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Caregiver burden of Mexican dementia patients: The role of dysexecutive syndrome, sleep disorders, schooling and caregiver depression

Óscar Rosas-Carrasco,¹ María de Guadalupe Guerra-Silla,² Laura del Pilar Torres-Arreola,³ Carmen García-Peña,⁴ Cristopher Isaac Escamilla-Jiménez⁵ and César González-González¹

¹National Institute of Geriatrics, ²Geriatrics Clinic, Memory Clinic. National Institute of medical Science and Nutrition Salvador Zubirán, ³Coordination of High Specialty Medical Units, Clinical Excellence Department, Mexican Institute of Social Security, ⁴Epidemiological and Health Research Unit, Aging Division, National Medical Center Century XXI, Mexican Institute of Social Security, ⁵The National Institute of Neurology and Neurosurgery "Manuel Velasco Suárez". Faculty of Medicine of the National Autonomous University of Mexico, Mexico City, Mexico

Aims: As a result of the accelerated growth of the elderly population, reconfiguration of families and member roles, and the increase of mental disorders, it is necessary to investigate the effects of this set of factors on the caregivers of patients with dementia in Mexico. Mental disorders of individuals have a negative impact on their physical and emotional quality of life, leading to greater dependence and making the caring experience a heavy burden. Several studies (none in Mexico) have used either the characteristics of the patient or caregiver to determine the burden, but few studies have included both profiles within a single study. The objective of the present study was to analyze the characteristics of the patients and caregivers associated with caregiver burden.

Methods: A multicenter study was carried out in six health institutions located in Mexico City, including 175 patients (and their caregivers) diagnosed with different types of dementia. We used the Spanish Caregiver Burden Screen. Descriptive analysis and logistic regressions were used to estimate the effect of the covariates on the caregiver burden.

Results: The results showed that patient variables have a greater impact on caregiver burden than caregiver-associated variables. Dysexecutive syndrome, sleep disorders, schooling and caregiver depression are associated with a higher level of caregiver burden.

Conclusions: Caregiver burden is a complex phenomenon. The results of the present study showed the need to implement multifactorial interventions targeting the caregiver to reduce the burden, strengthen the skills for patient management to avoid depression, improve patient health, and diminish functional dependence and future hospitalization. *Geriatr Gerontol Int* 2014; 14: 146–152.

Keywords: caregiver burden, dementia, dysexecutive syndrome, elderly, neuropsychiatric symptoms.

Introduction

The prevalence of dementia in the Mexican population aged 60 years and older is estimated to be 7.5%.¹ Dementia is characterized by the deterioration of intellectual

functions, and is regularly associated with behavioral, mood, executive function and sleep disorders.²

These factors negatively impact the physical and emotional quality of life of patients. In addition, these factors contribute to greater dependence of the older adult on their immediate family members, making caregiving a heavy burden.^{3,4}

Relatives who take care of individuals with dementia often describe the experience as stressful and frustrating.⁵ This experience has been called caregiver burden and is defined as "a multidimensional response to physical, psychological, emotional, social and financial stressors usually associated with the experience of caring".⁶ This phenomenon occurs when the caring experience

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Correspondence: Dr César González-González PhD, Instituto Nacional de Geriatria, Secretaría de Salud, Periférico Sur no. 2767, Edificio "D", Colonia San Jerónimo Lídice Delegación Magdalena Contreras C.P. 10200, México, D.F. Mexico. Email: cesar.gonzalez@salud.gob.mx

and growing demands of patients with dementia compromise the caregiver beyond capability. Caregiver burden is influenced by several factors, including kinship, social environment and culture.⁷

Previous studies have found an association between caregiver burden and the patient's clinical condition. The presence of behavioral disturbances (e.g. aggression, agitation, apathy, dysphoria and aberrant motor behavior),⁸⁻¹⁰ depression,¹¹ functional dependence,¹² impaired executive functions¹³ and co-residence¹² are the most important stressors.

Caregiver burden has also been associated with caregiver-specific factors, including sex, the number of hours caring, family support network, relationship with the patient, patient communication, history of anxiety and depression, and health status.^{7,14-16}

Mexico is experiencing demographic changes that are extraordinary and intense. The aging population will be undoubtedly one of the most important population issues of the century. In the near future, the elderly will have fewer children and grandchildren to care for them, and this could lead to increased caregiver burden.

Despite this scenario in Mexico, little is known about caregiver burden and its main associated factors. Therefore, the objective of the present study was to explore the patient and caregiver factors associated with caregiver burden.

Methods

Participants

A cross-sectional study was designed to integrate primary caregivers and patients with dementia. The patients and selected caregivers were interviewed at their scheduled visits at six general hospitals from different health institutions located in Mexico City: Hospital General Ángeles Mocol, Hospital "Juárez" de México, Hospital Regional "Gabriel Mancera" Instituto Mexicano del Seguro Social (IMSS), Hospital Psiquiátrico "Fray Bernardino Álvarez" Instituto Nacional de Neurología and Instituto Nacional de Ciencias Médicas y Nutrición. The study took place from January 2007 to January 2010.

Patients aged 60 years and older with the following dementia types were included: Alzheimer's disease (AD), vascular, mixed, frontotemporal, Lewy bodies and Parkinson's-associated. Enrolled patients were required to be able to read and write. The caregiver was included if he/she was able to read and write, and was an unpaid person who knew more than the patient about the patient's environment and care most of the time.

The main exclusion criteria were as follows: (i) acute and/or exacerbated chronic disease that had been present within 30 days before the interview that could affect the quality of response to questionnaires, accord-

ing to the medical staff of the study; (ii) decreased alertness (for any cause); (iii) severe aphasia; (iv) visual and hearing impairment making it difficult for the patient/caregiver to fill out the questionnaires; (v) the presence of other neurological diseases that could have influenced the diagnosis of dementia; and (vi) institutionalization of the patient.

Variables

Patient variables

Dementia was classified by a group of geriatricians according to international clinical criteria for different types of dementia into one of the following categories: possible AD,¹⁷ possible vascular dementia (VD),¹⁸ mixed dementia,¹⁹ frontotemporal,²⁰ Lewy bodies and Parkinson's-associated dementia.²¹

Dysexecutive Questionnaire (DEX). The Dysexecutive Questionnaire (DEX) is a 20-item questionnaire that uses a Likert scale ranging from 0 to 4 points. The analysis of this study considered a total score range from 0 to 80. The DEX was answered by the caregiver (proxy).²²

Mini-Mental State Examination. The Mini-Mental State Examination (MMSE) instrument was used as an indicator of the degree of cognitive impairment of the patients. We used the version validated in the Mexican population.²³

Geriatric Depression Scale. The 15-item Geriatric Depression Scale was used to assess depression in centenarians and it has been validated in the Mexican population. Scores range from 0 to 15, and we used a cut-off of 6 or more points to establish depression.

Barthel Index. The Barthel Index consists of 10 items that measure a person's ability to independently carry out the basic activities of daily living (ADL). It has been validated in Spanish and was answered by the caregivers.²⁴

Lawton Scale. The Lawton scale was used to evaluate the individual's performance regarding the instrumental activities of daily living (IADL) and was answered by the caregivers. The Lawton IADL scale contains eight items that have a summary score from 0 (low function) to 8 (high function).²⁵

Neuropsychiatric Inventory. The Neuropsychiatric Inventory (NPI-D) is a 12-item inventory that has been validated for the Spanish population. The NPI was used to evaluate the presence of 12 neuropsychiatric symptoms in the first subscale. It was answered by the caregivers.²⁶

Patient comorbidities. This parameter was assessed with the Charlson Index. This scale includes a list of 19 diseases and their complications. Patient comorbidities were determined by caregiver interview and clinical record review.²⁷

Sleep Disturbances Inventory. The Sleep Disturbances Inventory (SDI) is an eight-item questionnaire that assesses sleep disturbances and other abnormal behavior at night. The analysis considered a total score range of 0 to 8.²⁸

In addition, the following sociodemographic and clinical characteristics were included: sex, age (years), schooling (years), marital status (with or without partner), number of medications and length of time patient suffered from dementia by the time of diagnosis (in years).

Using the number of hours per day and days per week of care, we generated an indicator to determine full-time caregiving, which was defined as taking care of the patient 7 days a week and 24 h a day.

Caregiver variables

Screen for Caregiver Burden scale. The Screen for Caregiver Burden scale (SCB) is a 25-item scale that was used because it has been adapted and validated for the Mexican population.⁴ For the analysis, the total score ranged from 0 to 100.

Beck's Inventory for Depression and Anxiety. To examine caregiver depression, the standardized 21-item Beck's Inventory for Depression and Anxiety (BDI) for Mexico City's residents was used (score range 0 to 63).²⁹ In addition, caregiver anxiety was measured with a 21-item instrument that has been validated for the Mexican population (score range 0 to 63).³⁰

In addition, other caregiver characteristics were considered, including sex, relationship with patient (spouse, children, other), marital status (with partner without partner), schooling (years), comorbidity (number of illnesses), number of medications, belonging to a support group and type of support that the caregiver provides (financial, moral, help with ADL and IADL).

Ethical aspects. The present study was a secondary analysis of the database corresponding to the project, Validation of the Quality of Life in Alzheimer's Disease (QOL-AD) scale in Mexican patients with dementia. This original project was approved by the Institutional Committee of Human Biomedical Research INCMNSZ (reference number: 1599) and the National Scientific Research Committee of the IMSS (approval number: 2006-785-065). All the patients and caregivers gave written informed consent.

Statistical analysis

Descriptive analysis was carried out using frequencies and percentages for qualitative variables, and means \pm SD for quantitative variables. To estimate the effect of covariates on caregiver burden, a bivariate analysis was carried out using simple linear regression. The variables

associated with the caregiver ($P < 0.05$) were included in a multivariate model using multiple linear regression. For this analysis, we used STATA Statistical Software release 11 (StataCorp, College Station, TX, USA).

Results

In total, 175 patients were included. Of these patients, 62 (35.4%) were diagnosed with AD, 54 (30.9) with vascular dementia, 45 (25.7%) with mixed dementia and 14 (8%) with another type of dementia (frontotemporal, Lewy bodies and Parkinson's-associated). The sociodemographic and general health characteristics of the patients are shown in Table 1.

Regarding caregiver characteristics, the mean age was 57 ± 13.3 years (range 21–89 years). Most of the caregivers were women 144 (82.3%), and 31 (17.7%) were men. The mean level of caregiver schooling was 12.4 ± 5.2 years. In addition, 26 (14.9%) of the caregivers affirmed that they had joined some type of dementia support group (Table 2).

The mean caregiving days per week was 6 ± 1.8 days, with 15.3 ± 8.6 caregiving hours per day (data not shown). A total of 91 of the caregivers (52.0%) were full-time caregivers. The mean number of family members that looked after patients was 1.3 ± 1.2 . In addition, for 142 (81.1%) of the patients, their caregivers did not earn wages, and just 33 (18.9%) of the admitted cases involved at least one wage-earning caregiver. The mean SCB score was 21.8 ± 16.1 (range 0–72; Table 2).

Regression models

The patient model indicates that education, more dys-executive alterations and sleep disorders were associated with higher caregiver burden. In the caregiver model, age was associated with lower caregiver burden; meanwhile, education, full-time caring and depression were significantly associated with higher caregiver burden.

As shown in Table 3, in the patient-caregiver model, we included both the patient and caregiver characteristics, and carried out a stepwise regression in order to find the most parsimonious set of predictors that are most effective in predicting the caregiver burden (i.e. a model that uses the minimum number of parameters without losing predictive power).

Patients with a worse dysexecutive syndrome, low schooling and sleep disorders were associated with caregiver burden. Depression was the only caregiver variable that remained associated with caregiver burden in this final model.

These results show that the patient variables had a stronger impact than caregiver variables on caregiver

Table 1 General characteristic of the dementia patients

Characteristics	Mean	SD	Range	n (%)
Age (years)	80.1	8.4	(59–101)	
Sex (female)				120 (68.6)
Marital status (% with partner)				78 (44.6)
Schooling (years)	7.4	5.3	(0–24)	
Comorbidity (Charlson Index)	4.1	2.1	(0–10)	
Type of dementia				
Alzheimer's				62 (35.4)
Vascular				54 (30.9)
Mixed				45 (25.7)
Other				14 (8.0)
MMSE total score	17.0	6.5	(2–30)	
DEX total score	27.3	18.5	(0–77)	
GDS total score	5.0	3.3	(0–15)	
ADL (Barthel) # alterations	74.4	29.1	(0–100)	
IADL (Lawton) # alterations	5.1	5.4	(0–16)	
# Neuropsychiatric Symptoms	6.2	3.2	(0–14)	
Sleep disorders	3.1	1.8	(0–8)	

ADL, Barthel's Activities of Daily Living scale; DEX, Dysexecutive Questionnaire; GDS, Geriatric Depression Scale; IADL, Lawton's Instrumental Activities Daily Living scale; MMSE, Mini-Mental State Examination; NPI-D, Neuropsychiatric Inventory (12-item); SDI, Sleep Disorders Inventory.

Table 2 General characteristics of the caregivers

Characteristics	Mean	SD	Range	n (%)
Age (years)	57.0	13.3	(21–89)	
Sex (female)				144 (82.3)
Marital Status (with partner)				115 (65.7)
Schooling (years)	12.4	5.2	(0–26)	
Comorbidity (# illnesses)	1.5	1.5	(0–6)	
Relationship with patient				
Spouse				47 (26.9)
Children				92 (52.6)
Other				36 (20.5)
Attend to a support group (%)				26 (14.9)
Number of supports to the patient	3.1	1.1	(1–5)	
Full time caregiver (yes)				91 (52.0)
Time caring (months)	55.7	45.1	(1–174)	
No. family members that support the caregiver	1.3	1.2	(0–6)	
SCB (total score)	21.8	16.1	(0–72)	
BDI (Beck scale) (total score)	9.4	7.4	(0–33)	
BAI (Beck scale) (total score)	9.8	8.5	(0–50)	

BDI, Beck's Depression scale; BAI, Beck's Anxiety scale; SCB, Screen Caregiver Burden.

burden. DEX remained associated with caregiver burden from the descriptive analysis through the final multivariate model; and overall, the set of independent variables explain almost the half (0.495) of the variance in the dependent variable.

Discussion

There is a known and strong relationship between social factors and patient and caregiver health that impacts on caregiver burden; therefore, the importance of a study

Table 3 Patients and caregiver factors by caregiver burden (total score Screen Caregiver Burden)

Characteristics	Patient	Caregiver	Patient-caregiver (stepwise model)
Age (years)	0.038	-0.205*	
Sex (female)	-0.926	-0.024	
With spouse or partner	-0.998	3.774	
Schooling (years)	0.547*	0.412*	0.433*
Comorbidity (Charlson total score)	0.784		
MMSE total score	-0.257		
Dysexecutive (DEX) total score	0.335***		0.293***
GDS (total score) depression	-0.284		
ADL (Barthel's total score)	0.017		
IADL (Lawton's total score)	-0.070		
Neuropsychiatric symptoms NPI-D	0.552		
Sleep disorders SDI	2.098***		1.861***
Comorbidity (# illnesses)		0.461	
Spouse		1.000	
Children		-0.271	
Other		3.091	
Attend a support group (%)		4.187	
Number of supports for the patient		1.768	
Full-time caregiver (yes)		5.502*	
Time caring (years)		-0.288	
No. family members that support caregiver		0.955	
BDI (Beck scale) (total score)		0.918***	0.796***
BAI (Beck scale) (total score)		0.341	

Patient-caregiver stepwise model: ($F = 43.14$, $P < 0.001$; $R^2 = 0.495$). Standardized beta weights (Beta). * $P < 0.05$, ** $P < 0.01$, *** $P < 0.001$. ADL, Barthel's Activities of Daily Living scale; BAI, Beck's Anxiety scale; BDI, Beck's Depression scale; DEX, Dysexecutive Questionnaire; GDS, Geriatric Depression Scale; IADL, Lawton's Instrumental Activities Daily Living scale; MMSE, Mini-Mental State Examination; NPI-D, Neuropsychiatric Inventory (12-item); SCB, Screen Caregiver Burden; SDI, Sleep Disorders Inventory.

including these characteristics for the Mexican population is undeniable. Our descriptive analysis emphasizes that most caregivers are women and also the patient's partner, which is similar to results in other papers.¹⁶

Some patient sociodemographic characteristics, such as marital status, health conditions, multiple comorbidities and type of dementia, did not impact on caregiver burden in our population. The impact of sociodemographic characteristics vanished when adverse health conditions were present.

It must be emphasized that 52% of the studied caregivers were full-time. This situation reinforces that the caregiving activity falls to only one family member, making it difficult for him/her to have another job, and obstructing his/her own personal needs,¹⁴ which thereby increases the caregiver burden.

Previous studies found that low education of the patient was associated with caregiver burden.³¹ However, in the present study, we found the opposite effect; higher education levels of the patient were associated with increased caregiver burden. Perhaps the higher education level in our population implies some specific behav-

iors that stress the caregiver (e.g. arguments, refusing to take medication, or questions).

A central point of the present study was that dysexecutive syndrome was characterized by a lack of initiative, incapability to plan and organize, thinking disturbances, and apathy and communication changes, among other signs.³² These signs promote more dependency of the patient on the caregiver, causing him/her frustration. The present results found a strong association between dysexecutive syndrome and caregiver burden, which concur with the findings from a few other studies.¹³

Neuropsychiatric symptoms were not associated with caregiver burden, which is not consistent with several previous studies.^{9,33} Perhaps in our population, the small sample size, the analysis of the total score of NPI-D and the inclusion of different types of dementia with different degrees of severity impacted on the distribution of the neuropsychiatric results.

The presence of sleep disorders in the patient, as collected by the SDI, was associated with the caregiver burden, which is consistent with previous reports that

the caregiver's sleep might be interrupted by patient sleep disorders, and often becomes a reason for patient institutionalization.³⁴

Caregiver depression is strongly related to burden by directly impacting caregiver wellbeing.^{35–37} According to the results of the present study, it is necessary to develop diagnostic and interventional strategies to improve the caregiver's emotional status to guarantee the satisfactory well-being of the patient-caregiver dyad.

In conclusion, the present results show that the caregiver burden of demented patients is a very complex phenomenon, and influenced by both the patient- and caregiver-related factors. Therefore, caregiver burden in these types of studies should be considered in the context of the patient-caregiver dyad (patient-caregiver). The healthcare system in Mexico should consider implementing multifactorial interventions that focus on the caregiver to diminish burden and strengthen patient treatment skills, thus avoiding depression and hospitalization, and improving functional dependency.

Disclosure statement

The authors declare no conflict of interest.

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