

## Original article

# Carer's burden of peritoneal dialysis patients. Questionnaire and scale validation<sup>☆</sup>

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## ARTICLE INFO

## Article history:

Received 4 July 2017

Accepted 25 February 2018

Available online 17 October 2018

## Keywords:

Peritoneal dialysis

Carer's burden

Validation of the Peritoneal Dialysis

Carer Burden Questionnaire

Dependency

## ABSTRACT

**Introduction:** Carers of peritoneal dialysis patients may suffer from burden, the characteristics of which differ from burden due to dementia, cancer or other dependent conditions.

**Aims:** To ascertain the reliability and validity of the Peritoneal Dialysis Carer Burden Questionnaire (PDCBQ), previously created, and to design the burden scale.

**Methods:** Observational, multicentre study of carers and patients on peritoneal dialysis for more than 3 months. Sociodemographic characteristics of patients and carers, patient dependency, perceived health (SF-36) and carer burden (Zarit scale) were recorded, as well as PDCBQ via 3 scales: dependence, subjective burden and objective burden.

**Results:** One hundred seven patients and their carers from 8 hospitals were evaluable. Carers were mainly women (83.2%), aged  $57.50 \pm 14.69$  years, and 36.4% worked out of the home. The internal consistency of the Zarit scale and the PDCBQ were high (Cronbach's  $\alpha$  between 0.808 and 0.901). Significant correlation was found between the Zarit scale and PDCBQ ( $r = 0.683$ ). The concordance analysis between three degrees of Zarit scale and PDCBQ tertiles was good or acceptable (Kendall  $\tau$ -b: 0.570,  $p < 0.001$ ). The exploratory factor analysis of the main factors revealed 3 factors, which were successfully correlated with the design of the PDCBQ. A new carer burden scale was designed.

**Conclusions:** The study shows good reliability with high internal consistency of the PDCBQ. Factorial analysis shows good construct and good correlation, and acceptable concordance with the Zarit burden scale confirmed criterion validity. The questionnaire is suitable to be applied in clinical practice.

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DOI of original article:

<https://doi.org/10.1016/j.nefro.2018.02.006>.

<sup>☆</sup> Please cite this article as: Teixidó-Planas J, Tarrats Velasco L, Arias Suárez N, Cosculluela Mas A. Sobrecarga de los cuidadores de pacientes de diálisis peritoneal. Validación de cuestionario y baremos. Nefrología. 2018;38:535–544.

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## Sobrecarga de los cuidadores de pacientes de diálisis peritoneal. Validación de cuestionario y baremos

### R E S U M E N

#### Palabras clave:

Diálisis peritoneal  
Sobrecarga de cuidadores  
Validación del Cuestionario de Sobrecarga del Cuidador de Diálisis Peritoneal  
Dependencia

**Introducción:** Los cuidadores de pacientes en diálisis peritoneal pueden sufrir sobrecarga con características diferentes de la derivada de demencia, cáncer u otras enfermedades dependientes.

**Objetivos:** Analizar la fiabilidad y la validez del Cuestionario de Sobrecarga del Cuidador de Diálisis Peritoneal (CSCDP) elaborado anteriormente y establecer los baremos del mismo.

**Métodos:** Estudio observacional, multicéntrico de cuidadores y pacientes con más de 3 meses en diálisis peritoneal. Se registraron: características sociodemográficas de pacientes y cuidadores, dependencia de pacientes, salud percibida (SF-36) y sobrecarga del cuidador (escala de Zarit), además del CSCDP con 3 escalas: dependencia, sobrecarga subjetiva y sobrecarga objetiva.

**Resultados:** Fueron evaluables 107 cuidadores y pacientes de 8 hospitales. Los cuidadores fueron mayoritariamente mujeres (83,2%), con una edad media de  $57,50 \pm 14,69$  años; un 36,4% trabajaban fuera de casa. La consistencia interna de la escala de Zarit y del CSCDP fue elevada ( $\alpha$  de Cronbach entre 0,808 y 0,901). La correlación entre la sobrecarga del Zarit y la del CSCDP fue significativa ( $r=0,683$ ). La correspondencia entre 3 grados de sobrecarga del Zarit y los tertiles del CSCDP fue buena o aceptable ( $\tau$ -b Kendall: 0,570,  $p < 0,001$ ). El análisis factorial exploratorio de componentes principales mostró 3 componentes coincidentes con el diseño del CSCDP. Se han elaborado los baremos de sobrecarga del cuidador.

**Conclusiones:** El estudio demuestra buena fiabilidad con elevada consistencia interna del cuestionario CSCDP. El análisis factorial denota validez de constructo y la buena correlación y aceptable correspondencia con la escala de Zarit indican validez de criterio. El cuestionario resulta apto para aplicación clínica.

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## Introduction

Carers of patients receiving peritoneal dialysis (PD) or other chronic diseases can be at risk of work overload due to the burden of caring for and treating these dependent individuals.<sup>1-3</sup>

Overload is a key dimension in the evaluation of carers. Analysis of the variables affecting carers has led to the development of conceptual models that show overload to be caused by different factors and components.<sup>4-7</sup> This is why it is so important to measure the degree of overload in this population.

Several studies conducted over the past 30 years have revealed significant degrees of carer overload in connection with different diseases, and have highlighted the need to design respite protocols for carers.<sup>8-12</sup>

The burden of carers of patients on renal replacement therapy with haemodialysis (HD), PD and kidney transplant has already been evaluated using questionnaires that address various different dimensions: health-related quality of life,<sup>1,2,13-15</sup> emotional state,<sup>2,16,17</sup> depression,<sup>14-18</sup> vital satisfaction, family stress, marital relationship,<sup>19</sup> psychosocial repercussion,<sup>13</sup> exhaustion or burnout syndrome and, more specifically, subjective or objective caring-related personal overload.<sup>2,13,14,16,18,20</sup>

However, most studies have so far used general questionnaires to determine carer overload,<sup>1,2,14,16</sup> even though generic

measures may not be sensitive enough to identify differences, particularly in a research setting.<sup>21</sup> Few studies have used questionnaires designed specifically for PD<sup>22,23</sup> or HD plus PD.<sup>4</sup>

The characteristics of PD patients differ considerably from patients with dementia, cancer, or severe functional limitations, and, therefore, the stress factors affecting their carers also differ to a certain extent. Thus, some years ago our group developed the Overload Questionnaire for Carers of Patients on Peritoneal Dialysis (CSCDP, in its Spanish acronym). This instrument includes 3 dimensions: patient's degree of dependence, carer's subjective overload, and carer's objective overload, and has shown optimal reliability and validity for clinical use.<sup>24</sup>

Nevertheless, validation of health-related questionnaires or scales is an ongoing process, as the results and corresponding interpretation may vary depending on the specific characteristics of the population in which they are used.<sup>25</sup>

Questionnaires are validated on the basis of their reliability and validity. Reliability indicates the extent to which a measuring instrument produces accurate results on repeated tests. It is evaluated on the basis of internal consistency, stability over time, equivalence, and inter-observer agreement. Validity, meanwhile, shows the degree to which the instrument measures what it really intends to measure in terms of content, construct, and criteria.<sup>25-27</sup>

In this study, we have validated the CSCDP in a wider sample of carers using the 36-item short form (SF-36) health-related quality of life questionnaire<sup>28</sup> and the Zarit Burden Interview (ZBI)<sup>29-32</sup> to test the criterion validity. The ZBI has been translated into many languages, and is widely used and recommended.<sup>33-36</sup> It has also been used for carers of patients with chronic kidney failure on replacement therapy with HD,<sup>13,17,37,38</sup> PD<sup>1,2,17,22,23,38,39</sup> and kidney transplant.<sup>16</sup>

The objectives of this study have been to validate the CSCDP by analysing the reliability (internal consistency) and validity (construct validity and criterion validity compared to the ZBI), and to construct a number of rating scales from the questionnaire to determine the degree of overload of the carers in our study sample.

## Material and methods

All patients included in a PD programme from 8 hospitals were invited to take part in the study. To be included in the study, the patient must have been receiving PD for at least 3 months, and must be cared for by a primary carer. The primary carer was defined as the person close to the patient who, when asked, confirmed that he/she is responsible for the care of the patient on PD. Both participants, patient and carer, were asked to sign an informed consent form before inclusion in the study. The study was approved by the ethics committee of the reference hospital (H. Universitari Germans Trias i Pujol, Badalona) and complies with the principles of good clinical practice.

Data collected from the patients included age, gender, education, work status, concurrent diseases, Charlson index, choice of treatment modality, and degree of independence when performing PD. The tests administered were: the Mini-Mental State Examination,<sup>40</sup> the Karnofsky Performance Status scale,<sup>41</sup> which assesses the patient's physical capacity and degree of independence, and the Lawton-Brody Instrumental Activities of Daily Living Scale.<sup>42</sup> In the latter, we used the original 0-8-point score that measures the patient's degree of independence, and an alternative score developed by us that shows the degree of limitation resulting from not being able to perform the different activities, in order to correlate this with the degree of dependence. Health-related quality of life was assessed using the SF-36 questionnaire validated for the Spanish population.<sup>28,43</sup>

In the case of the carers, we recorded their personal characteristics and work status and the degree of kinship or relationship with the patient, and their score on the Mini-Mental State Examination, the SF-36<sup>28</sup> and the 22-item ZBI<sup>29,30</sup> adapted and revalidated for the Spanish population.<sup>31,32</sup> In this questionnaire, answers were scored from 0 to 4 (never: 0; rarely: 1; sometimes 2; quite frequently; 3; nearly always: 4). Following the system used by many other authors,<sup>17,34,37</sup> overload was classified into 4 different levels, according to the following scores: (1) from 0 to 20, slight overload or no overload; (2) from 21 to 40, mild to moderate overload; (3) from 41 to 60, moderate to severe overload, and (4) 61 or more, severe overload.

The CSCDP comprises 30 questions relating to 3 dimensions: patient dependence (8 items), subjective overload (12 items) and objective overload (10 items) of the PD carer.<sup>24</sup>

Unlike the previous study published by our group, each item is scored using a scale from 0 to 4, with 4 being the worst situation. These 2 tests were administered with an interval of between 15 and 30 days. The order was changed to avoid bias.

## Statistical analysis

For the statistical analysis, one-way ANOVA and the Bonferroni post hoc test were used to compare means between groups, the Student's *t*-test for 2 groups, Cronbach's  $\alpha$  for internal consistency, Pearson's correlation coefficient to compare scales, Kendall's  $\tau$ -*b* coefficient for the correspondence analysis, multiple linear regression for the analysis of explanatory variables, and exploratory factor analysis of principal components.

## Results

One hundred and sixteen patients and carers were included initially; of whom 9 were excluded because they did not complete the protocol, leaving 107 carers and patients from 8 hospitals for the final analysis.

The average age of patients was  $63.49 \pm 13.29$  years, and carers was  $57.50 \pm 14.69$  years; this difference was significant ( $p=0.002$ ). The patients had been receiving PD for  $24.07 \pm 19.15$  months, with a Charlson comorbidity index of  $7.05 \pm 2.71$ ; 34.6% were diabetic and 49.5% were treated with a cycler. There were no significant differences between centres (ANOVA).

The majority of carers were women, while the patients were mostly men ( $p<0.001$ ). Both carers and patients had a similar level of education. The work status of most patients was retired, and most carers were housewives.

PD had been prescribed by the patient's doctor in 35.5% of cases, and had been chosen by the patient or his/her family in 64.5% of cases; in 31.8% of these, it was chosen because it enabled them to pursue their leisure and free time activities (Table 1). Forty-three (40.2%) patients always needed help to perform PD, 14 (13.1%) needed help sometimes, and 50 (46.7%) never or hardly ever needed help.

The relationship between carers and patients was: spouses 83 (77.6%), children 17 (15.9%), father or mother 5 (4.7%) and other 2 (1.8%). The carer had been caring for the patient for: less than 6 months - 11 (10.3%); between 6 months and 1 year - 27 (25.2%); between 1 and 2 years - 27 (25.2%); between 2 and 3 years - 18 (16.8%) and more than 3 years - 24 (22.4%). Twenty-five carers had a full-time job (23.4%), 14 (13.1%) worked part-time, and 68 (63.6%) did not work outside the home. Nearly all (92.5%) carers lived in the same house as the patient.

## Results of the questionnaires administered

The results of the descriptive statistics are shown in Table 2. In the Mini-Mental State Examination, patient scores were significantly lower than those of the carers ( $p<0.001$ ). Eleven patients and 2 carers scored less than 23 points (cognitive impairment). The analysis by centres (ANOVA) found that the carers from centre 3 scored significantly lower on the

**Table 1 – Social and employment status of patients and carers.**

	Patients, n	(%)	Carers, n	(%)	
<i>Gender</i>					
Male	76	(71)	18	(16.8)	<i>p</i> < 0.001
Female	31	(29)	89	(83.2)	
<i>Level of education</i>					
Illiterate	5	(4.7)	0	(0)	
Primary education	57	(53.3)	68	(63.6)	
Secondary education	25	(23.4)	13	(12.1)	
Vocational training	13	(12.1)	17	(15.9)	
Higher vocational training	7	(6.5)	9	(8.4)	
<i>Employment status</i>					
Entrepreneur	5	(4.7)	4	(3.7)	
Liberal profession	3	(2.8)	5	(4.7)	
Permanent job	4	(3.7)	19	(17.8)	
Housewife	20	(18.7)	43	(40.2)	
Retired	47	(43.9)	15	(14)	
Others: temporary worker, student, etc.	28	(26.2)	21	(19.6)	
<i>Reason for choosing PD</i>					
Work/studies	7	(6.5)			
Leisure and free time	34	(31.8)			
Awaiting transplant	13	(12.2)			
No vascular access for HD	18	(16.8)			
Contraindication for HD	15	(14)			
Others	20	(18.7)			

HD: haemodialysis; PD: peritoneal dialysis.

**Table 2 – Results of the questionnaires administered to patients and carers.**

	Median	Mean	Standard deviation	Lower limit of 95% CI	Upper limit of 95% CI	Min.	Max.
<b>Patients</b>							
Mini-Mental	31	29.29	6.07	28.12	30.46	6	35
Karnofsky	60	63.68	18.53	60.11	67.25	30	100
Lawton–Brody	4	4.28	2.18	3.86	4.7	0	8
Lawton–Brody (alternative)	10	10.79	6.19	9.61	11.98	0	23
<b>Carers</b>							
Mini-Mental	33	31.83	3.39	31.18	32.48	21	35
Zarit overload	22	25.51	16.08	22.43	28.59	0	71
<b>CSCDP</b>							
Dependency	13	14.43	7.98	12.9	15.96	1	31
Subjective overload	9	9.57	7.29	8.17	10.98	0	35
Objective overload	11	12.75	8.65	11.09	14.41	0	35
Subjective + objective overload	21	22.32	14.39	19.56	25.08	0	68
Total questionnaire	34	36.75	18.03	33.29	40.2	7	89

95% CI: 95% confidence interval; CSCDP: Overload Questionnaire for Carers of Patients on Peritoneal Dialysis.

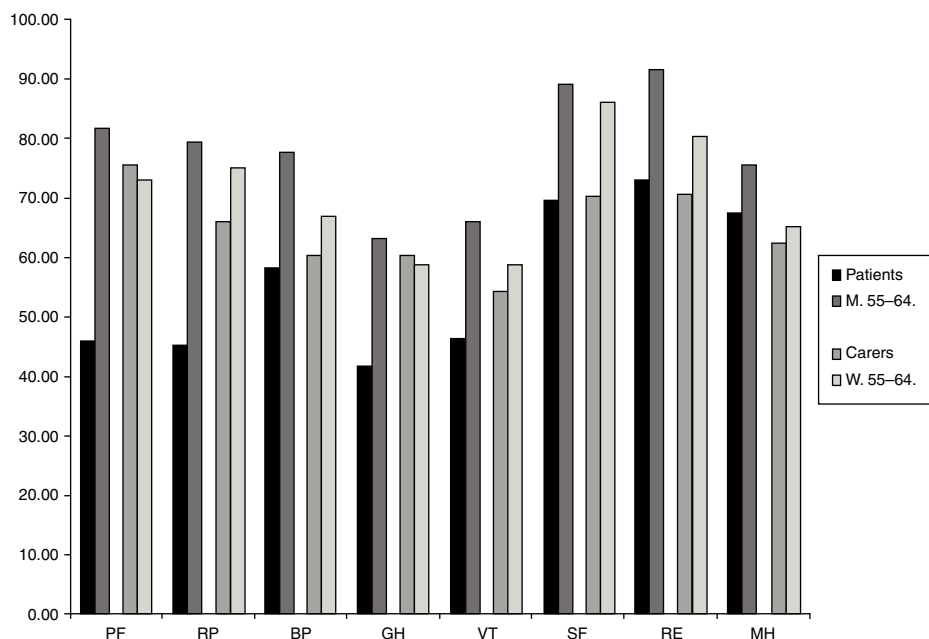
Mini-Mental State Examination than those from centres 5 and 8 (Bonferroni:  $p = 0.011$ ).

On the Karnofsky scale, the median score was 60 and the average score was 63.67%, corresponding to the need for occasional help. The ANOVA by centres showed significant differences between centre 3 and centre 8 (post hoc, Bonferroni:  $p = 0.002$ ).

On the Lawton–Brody scale, the average score using the instrument's own system showed moderate dependence, and light-to-moderate dependence using our alternative system. The reliability of this scale was good (Cronbach's  $\alpha$  0.760) with the instrument's own system, and somewhat better (Cronbach's  $\alpha$  0.835) with our alternative system.

The health status of carers (SF-36) was better than that of patients in terms of physical function ( $p < 0.001$ ), physical role ( $p < 0.001$ ), general health ( $p < 0.001$ ) and vitality ( $p = 0.02$ ); there were no differences in bodily pain, social functioning, emotional role and mental health (Fig. 1).

The health of the patients (mostly men) was significantly worse than that of men in the general population aged between 55 and 64<sup>43</sup> in all dimensions ( $p < 0.001$ ). The carers (mostly women) showed worse health status in terms of their physical role ( $p = 0.023$ ), bodily pain ( $p = 0.036$ ), social functioning ( $p < 0.001$ ) and emotional role ( $p = 0.011$ ) than women in the general population aged between 55 and 64<sup>43</sup> (Fig. 1).



**Fig. 1 – SF-36 Health Questionnaire.** The statistical evaluation is given in the text. BP: bodily pain; ER: emotional role; GH: general health; M. 55–64: general population of men aged between 55 and 64 years; MH: mental health; PF: physical functioning; PR: physical role; SF: social functioning; VT: vitality; W. 55–64: general population of women aged between 55 and 64 years.

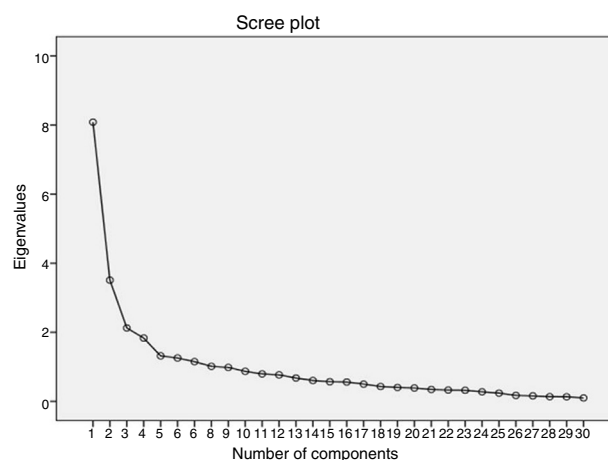
#### Overload Questionnaire for Carers of Patients on Peritoneal Dialysis

The results of the CSCDP, and the wide range between minimum and maximum scores, are shown in Table 2. The reliability of the questionnaire was excellent, with high internal consistency (Cronbach's  $\alpha$ ) in each dimension: dependence ( $\alpha$  0.808), subjective overload ( $\alpha$  0.812), objective overload ( $\alpha$  0.868) and total score ( $\alpha$  0.887).

Factor analysis initially showed 8 factors with an eigenvalue greater than 1, which explained the 67.6% of total variance. On the basis of the Scree plot (Fig. 2) we chose the first 3 factors which explained the 45.7% of variance (Table 3). Component 1 showed high factorial loading on objective overload items (items 21–30;  $r=0.417$ – $0.811$ ) and on 8 of the 12 items of the subjective overload dimension of the CSCDP ( $r=0.264$ – $0.644$ ). Component 2 only showed high factorial loading on items of the dependency dimension (items 1–8) of the CSCDP ( $r=0.350$ – $0.799$ ). Component 3 showed high factorial loading on 5 items of the subjective overload dimension ( $r=0.497$ – $0.745$ ).

#### Zarit Burden Interview

The ZBI showed a median of 22 and an average of  $25.51 \pm 16.08$  points, which indicates a slight-to-moderate overload on average among carers, with a wide range between minimum and maximum scores (0–71) (Table 2). Carers with overload: (1) slight or no overload (0–20): 48 (44.9%) carers; (2) mild to moderate (21–40): 39 (36.4%) carers; (3) moderate to severe (41–60): 17 (15.9%) carers, and (4) severe (61 or more): 3 (2.8%) carers. The reliability of the scale was excellent (Cronbach's  $\alpha$  0.901).



**Figure 2 – Scree plot of the main components of the Overload Questionnaire for Carers of Patients on Peritoneal Dialysis.**

Exploratory factor analysis of the principal components using the Kaiser KMO test (0.873) and the Bartlett sphericity test ( $\chi^2=1035.22$ ;  $p<0.001$ ) showed that the data were adequate for the purpose. The first 3 components explained 53.32% of the total variance, and the Scree plot showed that these were the most relevant (Table 4) and were therefore compared with the components of the CSCDP.

**Table 3 – Rotated component matrix of the Overload Questionnaire for Carers of Patients on Peritoneal Dialysis.**

Items <sup>a</sup>	Component		
	1	2	3
OLdep1		0.522	
OLdep2		0.790	
OLdep3		0.610	
OLdep4		0.799	
OLdep5		0.671	
OLdep6		0.749	
OLdep7		0.711	
OLdep8		0.350	
OLsubj9	0.549		
OLsubj10	0.428		
OLsubj11	0.615		
OLsubj12			0.596
OLsubj13			0.731
OLsubj14	0.399		
OLsubj15	0.644		
OLsubj16	0.509		0.497
OLsubj17			0.745
OLsubj18	0.264		
OLsubj19			0.537
OLsubj20	0.598		
OLobj21	0.576		
OLobj22	0.544		
OLobj23	0.729		
OLobj24	0.803		
OLobj25	0.811		
OLobj26	0.521		
OLobj27	0.672		
OLobj28	0.417		
OLobj29	0.798		
OLobj30	0.651		

<sup>a</sup> CSCDP items: OLdep: dependency overload; OLsubj: subjective overload; OObj: objective overload.

**Table 4 – Zarit Carer Overload Scale component matrix.**

Items	Component		
	1	2	3
9	0.687		
21	0.670		
16	0.659		
17	0.653		
8	0.643		
3	0.610		
18	0.607		
4	0.569		
15	0.560		
5	0.499		
1	0.354		
13		0.834	
7		0.700	
6		0.628	
10		0.622	
14		0.578	
2		0.574	
11		0.540	
12		0.496	
20			0.858
19			0.826

### Correlation between the Overload Questionnaire for Carers of Patients on Peritoneal Dialysis and the Zarit Burden Interview

The Pearson correlation test showed that ZBI scores correlated well with the total score of the questionnaire ( $r=0.683$ ), the subjective overload ( $r=0.602$ ) and objective overload ( $r=0.631$ ), and poorly with patient dependence ( $r=0.308$ ), with a high level of statistical significance in all correlations ( $p<0.001$ ).

In the exploratory factor analysis of principal components, component 1 of the ZBI showed poor correlation with the CSCDP dependence dimension ( $r=0.276$ ;  $p=0.004$ ) and good correlation with the subjective overload ( $r=0.619$ ;  $p<0.001$ ) and objective overload ( $r=0.599$ ;  $p<0.001$ ) dimensions. Similarly, component 2 of the ZBI showed poor correlation with the CSCDP dependence dimension ( $r=0.320$ ;  $p=0.001$ ) and good correlation with the subjective overload ( $r=0.505$ ;  $p<0.001$ ) and objective overload ( $r=0.603$ ;  $p<0.001$ ) dimensions. In contrast, component 3 of the ZBI showed no correlation with the CSCDP dimensions.

ZBI results were reduced to 3 levels for the purpose of correspondence analysis, grouping 3 and 4 into 3, as moderate and severe overload. The CSCDP dimensions were divided into tertiles. Correspondence between the 3 grouped levels of the ZBI and the tertiles of the CSCDP score was acceptable with the total score (Kendall's  $\tau$ -b 0.570), the objective overload (Kendall's  $\tau$ -b 0.650) and subjective overload (Kendall's  $\tau$ -b 0.450) dimensions, and poor with the dependence dimension (Kendall's  $\tau$ -b 0.247) (all with  $p<0.004$ ) (Table 5).

### Correlation between the SF-36 health survey and the Overload Questionnaire for Carers of Patients on Peritoneal Dialysis

In all the dimensions of the SF-36, the health status of patients showed significant inverse correlations ( $r=-0.213$  to  $-0.636$ ;  $p<0.030$ ) with the dependence dimension of the CSCDP, but no correlation with the carer subjective or objective overload dimensions. The health status of carers showed no correlation with the CSCDP dependency dimension, but significant inverse correlations were observed ( $r=-0.208$  to  $-0.416$ ;  $p<0.036$ ) between almost all dimensions of the SF-36 and the CSCDP subjective and objective overload dimensions.

### Comparisons

In the ZBI and the CSCDP, no significant difference was observed between carers of patients treated with continuous ambulatory PD or with automated PD (cyclers), or between carers who do or do not work outside the home. The carers of patients who needed help to perform PD had significantly higher scores in dependence ( $19.02 \pm 7.20$  vs.  $9.20 \pm 5.11$ ;  $p<0.001$ ) and total scores ( $43.11 \pm 18.87$  vs.  $29.50 \pm 13.98$ ;  $p<0.001$ ), but not in carer subjective or objective overload.

On the ZBI test, carers who had been caring for the patient for more than 2 years scored significantly higher than those who had been caring for less than 2 years ( $30.95 \pm 16.65$  vs.

**Table 5 – Correspondence between the Overload Questionnaire for Carers of Patients on Peritoneal Dialysis and the Zarit Burden Interview.**

Overload Questionnaire for Carers of Patients on Peritoneal Dialysis	Zarit Carer Overload Scale			Total rows
	No overload or slight overload	Mild to moderate overload	Moderate to severe overload	
Tertile 1	27	8	0	35
Tertile 2	18	15	3	36
Tertile 3	3	16	17	36
Total columns	48	39	20	107

Data presented as number of cases per cell.  
Statistical test: Kendall's  $\tau$ -b: 0.570;  $p < 0.001$ .

**Table 6 – Percentiles of the Overload Questionnaire for Carers of Patients on Peritoneal Dialysis.**

	TOTDEP	TOTSUBJ	TOTOBJEC	TOTAL.CSCDP	
N	Valid	107	107	107	107
	Missing	0	0	0	0
Percentiles	10	5.00	1.00	3.00	16.00
	20	7.00	3.60	5.00	22.00
	30	9.00	5.00	6.00	24.00
	40	11.00	6.00	8.00	32.00
	50	13.00	9.00	11.00	34.00
	60	16.00	10.00	13.80	37.80
	70	18.00	11.00	16.00	44.00
	80	23.00	15.00	21.40	52.00
	90	27.00	20.40	26.20	61.20

TOTAL.CSCDP: total questionnaire score; TOTDEP: dependency; TOTOBJEC: objective overload; TOTSUBJ: subjective overload.  
Table populated with the questionnaire scores. Items rated from 0 to 4.

22.27  $\pm$  14.92;  $p < 0.008$ ), whereas in the CSCDP this difference was not statistically significant ( $p = 0.069$ ).

### Explanatory variables

The multiple linear regression analysis showed that the Lawton-Brody scale was a significant explanatory variable for dependence, subjective, objective and total overload, and also for the ZBI. The Karnofsky scale was significant for dependence.

Sample data were used to construct the percentiles of each CSCDP dimension (Table 6) and cut-off points were established for the 3 degrees of CSCDP overload determined by tertiles (Table 7).

## Discussion

This study, carried out on 107 PD patients and their carers, confirms the results obtained in our previous paper in

which the CSCDP was developed.<sup>24</sup> It shows that the scale has excellent reliability and good validity, and can determine the rating scales and cut-off points for different degrees of carer overload. The sample of patients obtained from 8 hospitals with ongoing PD programmes supports the value of our results.

Carmona Moriel et al.<sup>22</sup> applied our questionnaire to 18 carers of PD patients using a 1–5 rating scale. They reported an average overload score of 41.89  $\pm$  14.93; if we had scored the items from 1 to 5, we would have obtained a similar average of 44.27  $\pm$  14.35 points for overload. These results indicate that the CSCDP obtains similar results in an independent sample.

The reliability of the questionnaire is confirmed, insofar as in the high internal consistency of the 3 definitive dimensions used in the first validation study<sup>24</sup> (Cronbach's  $\alpha$  0.86–0.89) has been reproduced in this new sample (Cronbach's  $\alpha$  0.887). Similarly, the acceptable results of the limited test-retest reported in our previous study shows the stability of the questionnaire over time.

**Table 7 – Cut-off points for 3 overload levels of the Overload Questionnaire for Carers of Patients on Peritoneal Dialysis.**

Degree of overload	Degree of dependency	Subjective overload	Objective overload	Total questionnaire
Slight or none	1–9	1–5	1–7	1–25
Mild to moderate	10–17	6–11	8–15	26–40
Moderate to severe	18 or more	12 or more	16 or more	41 or more

Based on the questionnaire score. Each item rated from 0 to 4.

Content validity was already evaluated by our group during development of the questionnaire by eliminating items that were not consistent with the purpose of the questionnaire.<sup>24</sup>

The exploratory factor analysis of the main components of the CSCDP reveals some interesting information with regard to construct validity. Component 2 correlates solely with patient dependency items, while component 1 correlates with all the objective or repercussion overload items, which is consistent with the design of the questionnaire. In contrast, subjective overload correlates with components 1 and 3, suggesting that some items in this dimension are perceived by the carers as an objective overload or as something with repercussions on their life, while the items that correlate with component 3 should relate to the carer's personal perception of caring for or helping the patient. Either way, the 2 overload dimensions measure the carer's perception of their relationship with the patient in respect of aspects that impact on the life and on the most personal feelings of the carer, which we conceive as overload. Moreover, the dependency dimension is well delimited and differentiated from the other 2 dimensions, all of which confirms the construct validity of the questionnaire.

To test the criterion validity, we compared the CSCDP with two similar questionnaires: the ZBI<sup>29,30</sup> and the SF-36.<sup>28</sup>

The ZBI, widely used internationally<sup>33-37</sup> and translated and validated in Spanish,<sup>31,32</sup> consists of 22 items to evaluate the carer's overload. Items are rated from 0 to 4 in the English versions and in some Spanish versions<sup>13,22,32</sup> and from 1 to 5 in other Spanish versions, including the validated version.<sup>31,32</sup> The results of this scale vary considerably, depending on the rating system used and the population studied.

The score awarded to the items (0-4 or 1-5) will determine the cut-off points for different degrees of overload. The version in English and languages other than Spanish, with 22 items and a rating scale of 0-4, considers 4 levels of overload (see the methods section), but is only an approximation, since the results vary greatly depending on the population studied or the patients' diseases.<sup>17,34,37</sup> In the validated Spanish version with a 1 to 5 rating scale, 3 degrees of overload were determined with 2 cut-off points: no overload-slight overload 46/47, mild overload-severe overload 55/56.<sup>31</sup> In a subsequent study, the cut-off points were re-set to 56/57 and 59/60, respectively, relative to a general health status questionnaire.<sup>32</sup> Most Spanish studies, even those using the 0-4 rating scale<sup>22,38</sup> or the 21-item ZBI<sup>44</sup> use this classification; the resulting confusion has been described by Álvarez et al.<sup>45</sup>

It is interesting to note that studies published in English have reported the wide range of mean scores, from 22.40 to 39.10, obtained when applying the ZBI in diseases such as cancer, dementia and acquired brain injury.<sup>34,46</sup> Likewise, in studies on carers of patients with PD, or PD vs. HD, the average scores range from 20.4 to 43.75, with no significant differences between the 2 treatments,<sup>2,13,14,37</sup> although a Japanese study reported surprisingly low scores of between 12.5 and 14.1 points in PD.<sup>39</sup>

In our subjects, the ZBI and CSCDP showed good correlation ( $r = 0.683$ ). This was confirmed in the overload dimensions, and is further evidence of criterion validity. Carmona Moriel et al. confirmed the very good correlation ( $r = 0.875$ ;  $p = 0.000$ ) between both questionnaires administered in the same visit.<sup>22</sup> In our study, however, they were separated by at least 15 days,

and were not administered in the same order, which may explain in part the different degree of correlation. This good correlation confirms the criterion validity of the CSCDP.

The analysis of correspondence between the 3 (grouped) levels of overload of the ZBI and the tertiles of the CSCDP shows acceptable, though not excellent, levels of correspondence (Kendall's  $\tau$ - $b$  0.570;  $p < 0.001$ ). This could be due to several factors: (1) changes in the carer's perception of overload in the time elapsed between the 2 questionnaires; however, the conditions that can lead to overload in the PD carer do not change in that 15-30 day period, so any perceived change would be minor; (2) the established degrees of overload do not correspond entirely; (3) the 2 instruments do not measure the same type of overload; for example, the dependency dimension of the CSCDP has very little correlation with the ZBI, and the exploratory factor analysis of the main components of the ZBI shows that 1 of the first 3 has no correlation at all with the CSCDP. When different scales measure different types of overload, this can affect the correspondence between different degrees used in the scales, and highlights the need to use questionnaires designed specifically for PD.

### The SF-36 Health Questionnaire

Unsurprisingly, the patients' perceived physical functioning, physical role, general health and vitality was worse than their carers, a finding also reported by other authors.<sup>1,39</sup> In addition, the health status of our patients was significantly worse in all dimensions than in the corresponding population group.<sup>43</sup> In contrast, carers (mostly women) scored worse in physical role, bodily pain, social functioning and emotional role than the corresponding population group.<sup>43</sup>

It is striking that in the CSCDP, dependency only correlated with the patients' health but not with the carers' overload, while the carers' subjective and objective overload correlated significantly with the health of the carers themselves - a correlation already reported by other authors.<sup>13,37</sup> In addition, in the CSCDP, carers of patients who needed help to perform PD and who, therefore, are more dependent scored higher in dependency, but not in subjective or objective overload. This means that, as shown in our previous study,<sup>24</sup> carers perceive the patient's health problems and dependency, including performing the PD, to be separate from their overload which, in contrast, they perceive as being affected by their own state of health.

### Scales

Table 7 shows the cut-off points for the 3 levels of dependency and overload in CSCDP scores (0-4 rating scale), based on their correspondence with the ZBI classification. Although these rating scales have not been finalised, they can already be used in clinical practice.

Overload among the carers of patients with various diseases has led to the introduction of respite programmes. Although these programmes are highly rated by carers, they provide little solid evidence, and further studies with better defined objectives are needed before firm conclusions can be drawn.<sup>8-12</sup>



### Limitations of the study

Unlike other studies on specific diseases, we did not determine cut-off points for depression or other borderline situations of carers.<sup>35</sup> Such data would be important when planning respite programmes for overburdened carers.

In summary, this study has re-confirmed the internal consistency reliability of the CSCDP. Factor analysis has shown the questionnaire to have good construct validity and good correlation, using the ZBI as a benchmark of general carer overload. This corroborates the criterion validity of the questionnaire.

The correspondence between the degrees of overload measured in these 2 instruments was only good or acceptable. This suggests that they do not measure the same type or intensity of overload, and could support the effectiveness of the questionnaire as a specific instrument for this patient population.

We found mild to moderate degrees of overload in our sample, with quite a wide range of scores. This is largely consistent with studies on general carer overload, and on dialysis carers.

The rating scale questions of the CSCDP can be used in clinical practice to differentiate the degrees of dependence or overload presented by carers of PD patients.

### Conflicts of interest

The authors declare that they have no conflicts of interest concerning the preparation and publication of this article.

### Acknowledgements

For their contribution, which was necessary to carry out the study: C. Bermúdez, Ana Rodríguez Carmona, Miguel Pérez Fontan, from H. Juan Canalejo, A Coruña; Dolores Carreras, Mercé Borrás, from H. Arnau de Vilanova, Lleida; Olga Celadilla, Gloria del Peso, Auxiliadora Bajo, Rafael Selgas, from H. La Paz, Madrid; Paquita Gruart, Maria Teresa Gonzalez, from H. de Bellvitge, L'Hospitalet de Llobregat; Conchita Blasco, Esther Ponz, from Consorci Hospitalari del Parc Taulí, Sabadell; Ester Vilaplana, from H. de la Vall d'Hebron, Barcelona; Antonio Morey, from H. Son Dureta, Palma de Mallorca.

### REFERENCES

1. Fan SL, Sathick I, McKitty K, Punzalan S. Quality of life of caregivers and patients on peritoneal dialysis. *Nephrol Dial Transplant*. 2008;23:1713-9, <http://dx.doi.org/10.1093/ndt/gfm830>. PMID: 18182410.
2. Griva K, Goh CS, Kang WC, Yu ZL, Chan MC, Wu SY, et al. Quality of life and emotional distress in patients and burden in caregivers: A comparison between assisted peritoneal dialysis and self-care peritoneal dialysis. *Qual Life Res*. 2016;25:373-84, <http://dx.doi.org/10.1007/s11136-015-1074-8>. PMID: 26195319.
3. De Bruin SR, Versnel N, Lemmens LC, Molema CC, Schellevis FG, Nijpels G, et al. Comprehensive care programs for patients with multiple chronic conditions: a systematic literature review. *Health Policy*. 2012;107:108-45, <http://dx.doi.org/10.1016/j.healthpol.2012.06.006>. PMID: 22884086.
4. Horsburgh ME, Laing GP, Beanlands HJ, Meng AX, Harwood L. A new measure of 'lay' care-giver activities. *Kidney Int*. 2008;74:230-6, <http://dx.doi.org/10.1038/ki.2008.163>. PMID: 18463611.
5. Carretero S, Garcés J, Ródenas F, Sanjosé V. The informal caregiver's burden of dependent people: theory and empirical review. *Arch Gerontol Geriatr*. 2009;49:74-9, <http://dx.doi.org/10.1016/j.archger.2008.05.004>. PMID: 18597866.
6. Zegwaard MI, Aartsen MJ, Cuijpers P, Grypdonck MH. Review: a conceptual model of perceived burden of informal caregivers for older persons with a severe functional psychiatric syndrome and concomitant problematic behaviour. *J Clin Nurs*. 2011;20:2233-58, <http://dx.doi.org/10.1111/j.1365-2702.2010.03524.x>. PMID: 21332854.
7. Wolfs CA, Kessels A, Severens JL, Brouwer W, de Vugt ME, Werhey FR, et al. Predictive factors for the objective burden of informal care in people with dementia: a systematic review. *Alzheimer Dis Assoc Disord*. 2012;26:197-204. PMID: 22075941.
8. Mason A, Weatherly H, Spilsbury K, Arksey H, Golder S, Adamson J, et al. A systematic review of the effectiveness and cost-effectiveness of different models of community-based respite care for frail older people and their carers. *Health Technol Assess*. 2007;11:1-157, iii. PMID: 17459263.
9. Garcés J, Carretero S, Ródenas F, Alemán C. A review of programs to alleviate the burden of informal caregivers of dependent persons. *Arch Gerontol Geriatr*. 2010;50:254-9, <http://dx.doi.org/10.1016/j.archger.2009.04.012>. PMID: 19481274.
10. Smits CH, de Lange J, Dröes RM, Meiland F, Vernooij-Dassen M, Pot AM. Effects of combined intervention programmes for people with dementia living at home and their caregivers: a systematic review. *Int J Geriatr Psychiatry*. 2007;22:1181-93. PMID: 17457793.
11. Zabalegui Yáñez A, Navarro Díez M, Cabrera Torres E, Gallart Fernández-Puebla A, Bardallo Porras D, Rodríguez Higuera E, et al. Eficacia de las intervenciones dirigidas a cuidadores principales de personas dependientes mayores de 65 años. Una revisión sistemática. *Rev Esp Geriatr Gerontol*. 2008;43:157-66. PMID: 18682133.
12. Tong A, Sainsbury P, Craig JC. Support interventions for caregivers of people with chronic kidney disease: a systematic review. *Nephrol Dial Transplant*. 2008;23:3960-5, <http://dx.doi.org/10.1093/ndt/gfn415>. PMID: 18658178.
13. Alvarez-Ude F, Valdés C, Estébanez C, Rebollo P, FAMIDIAL Study Group. Health-related quality of life of family caregivers of dialysis patients. *J Nephrol*. 2004;17:841-50. PMID: 15593060.
14. Belasco A, Barbosa D, Bettencourt AR, Diccini S, Sesso R. Quality of life of family caregivers of elderly patients on hemodialysis and peritoneal dialysis. *Am J Kidney Dis*. 2006;48:955-63. PMID: 17162150.
15. Suri RS, Larive B, Garg AX, Hall YN, Pierratos A, et al., FHN Study Group. Burden on caregivers as perceived by hemodialysis patients in the Frequent Hemodialysis Network (FHN) trials. *Nephrol Dial Transplant*. 2011;26:2316-22, <http://dx.doi.org/10.1093/ndt/gfr007>. PMID: 21421590.
16. Avsar U, Avsar UZ, Cansever Z, Set T, Cankaya E, Kaya A, et al. Psychological and emotional status, and caregiver burden in caregivers of patients with peritoneal dialysis compared with caregivers of patients with renal transplantation. *Transplant Proc*. 2013;45:883-6, <http://dx.doi.org/10.1016/j.transproceed.2013.03.004>. PMID: 23622578.
17. Cantekin I, Kavurmacı M, Tan M. An analysis of caregiver burden of patients with hemodialysis and peritoneal dialysis. *Hemodial Int*. 2016;20:94-7, <http://dx.doi.org/10.1111/hdi.12311>. PMID: 26549410.
18. Arechabala MC, Catoni MI, Palma E, Barrios S. Depresión y auto percepción de la carga del cuidado en pacientes en

- hemodiálisis y sus cuidadores. *Rev Panam Salud Publica*. 2011;30:74-9. PMID: 22159654.
19. Daneker B, Kimmel PL, Ranich T, Peterson RA. Depression and marital dissatisfaction in patients with end-stage renal disease and in their spouses. *Am J Kidney Dis*. 2001;38:839-46. PMID: 11576888.
  20. Suri RS, Larive B, Hall Y, Kimmel PL, Kliger AS, et al., Frequent Hemodialysis Network (FHN) Trial Group. Effects of frequent hemodialysis on perceived caregiver burden in the Frequent Hemodialysis Network trials. *Clin J Am Soc Nephrol*. 2014;9:936-42, <http://dx.doi.org/10.2215/CJN.07170713>. PMID: 24721892.
  21. Jones C, Edwards RT, Hounsborne B. Health economics research into supporting carers of people with dementia: a systematic review of outcome measures. *Health Qual Life Outcomes*. 2012;10:142, <http://dx.doi.org/10.1186/1477-7525-10-142>. PMID: 23181515.
  22. Carmona Romier CE, Nolasco Monterroso C, Navas Santos L, Caballero Romero J, Morales Medina P. Análisis de la sobrecarga del cuidador del paciente en diálisis peritoneal. *Enferm Nefrol*. 2015;18:180-8, <http://dx.doi.org/10.4321/S2254-28842015000300006>.
  23. Lopez Leon D, Rodrigues Calderon L, Carreño Moreno S, Cuenca I, Chaparro Diaz L. Cuidadores de pacientes en diálisis peritoneal: experiencia de participar en un programa de habilidad de cuidado. *Enferm Nefrol*. 2015;18:189-95, <http://dx.doi.org/10.4321/S2254-28842015000300007>.
  24. Teixidó J, Tarrats L, Arias N, Coscolluela A. Cuestionario de sobrecarga de cuidadores de pacientes de diálisis peritoneal. *Nefrologia*. 2006;26:74-83. PMID: 16649428.
  25. Prieto G, Delgado AR. Fiabilidad y validez. *Papeles del Psicólogo*. 2010;31:67-74. Available at: <http://www.papelesdelpsicologo.es/pdf/1797.pdf>
  26. Meneses J, Barrios M, Bonillo A, Coscolluela A, Lozano LM, Tubany J, et al. *Psicometría*. Barcelona: UOC; 2013. Available at: [https://www.researchgate.net/profile/Julio\\_Meneses/publication/293121344\\_Psicometria/links/584a694408ae5038263d9532/Psicometria.pdf](https://www.researchgate.net/profile/Julio_Meneses/publication/293121344_Psicometria/links/584a694408ae5038263d9532/Psicometria.pdf)
  27. Martín-Arribas MC. Diseño y validación de cuestionarios. *Matronas Profesión*. 2004;5:23-9. Available at: [www.enferpro.com/documentos/validacion.cuestionarios.pdf](http://www.enferpro.com/documentos/validacion.cuestionarios.pdf)
  28. Alonso J, Prieto L, Antó JM. La versión española del SF-36 Health Survey (Cuestionario de Salud SF-36): un instrumento para la medida de los resultados clínicos. *Med Clin (Barc)*. 1995;104:771-6. PMID: 7783470.
  29. Zarit SH, Orr NK, Zarit JM. The hidden victims of Alzheimer's disease. New York: New York University Press; 1985. p. 69-86.
  30. Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist*. 1980;20:649-55. PMID: 7203086.
  31. Martín M, Salvado I, Nadal S, Miji LC, Rico JM, Lanz P., et al. Adaptación para nuestro medio de la escala de sobrecarga del cuidador (Caregiver Burden Interview) de Zarit. *Rev Gerontol*. 1996;6:338-46.
  32. Martín-Carrasco M, Otermin P, Pérez-Camo V, Pujol J, Agüera L, Ballesteros-Rodríguez J, EDUCA study: psychometric properties of the Spanish version of the Zarit Caregiver Burden Scale. *Aging Ment Health*. 2010;14:705-11, <http://dx.doi.org/10.1080/13607860903586094>. PMID: 20544413.
  33. Martín-Carrasco M, Domínguez-Panchón AI, Muñoz-Hermoso P, González-Fraile E, Ballesteros-Rodríguez J. Instrumentos para medir la sobrecarga en el cuidador informal del paciente con demencia. *Rev Esp Geriatr Gerontol*. 2013;48:276-84, <http://dx.doi.org/10.1016/j.regg.2013.06.002>. PMID: 24161356.
  34. Hébert R, Bravo G, Préville M. Reliability, validity and reference values of the Zarit Burden Interview for assessing informal caregivers of community-dwelling older persons with dementia. *Can J Aging*. 2000;19:494-507, <http://dx.doi.org/10.1017/S0714980800012484>.
  35. Schreiner AS, Morimoto T, Arai Y, Zarit S. Assessing family caregiver's mental health using a statistically derived cut-off score for the Zarit Burden Interview. *Aging Ment Health*. 2006;10:107-11. PMID: 16517485.
  36. Van Durme T, Macq J, Jeanmart C, Gobert M. Tools for measuring the impact of informal caregiving of the elderly: a literature review. *Int J Nurs Stud*. 2012;49:490-504, <http://dx.doi.org/10.1016/j.ijnurstu.2011.10.011>. PMID: 22078211.
  37. Wicks MN, Milstead EJ, Hathaway DK, Cetingok M. Subjective burden and quality of life in family caregivers of patients with end stage renal disease. *ANNA J*. 1997;24:527-8, 531-8; discussion 539-40. PMID: 9392735.
  38. Romero Massa E, Rodríguez Castilla J, Pereira Díaz B. Sobrecarga y calidad de vida percibida en cuidadores familiares de pacientes renales. *Rev Cubana Enferm*. 2015;31. Available at: <http://www.revenfermeria.sld.cu/index.php/enf/article/view/299/134>
  39. Shimoyama S, Hiraoka O, Yahiro K, Mizumachi T, Schreiner A, Kakuma T. Health-related quality of life and caregiver burden among peritoneal dialysis patients and their family caregivers in Japan. *Perit Dial Int*. 2003;23 Suppl. 2:S200-5. PMID: 17986549.
  40. Lobo A, Ezquerro J, Gómez Burgada F, Sala JM, Seva Díaz A. El Minixamen Cognoscitivo (un «test» sencillo, práctico, para detectar alteraciones intelectuales en pacientes médicos). *Actas Luso Esp Neurol Psiquiatr Cienc Afines*. 1979;7:189-202. PMID: 474231.
  41. Karnofsky DA, Abelmann WH, Craver LF, Burchenal JH. The use of the nitrogen mustards in the palliative treatment of carcinoma. With particular reference to bronchogenic carcinoma. *Cancer*. 1948;1:634-56. Available at: [https://doi.org/10.1002/1097-0142\(194811\)1:4<634::AID-CNCR2820010410>3.0.CO;2-L](https://doi.org/10.1002/1097-0142(194811)1:4<634::AID-CNCR2820010410>3.0.CO;2-L)
  42. Lawton MP, Brody EM. Assessment of older people: self-maintaining and instrumental activities of daily living. *Gerontologist*. 1969;9:179-86. PMID: 5349366.
  43. Alonso J, Regidor E, Barrio G, Prieto L, Rodríguez C, de la Fuente L. Valores poblacionales de referencia de la versión española del Cuestionario de Salud SF-36. *Med Clin (Barc)*. 1998;111:410-6. PMID: 9834913.
  44. Espin Andrade AM. Factores de riesgo de carga en cuidadores informales de adultos Mayres con demencia. *Rev Cubana Salud Publica*. 2012;38:393-402. Available at: <http://www.redalyc.org/articulo.oa?id=21423096006>
  45. Álvarez L, González AM, Muñoz P. El cuestionario de sobrecarga del cuidador de Zarit. Cómo administrarlo e interpretarlo. *Gac Sanit*. 2008;22:618-9. PMID: 19080943.
  46. Higginson IJ, Gao W, Jackson D, Murray J, Harding R. Short-form Zarit Caregiver Burden Interviews were valid in advanced conditions. *J Clin Epidemiol*. 2010;63:535-42, <http://dx.doi.org/10.1016/j.jclinepi.2009.06.014>. PMID: 19836205.