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Original Research

Burden and associated pathologies in family caregivers of Alzheimer's disease patients in Spain

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ABSTRACT*

Objectives: To evaluate the profile of family caregivers of Alzheimer's disease patients, identify any signs of psychopathology, quantify the level of perceived burden on the caregiver, and determine the caregiver's relationship with their pharmacist.

Methods: A cross-sectional study was conducted at a community pharmacy in Pontevedra, Spain. Demographic variables were collected, and the following questionnaires were administered: the Beck Depression Inventory-II, STAI-Anxiety Questionnaire, Zarit Burden Scale, family APGAR scale, and the Duke-UNC questionnaire.

Results: The typical caregiver profile consists of a 55-year old first degree relative (mostly daughters) with a primary education who belongs to a functional or mildly dysfunctional family. Nearly one quarter (24%) of caregivers had a high perception of burden, with anxiety in 20% of caregivers and symptoms of depression in 20%. Family caregivers usually went to the same pharmacy as the patients (96%), were treated with psychotropic drugs (68%), and interacted with the pharmacist (92%).

Conclusion: This study confirmed that psychological distress and burden is present among family caregivers. Care for caregivers should be integrated into patient care as part of a national plan, including grants and subsidies, which will result in better care of Alzheimer's patients. Pharmacists are the most accessible health care professionals and can provide information about Alzheimer's disease management to caregivers to ease the burden of care.

Keywords: Alzheimer Disease; Caregivers; Cost of Illness; Pharmacists; Professional Role; Spain

INTRODUCTION

Dementia is a syndrome that can be caused by a number of progressive disorders that affect memory, thinking, behavior, and the ability to perform everyday activities. As of 2013, there were an estimated 44.4 million people with dementia worldwide¹, with an estimated cost of 604 billion USD in 2010.² Alzheimer's disease (AD) is the most common type of dementia. The manner in which AD patients perceive their disease is variable and unpredictable. Thus, many patients are not aware of their symptoms and therefore have anosognosia, a clinical syndrome characterized by the loss of knowledge of their own physical and/or cognitive status, while others recognize their alterations.³ AD is a devastating disease with a slow onset but relentless progression that results in total patient dependence on their caregivers.

In Spain, as in other Mediterranean countries⁴, family caregivers play an essential role in caring for patients with AD.⁵ Given the high demands on caregivers of AD patients, they may experience physical, psychological, social, or financial consequences as a result of caregiving.^{6,7} Caregivers may also experience higher levels of depression and stress hormones, reduced immune function, slow wound healing, and new onset of hypertension and coronary artery disease compared to non-caregivers.⁸

Studies conducted in the past 20 years reveal that informal caregivers are exposed to stressful situations that increase the risk of many physical and emotional problems such as anxiety and depression.⁹

Many caregivers are unaware of the problems that they may face and therefore are unable to find solutions.¹⁰ Most family caregivers simply adapt to the new situation and undergo difficult phases that can seriously affect their physical and emotional health.^{11,12} If a solution to this situation is not found, the caregiver may suffer from high stress levels, which can reduce their ability to care for the AD patient.¹³

Several factors are associated with the onset of caregiver burden, including the social support available to the caregiver, AD patient's health, and the presence/absence of anosognosia, which are relevant for caregivers and the support team.³ Apparently, depressive symptoms tend to appear when patients are able to perceive and interpret

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their own deficits as a result of disease progression.³

Family caregivers may benefit from learning methods to develop routines for continued patient care, keeping the patient as independent as possible using specific techniques, preventing complications, and maintaining good relationships with the professional team involved in patient care.¹⁴

This study analyzes the quality of life, health, and the relationship with the pharmacist of family caregivers and aims to improve their situation by implementing pharmaceutical care protocols in a community pharmacy setting.

METHODS

Design and location

A descriptive cross-sectional study was conducted for three months (September-December 2013) by administering various questionnaires in a community pharmacy located in an urban area of the city of Pontevedra (Spain).

Subjects

Informal family caregivers of AD patients were selected through non-probability consecutive sampling among those who visited a community pharmacy to receive medication or health products.

Inclusion criteria: The subjects included family caregivers who lived with the patient, were at least 18 years old, and were able to read and understand the measuring instruments and informed consent form.

Exclusion criteria: Family caregivers who did not live with the patient and those younger than 18 years of age were excluded. Caregivers were also excluded if they received financial compensation for the care of the patient.

Procedure

Once consent was obtained, the project was explained on an individual basis, and a subsequent appointment at the pharmacy was set. During that appointment, information was provided regarding the objectives of the study, the demographic characteristics were recorded, and questionnaires were administered. Interviews were conducted in the personal attention area (PAA) of the pharmacy, which is a private room with a locked door.

A questionnaire regarding the socio-demographic characteristics of the subject and the relationship with the pharmacist was administered (Online appendix). To measure depressive symptoms and their intensity in family caregivers, the Beck Depression Inventory-II (BDI-II) was used.^{15,16} This is a 21-question multiple-choice self-report inventory and is one of the most widely used instruments for measuring the severity of depression. A cutoff score of 18 was chosen because it maximizes diagnostic accuracy in terms of sensitivity, specificity, predictive power, and diagnostic efficiency.

We used the Zarit Burden Scale^{15,16} to measure the burden of the caregiver, and the severity of burden was defined using the following cutoff scores: <46 no overload, 46-47 to 55-56 mild overload, and >55-56 severe overload. The State-Trait Anxiety Inventory (STAI)¹⁸ was used, but only the Anxiety-State scale was included to analyze the existence of changes in the state of anxiety in this sample. Anxiety was defined using the following cutoff scores for Spanish citizens: >31 (women) and >28 (men).¹⁹

An assessment of a caregiver's satisfaction regarding their family functionality was determined according to the family APGAR questionnaire.^{20,21} This questionnaire consists of five questions regarding family functioning measured on a three-point scale ranging from zero (hardly ever) to two (almost always). The total score ranged from zero to 10 points, and families can be characterized as a functional family (7-10) or dysfunctional family (<7). Dysfunctional families were classified as mild (3-6) or severely dysfunctional (2 or lower).

The Duke-UNC Functional Social Support Questionnaire (FSSQ) is an 11-item instrument used to measure the strength of a person's social support network.^{22,23} A lower score indicates a lower level of perceived support. Functional Social Support was defined using the following cutoff scores for Spanish citizens: <32 (low support) and >32 (normal support).²³

Data analysis

The statistical analysis was performed using SPSS v.15.0 software. Qualitative data were expressed as percentages, and quantitative data were expressed as means and standard deviations (SD). The confidence limits (CL) were calculated at 95%. To determine the degree of association between two quantitative variables, the Pearson correlation was used, while the chi-square test was used to determine the strength of the relationship between qualitative variables. Statistical significance was set at $p < 0.05$. The Kolmogorov-Smirnov test was performed to test the normality of the variables studied.

RESULTS

Thirty caregivers agreed to participate in the study, but five did not complete the study for various reasons, including institutionalization of the AD patient (one case), caregiver health problems (one case), surveys with questions that were too long and tedious (two cases), and limited time availability (one case).

The socio-demographic characteristics of the family caregivers are shown in Table 1. The time from the diagnosis of AD was less than two years in one case (4.0%), two to eight years in 19 cases (76.0%), and longer than eight years in five cases (20.0%). Ten (40.0%) of the family caregivers worked outside of the home, of which seven (70.0%) received assistance from another person and three (30.0%) did not. Fifteen caregivers (60.0%) did not work

Table 1. Socio-demographic variables		
Variable		n (%)
Sex	Male	5 (20)
	Female	20 (80)
Mean age years (SD)		55 (12.8)
Range (years)		39 - 87
Marital status	Married	21 (84)
	Single	2 (8)
	Divorced	2 (8)
Education level	Primary	12 (48)
	Secondary	2 (8)
	High School	1 (4)
	Bachelor's Degree	8 (32)
	Master's Degree	2 (8)
Relationship	Daughter	15 (60)
	Son	1 (4)
	Wife	3 (12)
	Husband	4 (16)
	Daughter-in-law	1 (4)
	Niece	1 (4)
SD: standard deviation.		

outside of the home, and of these, two (13.3%) received help and 13 (86.7%) did not.

The results are presented in Table 2. The BDI-II questionnaire showed that 20% of family caregivers exhibited moderate to severe depression.

Regarding the level of anxiety assessed by the Anxiety-State section of the STAI questionnaire, which consisted of assessment levels between 0 and 60, the mean score was 23.92 (8.27), and we found five caregivers (20%) who showed anxiety.

The results obtained on the Zarit Burden Scale showed a mean score of 47.16 (13.55), with 48% of caregivers with no overload, 28% with mild overload, and 24% with severe overload.

The analysis of family function (APGAR questionnaire) showed that 56% of family caregivers reported that their families were highly functional, 40% reported moderately dysfunctional families, and 4% reported as severely dysfunctional families.

Perceived social support (Duke-UNC questionnaire) was considered low in 12 cases (48.0%) and normal in 13 (52.0%) cases. Nine caregivers received aid (36.0%), while 16 (64.0%) did not receive aid.

Data related to the caregiver's pharmacotherapy and their relationship with the community pharmacist is shown in Table 3.

Correlation between variables is presented in Table 4. The normality of the study variables was tested. The criterion of normality was fulfilled in all cases

Table 2. Results of the instruments		
Result		n (%)
BDI-II (Depression)	Normal	14 (56)
	Slight emotional disturbance	3 (12)
	Borderline depression	3 (12)
	Moderate depression	3 (12)
	Severe depression	2 (8)
	Extreme depression	0 (0)
STAI (Anxiety-State)	Higher than the 75th percentile	5 (20)
	Lower than the 75th percentile	20 (80)
Zarit (Overload)	Severe overload	6 (24)
	Mild overload	7 (28)
	No overload	12 (48)
Duke-UNC (Perceived social support)	Low	12 (48)
	Normal	13 (52)
APGAR (Family function)	Severely dysfunctional	1 (4)
	Moderately dysfunctional	10 (40)
	Highly functional	14 (56)

except for the variable "educational level" ($p=0.02$). A significant relationship was found between the educational level of caregivers and the time since the diagnosis of AD (0.526, $p<0.01$) as well as with the score on the Zarit Burden Scale (0.429, $p<0.05$). A significant relationship was also found between the BDI- II score and the score on the Zarit Burden Scale (0.685, $p<0.0001$).

Relationships were also found among the following qualitative variables: work outside of the home and the need for extra help (8.36, $p=0.004$); work outside of the home and requests for information from the pharmacist regarding general health, anxiety, depression, etc. (6.25, $p=0.012$); the need for additional support and requests for herbal teas, such as linden and valerian, for overall health improvement (4.99, $p=0.025$) and vitamin infusions for the family caregiver (8.55, $p=0.003$); use of psychotropic drugs by the family caregiver with the advice or supervision of the pharmacist (7.84, $p=0.005$); infusions of family caregiver and collaboration with the pharmacist (3.15, $p=0.076$); and application of vitamin treatment and the use of psychotropic drugs (3.71, $p=0.054$).

DISCUSSION

The caregiver profile was consistent with a 55-year-old first-degree relative (mostly daughters) with a primary education who belonged to a functional or mildly dysfunctional family. Nearly one quarter (24%) of caregivers had a high perception of burden, with anxiety in 20% of caregivers and symptoms of depression in another 20%. The perceived social support was low for almost half of the caregivers,

Table 3. Data related to the pharmacy and medication received by the family caregiver.		
	Yes n (%)	No n (%)
Family caregiver always goes to the same pharmacy	24 (96)	1 (16)
Family caregiver requests infusions	12 (48)	13 (52)
Family caregiver requests vitamins	6 (24)	19 (76)
Family caregiver treated with psychotropic drugs	17 (68)	8 (32)
Family caregiver requests information	10 (40)	15 (60)
Family caregiver only collects medication from the pharmacist without seeking advice	5 (20)	20 (80)
Family caregiver works with the community pharmacist	23 (92)	2 (8)
Family caregiver is satisfied with the treatment received at the pharmacy	25 (100)	0 (0)

Table 4. Correlation between variables									
Time of diagnosis of AD	0.226								
Time of caregiver	0.211	0.989**							
Persons correlation	-0.112	-0.159	0.002						
Depression	-0.250	-0.036	0.002	-0.002					
Anxiety	-0.129	0.055	0.039	-0.066	0.364				
Overload	-0.199	-0.073	-0.036	-0.043	0.685**	0.277			
Family function	-0.023	-0.145	-0.178	-0.077	-0.555**	-0.275	-0.415*		
Perceived social support	0.396*	0.092	0.047	-0.175	-0.435*	0.107	-0.381	0.595**	
Education level	0.227	0.526**	0.459	-0.358	-0.356	0.087	-0.429*	0.238	0.555**
	Age	Time of diagnosis of AD	Time of caregiver	Persons correlation	Depression	Anxiety	Overload	Family function	Perceived social support

* Significant correlation (0.05, bilateral). ** Significant correlation (0.01, bilateral).

and only 36% received help from others, including other family members. These data are consistent with the findings of a survey conducted by the Alzheimer's Foundation of Spain²⁴ and four national associations affiliated with Alzheimer Europe.²⁵ Despite the small size of our group and the limitation of the sample to a specific geographic region, the characteristics of caregivers were very similar to those found in other studies.²⁶

The caregiver profile appears to be independent of cultural traits or social variables in a majority of women. On the other hand, our results are also consistent with those found for caregivers of dependent elderly relatives with dementia, but not with those of AD patients.²⁷

By analyzing the correlations between the demographic characteristics of family caregivers and several psychopathological characteristics, we found that caregivers have higher risk of anxiety and depression if they have a high perception of burden. Furthermore, this level of perceived burden was lower for more functional families, which had a favorable effect on the perceived social support and level of depression.

The results also showed that a low perception of burden was associated with a high educational level. This result is also consistent with previous studies.^{28,29}

Despite the expected association between the time evolution of the disease and caregiver burden, we did not find a correlation between these variables, which has also been confirmed by other authors.^{30,31} One explanation for this finding could be the further deterioration of the patient, decreasing the patient's activity level (less agitation, fewer behavioral disturbances, etc.). Another explanation could be that caregivers gain more experience and ability to care for the patient over time.

The high percentage of caregivers treated with psychotropic drugs (anxiolytics, antidepressants, sleep aids, etc.), indicates the psychological burnout among these individuals. In addition, 48% of the

caregivers had requested relaxing plants from the pharmacy to improve their symptoms of nervousness, anxiety, and lack of sleep, and 24% had requested vitamins or tonics to improve their fitness.

The survey revealed that 96% of family caregivers use the same pharmacy as the patient. More than a third of caregivers asked the pharmacist for information about the disease, anxiety, depression, etc. According to the Alzheimer Foundation of Spain, only 4% of caregivers were informed of the services available, 8% were informed of the existence of associations of relatives of Alzheimer's patients²⁴, and 34% received no information from the doctor about the treatments available.²⁵

In addition, electronic prescriptions have allowed the caregiver loose contact with the doctor, which does not allow the doctor to see his/her symptoms. This situation increases the feeling of loneliness and the emotional and social isolation.³² Instead, by going to their usual pharmacy, the caregiver experiences a friendlier environment and is comfortable discussing his/her problems with the pharmacist and to relate how these problems affect his/her health and life. This environment of trust is useful for the development of assistance programs and comprehensive support for caregivers of AD patients. However, this intervention should be carried out by well-trained professionals who can offer specific coping skills and control and improve emotional problems of caregivers.^{33,34}

There is an important sense of psychological distress (anxiety and depression) and stress among caregivers. Pharmacists are likely the most accessible health care professionals for the caregiver. Pharmacists can provide accurate information about AD and its management, which is an important tool to ease the burden of care.

Among the limitations of the study, we emphasize the small sample size. Of the 30 initial candidates who agreed to participate, five did not complete the study, representing a loss of 17%. This loss, although important, is less than that observed in

another study (29.3%).³⁵ Another problem identified in the study was related to the time required to complete the surveys, which forced the caregiver to be away from home longer than usual. Some caregivers reported anxiety and guilt about spending so much time away from home. This finding was not taken into account if the caregiver belonged to an association for families of AD patients or some type of group therapy. Future studies should incorporate this variable. Membership in an association for relatives of AD patients can help caregivers to face this situation by increasing the degree of acceptance of the disease, improving patient management, providing space and time for respite, balancing the burden of care, and increasing the motivation and enthusiasm for new activities performed by the family caregiver.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

SOBRECARGA Y PATOLOGÍAS ASOCIADAS EN LOS FAMILIARES CUIDADORES DE ENFERMOS DE ALZHEIMER EN ESPAÑA

RESUMEN

Objetivos: Evaluar el perfil de los familiares cuidadores de enfermos de Alzheimer, identificar signos de psicopatología, cuantificar el nivel de sobrecarga percibido en el cuidador, y determinar la relación del cuidador con su farmacéutico.

Métodos: Se realizó un estudio transversal en una farmacia comunitaria de Pontevedra, España. Se recogieron las variables demográficas y se administraron los siguientes cuestionarios: el Beck Depression Inventory-II, el cuestionario STAI-Anxiety, la escala Zarit Burden, la escala familiar APGAR, y el cuestionario Duke-UNC.

Resultados: El perfil típico del cuidador consiste en un pariente en primer grado (generalmente hijas) de 55 años con educación primaria que pertenece a una familia funcional o ligeramente disfuncional. Casi un cuarto (24%) de los cuidadores tiene una percepción de elevada sobrecarga, con ansiedad en el 20% de los cuidadores y síntomas de depresión en el 20%. Los familiares cuidadores generalmente (96%) iban a la misma farmacia que fueron los enfermos, estaban tratados con fármacos psicotrópicos (68%), e interactuaban con el farmacéutico (92%).

Conclusión: Este estudio confirma que el estrés psicológico y la sobrecarga están presentes entre los familiares cuidadores. El cuidado del cuidador debería estar integrado en los cuidados del paciente como un plan nacional, incluyendo subsidios, que producirán una mejor atención de los pacientes con Alzheimer. Los farmacéuticos son los profesionales más accesibles y pueden proporcionar información sobre el manejo de la enfermedad de Alzheimer a los cuidadores para reducir la sobrecarga.

Palabras clave: Enfermedad de Alzheimer; Cuidadores; Coste de la Enfermedad; Farmacéuticos; Papel Profesional; España

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