivos.** Conocer el perfil del cuidador de los pacientes ingresados en una unidad de hospitalización a domicilio (HaD) y estudiar la presencia de morbilidad y esfuerzo en dichos cuidadores.

**Diseño.** Estudio descriptivo transversal, basado en entrevista personal.

**Emplazamiento.** Área de Salud 11 de la Comunidad Valenciana.

**Participantes.** Un total de 215 cuidadores de pacientes ingresados en HaD durante el año 2001, seleccionados mediante muestreo sistemático.

**Mediciones principales.** Cuestionario de entrevista personal domiciliaria que recoge diversas variables descriptivas: malestar psíquico (escala de ansiedad-depresión de Goldberg), sensación de apoyo social (Duke), índice de esfuerzo del cuidador y perfil de la persona cuidada.

**Resultados.** El perfil de cuidador «tipo» corresponde a una mujer de 55 años, familiar de primer grado del paciente, con estudios primarios, con ansiedad en un 32%, depresión en un 22% y alto índice de esfuerzo en un 11%, inmersa en una familia normofuncional y con buen apoyo social. El paciente suele ser un varón de 70 años con una enfermedad crónica, algún grado de dependencia y buen estado mental. Al correlacionar las variables entre sí se observa que los cuidadores presentan más riesgo de ansiedad, depresión e índice de esfuerzo cuanto mayor es el grado de dependencia física y el deterioro mental del paciente, así como un menor apoyo social y cuanto mayor tiempo lleva cuidando de éste. Presenta más riesgo de ansiedad y depresión a mayor índice de esfuerzo, y más ansiedad e índice de esfuerzo a mayor disfunción familiar. El índice de esfuerzo es el factor que explica con más consistencia la variabilidad en ansiedad y depresión.

**Conclusiones.** Existe un importante sentimiento de malestar psíquico (ansiedad y depresión) y esfuerzo entre los cuidadores. La asistencia al cuidador debería integrarse en la atención al paciente.

**Palabras clave:** Atención domiciliaria. Cuidados. Apoyo social.

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## Introduction

Sociodemographic changes in recent years have made it necessary to create alternatives to hospitalization, and one such alternative is home care. Patients are selected for home care (also termed domiciliary hospitalization) only if a principal caretaker is available, and both the caretaker and the patient are willing to use this alternative. If these circumstances are not present the patient should stay in the hospital.<sup>1</sup>

Caregivers for patients with cognitive impairment or a large degree of physical dependence have been widely studied within the setting of home care.<sup>2-5</sup> Home care, with its differences in comparison to traditional hospitalization, greater use of hospital-range caregiving measures, and greater instability of the patient, requires a particular caregiver profile. Because a patient can be admitted to home hospitalization only if the caregiver's profile is appropriate, home care managers at the hospital need to know the caregivers' profile, and whether they are subjected to an excessive burden of care.

The aims of this study were to determine the profile of caregivers for patients in home care, to investigate the presence of mental illness and caregiver burden, and to analyze the factors associated with their degree of psychological distress.

## Material and methods

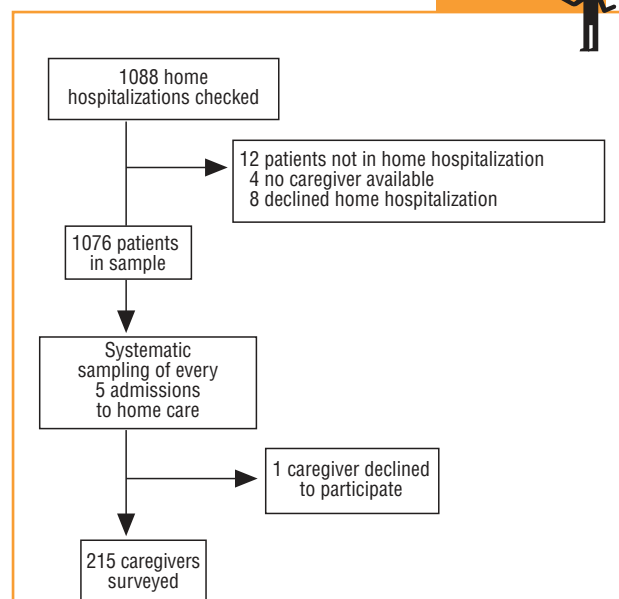
The population for this descriptive cross-sectional study consisted of caregivers for patients in home care in Health Area 11 of the Community of Valencia (Eastern Spain). This coastal area comprises a large city and an otherwise mostly rural area. Large numbers of tourists spend time in the area, and there are many essentially permanent residents not included in the census (retired persons from other parts of Spain who spend most of the year near the seaside). The 1999 census lists 146 649 inhabitants, with a dependence index (ie, the population  $\geq 65$  years/the population  $\leq 14$  years/the population between 15 and 64 years of age) of 0.47 and an aging index (population  $\geq 65$  years/population  $\leq 14$  years) of 0.96.

Patients admitted to home care are referred from the hospital emergency service, from a regular inpatient ward (short-stay unit or regular inpatient area) and from primary care centers (no previous hospital stay). During the year 2001, a total of 1076 patients with a mean age of  $71.0 \pm 15.4$  years used home care, 59.4% of whom were men.

The study sample consisted of caregivers (persons directly responsible for the care of patients at home) who agreed voluntarily to participate in the study, and who provided home care between 1 January and 31 December 2001. Participants were chosen by systematic sampling of the caregiver who accompanied every fifth patient.

During this period home hospitalization was not provided for 12 patients, in 4 cases because no caregiver was available, and in 8 cases because the patient refused voluntary home care. Only one caregiver declined to participate in the study. The total number of caregivers who participated was 215.

## Material and methods



## General scheme of the study

Descriptive, cross-sectional study based on personal interviews of a systematic sample of caregivers for home care patients.

The variables investigated are described below:

### Patient variables

- Age, sex, disease group recorded upon admission as relapse of chronic disease, patients with oncological disease receiving palliative treatment, or acute illness with no history of chronic disease.
- Functional capacity was evaluated with the 20-point *Barthel Index of Activities of Daily Living*, and was classified as independent (score of 20), slight dependence (19-15), moderate dependence (14-10), severe dependence (9-5) or total dependence (4-0).
- Cognitive status was evaluated with Pfeiffer's *Short Portable Mental Status Questionnaire*, and was scored as normal (0-4 errors), moderate cognitive impairment (5-7 errors) or severe cognitive impairment (8-10 errors). One point was subtracted if the patient had received only primary level education, and one point was added if the patient had completed secondary education.
- Hospital stay before starting home care was recorded in days, as was the duration of home care. Referral upon discharge was recorded as primary care, admission to a hospital ward, or death.

### Caregiver variables

- Age, sex, and level of education, recorded in four categories as unable to read or write, primary level education, secondary

level education or technical school, or university level education. *Relationship with the patient* was recorded as first degree (parents, children, spouse, sibling) or second degree (other). *Marital status* was recorded as unmarried, married, widowed or separated. *Paid employment* was recorded as a dichotomous (yes/no) variable. *Time* spent caring for the patient was recorded in months. Screening for psychological distress was done with the *Goldberg Anxiety and Depression Scale*. Symptoms that lasted more than 2 weeks and those in which a clear response was obtained were scored as positive. Anxiety was considered present when the score was  $\geq 4$ , and depression was recorded when the score was  $\geq 2$ . The 13-item *Robinson Caretaker Strain Index* was also used; each positive response was scored one point, and the caretaker was considered to have high level of strain if the total score was  $\geq 7$ . *Chronic illnesses* were recorded as headache, backache (cervical, dorsal or lumbar), chronic venous insufficiency, or non-specific muscle pain (yes/no). Caregivers' *preference regarding*

*place of work* was recorded as their response to the question «Do you think you would have done your job as caregiver better in the hospital than at home?»

#### Family environment variables

The degree of satisfaction with family functioning was evaluated with the self-administered *Family APGAR Scale*. Items were scored on a 0-to-2 Likert scale, and total score ranged from 0 to 10. Scores  $\geq 7$  were considered to indicate normal functioning, 4-6 slight dysfunction, and  $\leq 3$  severe dysfunction. Social support was evaluated with the self-administered *Duke-UNC Functional Social Support Questionnaire*. Items were scored on a 1-to-5 Likert scale, with total scores ranging from 11 to 55. Scores  $\leq 32$  were considered to reflect low social support. *Total number of persons in the household* was noted. *Help received by the caregiver* was determined as the response to the question «Do you receive help in caring for the patient from an older son or daughter, the social services, or a private home care assistance service?» Whether the

**TABLE 1**  
**Description of patients, caregivers and setting**

Characteristics of patients		Characteristics of caregivers		Characteristics of the setting	
Age (years)	70.62 $\pm$ 15	Age (years)	55.33 $\pm$ 14.63	Help available (yes)	64.2%
Sex (men)	60.9%	Sex (women)	87%	Patient moved (yes)	9.3%
Disease group		Marital status		Family APGAR	
Chronic	68.8%	Unmarried	12.1%	Normal function	93%
Oncological	20.0%	Married	80.9%	Slight dysfunction	5.1%
Acute	11.2%	Widowed	5.1%	Severe dysfunction	1.9%
		Separated	1.9%		
Barthel index		Education		Duke-UNC	
Independent	47.0%	Unable to read or write	12.1%	Good social support	96.3%
Slight dependence	20.0%	Primary	72.1%	Poor social support	3.7%
Moderate dependence	10.2%	Secondary/Technical	11.6%		
Severe dependence	4.7%	University	4.4%		
Total dependence	18.1%				
Mental state		Prefers hospital setting for providing care (yes)	11.6%	No. of persons in household	3.11 $\pm$ 1.41
Normal	85.1%				
Moderate deficit	7.9%				
Severe deficit	7.0%				
Mean stay in home care	3.73 $\pm$ 9.28	Paid employment (yes)	31.6%		
Mean stay in home care	10.32 $\pm$ 6.62	Chronic disease (yes)	51.2%		
Discharged to		Time caring for patient (months)	38.16 $\pm$ 67.50		
Primary care	88.4%				
Death	6.5%				
Re-admitted to hospital	5.1%				
		First degree relative (yes)	94%		
		Anxiety (yes)	32.1%		
		Depression (yes)	22.3%		
		Strain index (yes)	11.6%		

patient stayed at the home of more than one relative was also noted.

### Data collection

Patient-related variables were recorded from the medical record, and information on other variables was obtained by face-to-face interview at the patient's home. On the first day of home care the caregivers were given information about the study, and an appointment was scheduled for a future date during the period of home care, once the caregiver had adapted to the home. To avoid bias, all interviews were done by three researchers previously trained in roll-play sessions in the administration of the questionnaire.

### Data analysis

The data were imported in the Microsoft Excel 2000 spreadsheet and analyzed with version 9.0 of the SPSS for Windows. Statistical analysis was done in three phases:

1. Univariate analysis: frequency distributions for qualitative variables, and central tendencies and dispersions for quantitative variables.
2. Bivariate analysis was done to compare the results for qualitative variables with the chi-squared test; strength of association was determined by calculating the odds ratio and 95% confidence interval. For comparison of the means, normal distribution was confirmed with the Kolmogorov-Smirnov test and equality of the variances was tested with Student's *t* test or Mann-Whitney's U test. The degree of association between quantitative variables was determined with Pearson's correlation coefficient or Spearman's rho.
3. Variables that had an overall influence on mental illness and caregiver burden were identified with multiple linear regression with the enter method for three dependent variables (anxiety, depression and strain), using as predictive variables those that yielded significant results in the preceding bivariate analysis. The results were considered statistically significant at  $P < .05$ .

## Results

The characteristics of the 215 caregivers studied here are summarized in Table 1. Our analysis of the factors related with anxiety, depression and strain (Tables 2, 3, and 4) showed that a higher risk for these problems was associated with greater physical dependence and mental impairment in the patient, less social support, and longer periods spent caring for the patient. The risk of anxiety and depression was greater with higher strain index values, and anxiety and strain increased with the degree of family dysfunctioning. Lack of paid employment was associated with greater depression and strain; chronic illness was associated with depression, and lack of help with caregiving was associated with anxiety.

Multivariate analysis with all predictor variables shown in Tables 5, 6 and 7 accounted for 42.2% of the variability in anxiety, 33.5% of the variability in depression, and 32.8% of the variability in strain index.

For anxiety, 24.10% of the variability was found to be significantly dependent on strain index, 2.59% on time spent caring for the patient, and 2.05% on whether any help was received in caring for the patient. For depression, 20.79% of the variability was explained by the strain index and 3.96% by whether the caregiver had a chronic illness. Variability in the strain index was influenced by physical disability in the patient according to the Barthel scale (10.95%), and by social support (Duke-UNC) (8.53%).

**TABLE 2** Bivariate analysis: factors related with anxiety and depression

	Anxiety				Depression			
	Yes	No	95% CI	R (95% CI)	Yes	No	95% CI	R (95% CI)
Caregiver's age	56.01±13.31	55.00±15.25	NS		58.81±12.12	54.32±15.16	NS	
Barthel	11.74±8.63	15.67±6.62	(-6.26 to -1.60)	0.2828	9.75±8.98	15.75±6.50	(-8.78 to -3.22)	0.3435
				(-0.138 to 0.051)				(-0.101 to -0.046)
Mental	2.33±3.20	1.22±2.35	(0.26-1.97)	0.1732	3.08±3.58	1.14±2.21	(0.85-3.03)	0.2683
				(0.037-0.284)				(0.082-0.238)
Duration of previous hospital stay, days	6.48±15.32	2.42±3.41	(0.33-7.77)	0.1516	4.40±6.11	3.53±10.01	NS	
				(0.605-0.077)				
Stay in home care, days	10.54±6.17	10.21±6.85	NS		9.98±6.12	10.41±6.78	NS	
No. persons	3.09±1.45	3.12±1.39	NS		3.15±1.54	3.10±1.37	NS	
Time providing care, months	57.155±88.86	29.05±52.36	(5.155-51.053)	0.2408	68.29±97.01	29.39±53.38	(9.63-68.164)	0.1974
				(0.004-0.014)				(0.002-0.008)
Strain index	5.52±3.03	2.33±2.47	(2.37-4.02)	0.6172	6.10±2.87	2.56±2.61	(2.68-4.40)	0.5319
				(0.421-0.596)				(0.221-0.342)
Duke-UNC	44.19±8.35	48.08±5.71	(-6.09 to -1.68)	0.3847	44.27±8.35	47.56±6.51	-5.48 to -1.11	0.1732
				(-0.185 to -0.094)				(-0.071 to -0.009)
Family APGAR	8.33±2.01	9.0±1.28	(-1.19 to -0.14)	0.2408	8.38±2.03	8.90±1.611	NS	
				(-0.589 to -0.173)				

NS indicates not significant; 95% CI, 95% confidence interval; R: Pearson's correlation coefficient.

**TABLE 3** Bivariate analysis: factors related with strain index

	Strain			
	Yes	No	95% CI	R (95% CI)
Caregiver's age	55.0±13.7	55.37±14.78	NS	
Barthel	5.32±6.84	15.61±6.78	(-13.13 to -7.44)	0.4159 (-0.217 to -0.118)
Mental	3.72±3.73	1.29±2.4	(0.85-4.0)	0.2774 (0.167-0.46)
Duration of previous hospital stay, days	6.4±10.73	3.37±9.04	NS	
Stay in home care (days)	12.52±6.33	10.03±6.62	NS	
No. persons	3.60±1.83	3.04±1.33	NS	
Time providing care, months	69.75±80.52	34.14±64.81	(0.510-70.693)	0.2073 (0.003-0.015)
Duke-UNC	42.52±9.68	47.39±6.26	-8.91 to -0.75	0.3820 (-0.224 to -0.114)
APGAR	7.96±2.46	8.89±1.40	-1.97 to -0.0948	0.2846 (-0.799 to -0.30)

NS indicates not significant; 95% CI, 95% confidence interval; R, Pearson's correlation coefficient.

## Discussion

Any evaluation of our results should consider the selection criteria we used in this study. The 12 patients who did not enter home care because of the lack of a primary caregiv-

er or because of motives that the caregiver did not specify may represent cases with the greatest burden of care, involving patients who should remain in the hospital. Another limitation is the rootedness of the population in our area of study, where family networks are an important source of support. (Only one caregiver, a retired person, was from a region outside the study area and had moved to the region where the study was carried out). Because of these factors, and the variety in the degrees of mental illness, disability and time spent caring for the patient, our results should be extrapolated to other populations with caution. With regard to the instruments we chose, all have been validated for use in Spain except for the strain index, but we feel that their use in many other published studies justifies their choice for the present study.

The caregiver profile in our study was similar to that found in earlier reports.<sup>2-11</sup> Typically, the caregiver was a married, middle-aged women, a first degree relative of the patient, with primary level education. Caregivers who are

**TABLE 4** Bivariate analysis: factors related with anxiety, depression and strain

	Anxiety			Depression			Strain	
Anxiety score	95% CI	R (95% CI)	Puntuación depresión	95% CI	R (95% CI)	Puntuación esfuerzo	95% CI	R (95% CI)
Employed								
Yes	1.78±2.21	NS		0.5±1.23	(0.0239-0.2420)	0.164	2.54±2.88	(0.035-0.1645)
No	2.59±2.60			1.07±1.73		(0.108-1.028)	3.73±3.05	(0.316-2.051)
Chronic disease								
Yes	2.65±2.61	NS		1.23±1.81	(0.3030-0.086)	0.216	3.45±2.93	NS
No	2.01±2.37		0.53±1.29		(1.118-0.270)	3.25±2.44		
Help								
Yes	1.94±2.48	(0.013-0.282)	(0.408-1.786)	0.77±1.65	NS		3.04±3.02	NS
No	3.04±2.41			1.10±1.13			3.91±3.03	
Relationship								
1st degree	2.38±2.53	NS		0.93±1.65	NS		3.37±3.07	NS
2nd degree	1.69±2.10			0.23±0.60			3.15±2.73	
Patient moved								
Yes	2.65±3.01			1.40±2.37			4.35±3.39	
No	2.30±2.46	NS		0.84±1.51	NS		3.23±2.99	NS

NS indicates not significant; 95% CI, 95% confidence interval; R, Pearson's correlation coefficient.



**TABLE 5** Multivariate analysis: variables predictive of anxiety

	Regression coeff.: beta	95% CI	Partial correlation coeff.
Strain index	0.524	(0.33-0.545)	0.491
Time providing care, months	0.138	(0.001-0.010)	0.161
Help	-0.117	(1.204-0.026)	0.143
Duke-UNC	-0.098	NS	-0.103
Barthel	-0.068	NS	-0.072
Mental	0.060	NS	-0.061
Duration previous hospital stay, days	0.034	NS	0.044
Family APGAR	-0.020	NS	-0.024
Adjusted R <sup>2</sup>	0.422		

**TABLE 6** Multivariate analysis: variables predictive of depression

	Regression coeff.: beta	95% CI	Partial correlation coeff.
Strain index	0.507	(0.199-0.345)	0.456
Chronic disease	0.183	(0.191-0.992)	0.199
Barthel	-0.128	NS	-0.124
Duke-UNC	-0.073	NS	-0.081
Time providing care, months	0.046	NS	0.050
Mental	0.004	NS	0.004
Employed	-0.001	NS	-0.001
Adjusted R <sup>2</sup>	0.335		

relatives of the patients are a risk group for mental illness,<sup>6</sup> and have been considered «hidden patients».<sup>5</sup>

Earlier studies have reported percentages of anxiety ranging from 45% to 80%;<sup>2,6-9,12</sup> in the present study anxiety was found in 32% of the caregivers. The corresponding values for depression ranged from 16% to 60%,<sup>2,7,9,12</sup> with a frequency of 22.3% in the present study. The strain index reported by other authors ranged from 27.8% to 60%,<sup>2,3,7</sup> and was 11.6% in the present study. These findings may be explainable in part by the «protective» effect of home care on the caregiver, despite the fact that the patient requires more intensive care because of his or her unstable condition, or because the care measures provided are similar to those available on a hospital ward.

Our results after bivariate analysis were similar to those of earlier studies. The degree of mental distress in caregivers was associated with the patients' degree of physical disability,<sup>5,10,13</sup> the time devoted to caregiving,<sup>2,10,13</sup> a high

**TABLE 7** Multivariate analysis: variables predictive of strain

	Regression coeff.: beta	95% CI	Partial correlation coeff.
Barthel	-0.339	(-0.188 to -0.082)	-0.331
Duke-UNC	-0.290	(-0.184 to -0.070)	-0.292
APGAR	0.108	NS	0.116
Employed	-0.105	NS	-0.126
Mental	0.082	NS	0.077
Time providing care, months	0.059	NS	0.064
Adjusted R <sup>2</sup>	0.328		

strain index<sup>2,7</sup> and chronic disease in the caregiver.<sup>2</sup> Other studies have shown that depression in the caregiver is associated with lack of support.<sup>7</sup>

#### Discussion Key points



### What is known about the subject

- Sociodemographic changes have made it necessary to create alternative forms of care, including home hospitalization.
- For a patient to be eligible for home care, a principal caregiver is required and willingness to accept home care is needed on the part of both the caregiver and the patient. In the absence of these factors the patient should remain in the hospital.
- Caregiver profile and psychological distress have been studied in the primary care setting, but little is known about these aspects in caregivers who provide home care.

### What this study contributes

- The typical caregiver was a 55-year-old woman who was a first-degree relative of the patient, with primary level education, who formed part of a normally functional family and who had good social support.
- Feelings of psychological distress (32% with anxiety, 22% with depression) and strain (high strain index in 11%) were common among caregivers.
- The main predictors of distress in caregivers were greater physical dependence, cognitive deterioration in the patient, less social support and greater periods of time devoted to providing care.

In earlier studies that included regression analysis, caregiver anxiety and depression were found to be correlated with score on the daily living activities index and the patient's mental status.<sup>5</sup> Availability of help with caregiving and being a relative of patient were associated with anxiety scores.<sup>11</sup> We do not feel that these findings should be considered discordant from ours, as we found that the variable with the greatest impact on anxiety and depression was caregiver strain, a factor that was not measured with the index we used, as such, in the two studies cited above.

Because of the limitations discussed above, our results do not allow us to claim a causal relationship between anxiety or depression and predictive factors. However, they should help encourage the systematic collection of information regarding caregivers' social support (Duke-UNC questionnaire) and strain index in all cases of home care. Moreover, recognition of psychological distress in the caregiver is useful in itself. Caregivers may benefit from the mobilization of resources to counteract, in part, the burden of care. Patients may recover more quickly or enjoy a better stay in home care if the caretaker is not subjected to distress. The health care team may be better informed about the support resources available to caregivers to ensure continuity of care and treatment. The hospital and other units that refer patients to home care may be able to discharge patients sooner and with greater assurances that the patient will not need to be readmitted because of withdrawal of family-provided care.

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## COMMENTARY

# Burden of Care and Quality of Life in Informal Caregivers for Disabled Patients

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Informal caregivers are persons from within the circle of family members (in more than 80% of the cases), friends or neighbors who take responsibility for the care of dependent persons who live in their area, and who do not receive payment for this work. Because these persons are usually women, we will use the feminine gender to refer to them in this editorial.

The conditions under which this care is provided are often less than ideal, and in attempts to analyze the consequences of being the principal care provider for a dependent person, one of the key concepts is burden of care. This term was first used in the early 1960s to study the effect on the family of keeping psychiatric patients in the community. Within the area of informal care, the term has been widely used since the 1980s to refer to the impact of caring for a person diagnosed with dementia.

Burden of care has both objective and subjective components. The former refer directly to the tasks the principal caregiver must perform, and particularly to the time devoted to care, the physical burden involved, and exposure to stressful situations arising from certain symptoms or behaviors in the patient. Accordingly, the word «demands» is used in its widest sense to mean those demands the caregiver is exposed to in the course of caring for a dependent person.

The subjective components are the way in which the caregiver perceives caring tasks, and specifically the emotional response to the experience of caring for a relative. Different authors have supported the relevance of this concept, and have emphasized that the important factor is not so much the number of situations in which the caregiver is exposed to as the degree to which these situations are judged to be negative. When emotional arousal is intense, very frequent, or prolonged, the caregiver's health, well-being and behavior can be affected. However, other authors have questioned the concept of burden of care as a useful variable for measuring the effects on principal caregivers of caring for a disabled patient, because of the lack of a clear conceptual model that distinguishes between objective and subjective burden.<sup>1</sup> A frequent alternative has

## Key points

- Prolonged caregiving for a dependent patient often affects the caregiver's quality of life.
- Primary care practitioners should evaluate the burden of care and how it affects health-related quality of life in caregivers, in order to develop measures aimed at preventing mental and physical deterioration.
- Evaluations of quality of life will make it possible to develop intervention strategies for caregivers and thus indirectly achieve better care for patients.

been to evaluate psychological well-being, a central component of health-related quality of life (HRQL).<sup>2</sup> The findings of some studies uphold the conceptual distinction between burden of care and quality of life, and suggest that the latter may improve even in the presence of caregiver burden. In addition, research on caregiver health should be complemented, as noted in the article by Moral Serrano et al, with measures of quality of life or related characteristics.<sup>3</sup> Moreover, the correlation between measures of HRQL and caregiver burden is, for some processes, only weak or moderate.<sup>4</sup>

Greater dependence on the part of the patient increases the level of caregiver strain, which in turn generates conflicting feelings of rage, grief, isolation and resentment. These emotions affect the caregiver's health and well-being, and eventually her HRQL, to the point that caregiving has been related with greater mortality.<sup>5</sup> In accordance with the conclusions reached by Moral Serrano et al, recognizing psychological distress in the person responsible for caring for the patient offers help to the caregiver in that resources are mobilized that can relieve, in part, the



decrease in her quality of life. This in turn offers help for the patient, who will receive better care if the caregiver is not subjected to distress, and for the patient's health care team, who can thus better understand how much support they can count on from the caregiver to ensure continuity of care and treatment.

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**INSTRUMENTS****FAMILY FUNCTIONING: FAMILY APGAR**

	Nearly always	Almost never	Sometimes
A. Are you satisfied with the help you receive from your family when you have a problem?	.....	.....	.....
B. Do you discuss problems at home among yourselves?	.....	.....	.....
C. Do you make important decisions together?	.....	.....	.....
D. Are you satisfied with the time you and your family spend together?	.....	.....	.....
E. Do you feel your family loves you?	.....	.....	.....

**BARTHEL INDEX****BOWELS**

Incontinent (or needs to be given enemas).....	0
Occasional accident (maximum 1 per week).....	1
Continent.....	2

**BLADDER**

Incontinent, catheterized or needs help.....	0
Occasional accident (maximum 1 per 24 hours).....	1
Continent (for more than 7 days).....	2

**GROOMING**

Needs help with personal care.....	0
Independent face/hair/teeth/shaving.....	1

**TOILET USE**

Dependent.....	0
Needs help but can do some things alone.....	1
Bath: in and out without supervision, wash alone.....	2
Independent (on and off, wiping, dressing)	

**BATHING**

Dependent.....	0
Independent.....	1
Shower: no supervision/no help	

**DRESSING**

Dependent.....	0
Needs help but can do about half unaided.....	1
Independent (including buttons, zips, shoelaces) .....	2

**FEEDING**

Unable.....	0
Needs help cutting, spreading butter, etc.....	1
Independent (food can be placed within reach).....	2

**TRANSFERS BED TO CHAIR AND BACK**

Unable, no sitting balance.....	0
Major help (1-2 people) but can sit.....	1
Minor help (verbal or physical).....	2
Independent.....	3

**MOBILITY**

Immobile.....	0
Independent in wheelchair, including corners.....	1
Walks with help of one person (verbal or physical).....	2
Independent but may use any aid if needed.....	3

**STAIRS**

Unable.....	0
Needs help (verbal or physical, with an aid) .....	1
Independent up and down.....	2

**CAREGIVER STRAIN INDEX (Yes/No)**

1. Sleep is disturbed (e.g., because the patient is in and out of bed or wanders around at night).
2. It is inconvenient (e.g., because helping takes so much time or it takes a long time to reach the patient's home).
3. It is a physical strain (e.g. lifting in and out of a chair).
4. It is confining (e.g. helping restricts free time or cannot go visiting).
5. There have been family adjustments (e.g. because helping has disrupted routine and there is no privacy).
6. There have been changes in my personal plans (e.g. had to turn down a job, could not go on vacation).
7. There have been other demands on my time (e.g. from other family members).
8. There have been emotional adjustments (e.g. because of severe arguments).
9. Some behavior is upsetting (e.g. incontinence, patient has trouble remembering things, patient accuses people of taking things).
10. It is upsetting to find that the patient has changed so much from his/her former self (e.g., hs/she is a different person than he/she used to be).
11. There have been work adjustments (e.g. because of having to take time off).
12. It is a financial strain.
13. Feeling completely overwhelmed (e.g., because of worry about the patient or concerns about how treatment should continue)

## INSTRUMENTS (continuation)

### PFEIFFER'S SHORT PORTABLE MENTAL STATUS QUESTIONNAIRE

1. What is today's date? DAY... MONTH..... YEAR.....
2. What is the day of the week? .....
3. What is the name of this place or building?.....
4. What street do you live on?.....
5. How old are you?.....
6. When were you born? DAY... MONTH..... YEAR.....
7. Who is the current president?.....
8. Who was the president before him/her?.....
9. What is your mother's name?.....
10. If we give you 20 of something and then take away 3,.....are left, and if we take away 3 more, .....,  
 ..... are left (until zero is reached)

### GOLDBERG ANXIETY AND DEPRESSION SCALE (Yes/No)

#### Anxiety scale

1. Have you felt keyed up or on edge?
2. Have you been worrying a lot?
3. Have you been irritable?
4. Have you had difficulty relaxing?  
 If 2 or more items are answered Yes, ask the  
 following questions:
5. Have you been sleeping poorly?
6. Have you had headaches or neck aches?
7. Have you had any of the following:  
 trembling, tingling, dizzy spells, sweating, diarrhea?  
 (autonomic symptoms)
8. Have you been worrying about your health?
9. Have you had difficulty falling asleep or staying asleep?

#### Depression scale

1. Have you felt low on energy?
2. Have you lost interest in things?
3. Have you lost confidence in yourself?
4. Have you felt desperate or hopeless?  
 If any item was answered Yes,  
 ask the following questions:
5. Have you had difficulties concentrating?
6. Have you lost weight? (because of lack of appetite)
7. Do you wake up too early in the morning?
8. Have you felt slow?
9. Do you think you tend to feel worse in the morning?

### DUKE-UNC FUNCTIONAL SOCIAL SUPPORT QUESTIONNAIRE

The list below contains things that people can do for us or give us, that provide help or support. Please read each statement carefully and place a check in the square closest to your situation.

A = as much as I would like. B = almost as much as I would like. C = neither too much not too little. D = less than I would like.  
 E = much less than I would like.

	A	B	C	D	E
1. I get visits from my friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I get help around the house	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I get praise for a good job	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I have people who care what happens to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I get love and affection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I get chances to talk to someone about problems at work or with my housework	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I get chances to talk to someone about my personal and family problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I get chances to talk to someone about money matters	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I get invitations to go out and do things with other people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I get useful advice about important things in life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. I get help when I'm sick in bed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>