Enfermería Global
ISSN 1695-6141
Revista electrónica trimestral de Enfermería
Nº58
Abril 2020
www.um.es/eglobal/

ORIGINALES

Women with high level of education, victims of the care of people with Alzheimer's

Mujeres con elevado nivel de estudios, víctimas del cuidado de personas con Alzheimer

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https://doi.org/10.6018/eglobal.392231

Received: 1/08/2019
Accepted: 9/11/2019

ABSTRACT:

The aim of this job is to know the existing relationship between the task of caring patients with Alzheimer's disease, caregivers' gender and their level of academic studies. Descriptive study, 69 persons diagnosed with Alzheimer's disease and their respective familiar caregivers as subjects of the study. Age, gender, academic level, burden, depression, anxiety level, quality of life and social loneliness have been measured in caregivers. Age, gender, dependency level and neuropsychological state have been measured in patients. Data collection was done in 2016. Logistic regression analysis was performed. Caregivers with high levels of academic studies suffer more burden, being women in their majority. They are more likely to present social loneliness and higher levels of anxiety and a worse quality of life than men. The burden may be due to a greater number of responsibilities to respond to, and to the inability to combine it with the role of caregiver. We can conclude that women become victims of caring Alzheimer' patients.

Key words: Alzheimer's disease, Academic studies, Burden, Family caregivers, Gender.

RESUMEN:

Objetivo: Conocer la relación existente entre la tarea de cuidar a pacientes con Enfermedad de Alzheimer, el Género de los cuidadores y su nivel de formación académica.

Método: Estudio descriptivo, como sujetos de estudio 69 personas diagnosticadas de Enfermedad de Alzheimer y sus respectivos cuidadores familiares.

En los cuidadores se analizó: la edad, el género, el nivel de estudios, carga, depresión, nivel de ansiedad, calidad de vida y soledad social. En los pacientes se valoró la edad, género, nivel de

dependencia y estado neuropsicológico. La recogida de datos se realizó en 2016. Entre otros análisis se realizó análisis de regresión logística.
Resultados: Se obtuvo que los cuidadores con estudios superiores sufrían mayor carga, siendo mujeres en su mayoría. Mujeres con más probabilidad de presentar soledad social, altos niveles de ansiedad y peor calidad de vida que los hombres. La carga puede ser debida al gran número de responsabilidades y a la imposibilidad de combinarlas con el papel de cuidador.
Se puede concluir que las mujeres llegan a ser víctimas del cuidado de personas con Enfermedad de Alzheimer.

Palabras clave: Enfermedad de Alzheimer, Estudios Académicos, Carga, Cuidadores familiares, Género.

INTRODUCTION

Alzheimer's disease is the most common type of dementia, affecting a wide range of people with dementia(1), from 204.13 in Israel to 15.51 in India by 1000 persons; in Spain 39.03. In Spain the incidence is 1.4 by 1,000 persons/year from 65 years(2).It is a disease for which there is no curative treatment, and whose symptoms and functional damages are aggravated as it progress. Alzheimer's disease is characterized by its chronicity, dependency status, presence of neuropsychiatric disorders and the deterioration of memory and cognitive skills that accompany it, such as speaking coherently, recognize or identify objects, etc. (3).

The increase in the prevalence of chronic diseases, including Alzheimer's disease, is caused as a result of the population aging that is being experienced nowadays. The increase in the number of elderly people in situation of dependency implies an increase in care needs, and therefore in caregivers to provide them. This role is very often assume by family, being denominated informal or familiar caregiver, the family member who carries out the task of caring.

Informal cares are the 80% of all long-term care in Europe(4). Informal care that usually is provided by women(4)

Familiar caregivers of people with Alzheimer's disease face high levels of dependence of their relatives, inability to perform basic and instrumental activities of daily living, and in addition neuropsychiatric disorders and behavioral problems of the patient(5).

These caregivers, often referred to as "hidden or unknown patients," are at increased risk for anxiety, depression, sleep disorders, reduced quality of life, increased cardiovascular morbidity, increased mortality, etc…; therefore, they can be considered as a population at risk, susceptible to suffer both physical and mental illness(6). Furthermore, familiar caregivers spend most of their time to perform the role of caregiver(7), what causes changes that may affect their physical and psychological health, as well as their family and social life.

Impact of caring is influenced by both objective and subjective components(8). Objective components as the dedication and the performance of the caregiver role; and subjective components that are related to how the situation is perceived and, in particular, they are related to the caregiver emotional response to the experience of caring. There is some relationship between gender and subjective burden(8).

Functional impairment of patients with Alzheimer's disease is one of the main problems that directly affect the quality of life of familiar caregivers(9-15) On the other hand, there are studies that indicate that non-pharmacological intervention programs in Alzheimer's patients have a positive effect on both, them and their caregivers(16) In this line the day care centers are presented as a solution to reduce the caregiver burden and help family caregivers to cope with demands(17)

Moreover, it has also been seen that the coping strategies used by familiar caregivers determine their high levels of burden, anxiety and depression, as in the studies of García-Alberca et al.(18) and of Iavarone et al.(19), in which they observed higher levels of anxiety and depression in those caregivers that did not use suitable coping strategies (decision making, coping with behavioral problems, etc.). Something similar was concluded in the study conducted by Cheng et al.(12), in which they found that the self-efficacy of the caregiver to face problems related to care was associated with lower levels of burden. Therefore, it can be said that there is a relationship between how to address the different situations that arise from the task of caring and the quality of life that caregivers present, understood that as the level of burden, anxiety and depression they experience.

Additionally, sociodemographic characteristics of caregivers influence their quality of life, level of burden, anxiety, depression, etc(20) , type of diagnosis (21) the kinship that keeps with the person cared(14), the time they dedicate to the task of caring(22), etc. have been related to the appearance of these pathologies in caregivers.

With that background, the research group wanted to know the existing relationship between the task of caring for patients with Alzheimer's disease, caregivers' gender and their level of academic studies, since care has become a gender issue and women are traditionally in charge of relatives care.

METHODS

Design

Descriptive study, with two related groups: caregivers and their relatives suffering Alzheimer’s disease. The Theoretical Framework is Women’s Health.

Inclusion and exclusion criteria

Inclusion criteria were patients diagnosed with Alzheimer’s disease and their respective familiar caregivers; caregivers with at least 6 months dedicated to care and patients and caregivers belonging to a province of the south of Spain. Exclusion criteria were patients undiagnosed of Alzheimer’s disease or diagnosed with other dementias; independent patients or with low dependence to perform basic activities of daily living (score > 90 on Barthel Index); formal caregivers or those who received some material compensation for the work they developed; caregivers who had been playing the role of caregiver for a short period of time (less of 6 months); and patients or caregivers with difficulty to understand local language.

Sample and setting

Accepting an alpha error of 0.95 for an accuracy of +/- 0.11 units in a bilateral contrast for an estimated proportion of 0.34(12), a random sample of 72 patients with their respective caregivers was required assuming that the population of Alzheimer’s patients in the city, reference of the study in Spain, is 8000 (in 2016). A replacement rate of 1% has been estimated. One was a formal caregiver and two did not response, so finally, a random sample of 69 patients with their caregivers, other 69 people, was gathered.

Variables

To assess the state of caregivers and patients, the next variables were taken into account: In caregivers → sociodemographic characteristics such as age, gender, academic level, between others; level of burden, depression, anxiety, quality of life, social loneliness and level of dependence. In patients → neuropsychological state, level of dependence for basic activities of daily living and sociodemographic characteristics (age, duration of dementia, etc…).

Measure instruments

Sociodemographic questionnaire: Of caregivers: age, gender, kinship, level of studies, time being caregiver and patient-caregiver coexistence. Of patients: age, gender, kinship, time with the diagnosis of dementia. *Zarit Burden Interview:* To measure caregiver burden(23). *Beck Depression Inventory:* To measure level of depression of caregivers(24). *Beck Anxiety Inventory:* To measure level of anxiety of caregivers(25). *SF-36:* To measure caregiver quality of life(26). *ESTE-II Scale:* To measure social loneliness of caregivers(27). *Pfeiffer test:* To measure caregivers cognitive state(28). *Barthel Index:* This instrument was applied to Alzheimer's disease patients. It is a 10-item scale used to measure performance in basic activities of daily living(29). *Mini-Mental State Examination:* To measure patient's cognitive state(30).

Data collection

Selection of participants by a treatment group of patients with Alzheimer's disease, composed by: Psychologist, Social Worker, Physiotherapist, Occupational Therapist and Nurse. To communicate to potential participants that they have been selected for a study because of their condition of familiar caregivers of people with Alzheimer's disease. To explain what the study consisted of and, if they wanted to participate, quote them for a personal interview. Checking that they fulfilled inclusion and exclusion criteria, and resolution of possible doubts. To provide the information sheet and the informed consent to caregivers and patients (or legal guardians in default).To collect sociodemographic information of the participants and to manage the instruments of data collection.

Ethical considerations

All participants (or legal guardians in default), signed an informed consent by which they accepted their participation in the study. The proposed research respects the fundamental principles of the Declaration of Helsinki, the Council of Europe on Human Rights and Biomedicine, the UNESCO Universal Declaration on the Human Genome and Human Rights and the Oviedo Council on Human Rights and Biomedicine. The project has the approval of the Ethics Committee (reference 2949).

Data analysis

Results have been analyzed using the program SPSS Statistics version 22 (IBM Corp, Armonk, NY, USA) for statistical analysis, licensed to the University of Castilla La Mancha (Spain). Qualitative variables were described as count and percentages, while quantitative were summarized with mean and standard error of the mean. Variables were related using chi-square test in the case of qualitative ones, and variance analysis of quantitative data. For statistical significance it has been considered a p<.05. For significant differences between groups the analysis of variance of a factor and multifactorial with post-hoc of Student-Newman-Keuls multiple comparisons adjustment were carried out. On hypothesis contrast, the normality of the sample was verified by the Shapiro-Wilk test, being significant if p<.05, which assumes that the samples do not follow a normal distribution. Because of this, non-parametric tests were used: the “U” of Mann-Whitney and the Kruskal-Wallis test according to the grouping variable. If the Shapiro-Wilk test was not significant, normal sample distributions were assumed and parametric tests were used: Student's T-test or ANOVA of one factor depending on the clustering variable. In making predictions between variables logistic regression analysis were performed.

RESULTS

As shown in Table 1, 69 familiar caregivers were recruited, from which 49 (71%) were women and 20 (29%) were men. They had a mean age of 58.77 ± 11.23 years old. Most of caregivers, 43 (62.3%), were sons or daughters of the person cared, and 45 (65.2%) lived with the person they cared. Familiar caregivers had been caring a mean of 6.59 ± 6.16 years. Regarding to the educational level, most part of caregivers, 29% of them, had completed tertiary education (32.7% of the women and 20% of the men had that educational level).

Table 1. Sociodemographic Characteristics of 69 Caregivers

Characteristics	**Mean**	***SD***	**Range**	**Number**	**%**
Age (years)	58.77	11.23	(38-82)		
Female				49	71
Male				20	29
Years caring	6.59	6.16	(1-44)		
Relationship with patients					
• Son/daughter				43	62.3
• Husband/wife				23	33.3
• Brother/sister				1	1.4
• Other				2	2.9
Live with patient					
• Yes				45	65.2
• No				17	24.6

• Partial time				7	10.1
Educational level					
• Without studies/Primary incompleted				9	13
• Primary completed				15	21.7
• Secondary incompleted				5	7.2
• Secondary completed				14	20.3
• Tertiary/University studies incompleted				6	8.7
• Tertiary/University studies completed				20	29
Zarit Burden Interview	29.16	13.98	(6-62)		
• Without burden				60	87
• Low burden				5	7.2
• Intense burden				4	5.8
Beck Depression Inventory	8.3	7.34	(0-31)		
• Without depression				64	92.8
• Clinical depression				5	7.2
Beck Anxiety Inventory	11.13	9.54	(0-39)		
• Low anxiety				59	85.5
• Moderate anxiety				7	10.1
• Severe anxiety				2	2.9
ESTE-Scale	8.36	4.289	(1-20)		

- Low social loneliness				49	71
- Medium social loneliness				18	26.1
- High social loneliness				0	0

Note: SD=Standard Deviation. %=Percentage

The level of academic studies stratified by caregiver gender can be seen in Table 2. Familiar caregivers of people with Alzheimer's disease had a mean burden of 29.16 ± 13.98; a mean anxiety of 11.13 ± 9.54 and a mean depression of 8.3 ± 7.34. The average social loneliness was of 8.36 ± 4.289 points.

Table 2. Academic level by gender of 69 Caregivers

	Men		**Women**	
	n	**%**	**n**	**%**
Without studies/Primary incompleted	1	5	8	16.3
Primary completed	6	30	9	18.4
Secondary incompleted	4	20	1	2
Secondary completed	4	20	10	20.4
Tertiary/University studies incompleted	1	5	5	10.2
Tertiary/University studies completed	4	20	16	32.7

As shown in Table 3, patients had a mean age of 79.83 ± 7.93 years old. From the 69 included on the study, 21 (30.4%) were men, while 48 (69.6%) were women. 43,5% of the patients had been diagnosed of Alzheimer's disease between 1 and 5 years ago. 28 (40.6%) patients had a total dependence to perform basic activities of daily living, and 41 (59.4%) had a severe cognitive impairment.

Table 3. Characteristics of 69 Alzheimer's disease Patients

Characteristics	**Mean**	***SD***	**Range**	**Number**	**%**
Age (years)	79.83	7.93	(58-95)		
Female				48	69.6
Male				21	30.4
Duration of dementia (years)					
- < 1				2	2.9
- Between 1 and 5				30	43.5

- Between 6 and 10				24	34.8
- > 10				13	18.8
Barthel Index					
- Total dependence				28	40.6
- Severe dependence				17	24.6
- Moderate dependence				21	30.4
- Low dependence				1	1.4
Mini-Mental State Examination					
- Severe cognitive deterioration				41	59.4
- Moderate cognitive deterioration				22	31.9
- Low cognitive deterioration				4	5.8

Note: SD=Standard Deviation. %=Percentage

On hypothesis contrast, using caregiver burden as dependent variable, it has been found that statistically significant differences exist between educational levels, when comparing caregivers burden between groups “without studies/primary uncompleted” [23.33 (SD 10.27)], and “tertiary/university studies completed” [33.25 (SD 11.34)] (p=.03). Also, between groups “primary completed” [22 (SD 11.86)], and “tertiary/university studies completed” [33.25 (SD 11.34)] (p<.001). It can be said that caregivers with high level of studies suffer more burden and, as it has been seen, the majority of caregivers with this level of studies were women. Results obtained on hypothesis contrast are shown in Table 4.

Table 4. Hypothesis contrast: significant associations

	Mean	***SD***	**Mean**	***SD***	***p***
Variables	**Without studies/ Primary incompleted**		**Tertiary/University studies completed**		
Burden	23.33	10.27	33.25	11.34	=.03
	Primary completed		**Tertiary/University studies completed**		
Burden	22	11.86	33.25	11.34	<.001
	Depression		**Without depression**		

Burden	52.4	8.74	27.34	12.64	<.001
	Moderate dependence		**Severe dependence**		
Burden	25.43	12.88	35.65	12.15	=.018
	Severe dependence		**Total dependence**		
Burden	35.65	12.15	27.39	14.55	=.016
	Total coexistence		**No coexistence**		
Social Loneliness	9.36	4.66	6.81	2.81	=.045
	Total coexistence		**Partial coexistence**		
Social Loneliness	9.36	4.66	5.57	2.30	=.041
	Medium social loneliness		**Low social loneliness**		
Caregiver's age	65.67	10.41	55.92	10.53	<.001
Variables	**Depression**		**Without depression**		
Social Loneliness	13.33	4.04	8.13	4.20	=.039
	Women		**Men**		
Anxiety	12.73	9.73	7	7.83	=.013
	Women		**Men**		
Quality of life					
• Vitality	58.9	18.89	72.44	25.87	=.012
• Social function	81.18	22.01	91.23	19.80	=.028
• Emotional role	75.51	36.50	91.23	26.86	=.048

Note: SD=Standard Deviation

Additionally, there are statistically significant differences on caregivers burden when comparing caregivers with depression [52.4 (SD 8.74)], and without depression [27.34 (SD 12.64)] (p<.001). So there is more burden when the caregiver also suffers depression (Table 4).

Moreover, when comparing burden of caregivers of patients with moderate dependence [25.43 (SD 12.88)], and burden of caregivers of patients with severe dependence [35.65 (SD 12.15)], there have been found statistically significant differences, so the burden is higher when the level of dependence is higher (p=.018). But when comparing burden between caregivers of patients with severe dependence [35.65 (SD 12.15)] and caregivers of patients with total dependence [27.39 (SD 14.55)], it was found that caregivers suffered more burden when the level of dependence of patients was lower (p=.016) (Table 4).

When stratifying data according to gender of the caregiver, we found statistically significant differences in anxiety levels and in quality of life levels. In terms of anxiety level, women [12.73 (SD 9.73)] had higher levels than men [7 (SD 7.83)] (p=.013). With regard to the level of quality of life, women presented lower quality of life than men in the items vitality (p=.012), social function (p=.028) and emotional role (p=.048) (Table 4).

Focusing on social loneliness, there are higher social loneliness in those caregivers who live with the patient against those who do not (p=.045). This social loneliness is higher when they live always together than when it is for seasons (p=.041). It has been also found a relationship between social loneliness and caregivers’ age. Caregivers with medium social loneliness have higher ages than those with low social loneliness (p<.001), increasing social loneliness scale as caregiver's age increased. Furthermore, caregivers who have depression feel higher social loneliness that those who do not have depression (p=.039) (Table 4).

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A logistic regression was performed to relate the variables associated with social loneliness, with women being 8.1 times more likely (95% CI = 1.23-53.45) to present social loneliness than men (p=.03). In addition, for each year of age of the caregiver, the probability of suffering social loneliness increased in 1.08 (95% CI = 1.01-1.16) (p=.028). Finally, people with mild burden were 105 times more likely to suffer social loneliness (95% CI = 4.39-2585) than those without burden (p=.004). Logistic regression results are shown in Table 5.

Table 5. Logistic regression: social loneliness of caregiver

	OR (95% CI)	***p***
Gender		
Men	Reference	
Women	8.1 (1.23-53.45)	.03*
Age	1.08 (1.01-1.16)	.028*
Burden		
Without burden	Reference	
Mild burden	105.52 (4.39-2585)	.004*
High burden	9.9 (0.68-144)	.093

Note: Factors associated with caregivers' social loneliness.
OR=odds ratio; CI= confidence interval *p<0.05.

DISCUSSION

The majority of caregivers included in this study are women (71%), which is certainly the most predominant feature among these caregivers, confirming the female sex as a defining feature of them, which is possibly due to the cultural conception that caring is a function attached to women as part of their gender role. Other studies show such predominance of female sex over male sex(11, 31,32)

In this study, significant associations were identified between caregiver's gender and affectations such as their anxiety level and their quality of life, being the level of anxiety higher among women, as in the study of García-Alberca et al.(18), whereas the level of quality of life was higher in men (in the items of vitality, social function and emotional role). We also detected an association between the female gender of caregivers and their level of social loneliness, although no other studies have been found that reflect such association.

The age of these caregivers also appears to be well defined, being medium or high ages in the majority of studies. Age influences the caregiver's experience of care, as we found, caregivers' social loneliness increased as their age did. Dalpai et al.(33) report that greater age has relation with higher care burden, lower quality of life and more frequent depression in informal caregivers.

In the present study, high levels of academic studies have been detected among caregivers, which is not usually when comparing to the characteristics of familiar caregivers in Spain. For example, in the study carried out by Toribio-Díaz et al.(34), only 10,8% of principal caregivers had university studies. As seen in the results, having a high level of studies implies an increase in the level of burden of caregivers, which may be due to a greater number of responsibilities to respond to, and to the inability to combine it with the role of caregiver.

Relationship with patients is also a defining characteristic of familiar caregivers, who are very often sons/daughters or husbands/wives of the person cared(34-38). In this study we also confirm this fact, being 62.3% daughters or sons, and 33.3% husbands or wives. This can be explained because these are the relationships in which it exists a greater union between the caregiver and the person cared and, consequently, they probably feel the responsibility to perform the task of caring. In our study we have not found associations between the variable “relationship” and others like “burden” or “depression”, but there are studies that affirm higher level of burden and higher level of depression when the caregivers are sons or daughters of the person cared(12, 14, 34,37).
Living with the person cared has also repercussions on how the caregiver lives the experience of caring. As we found higher social loneliness in those caregivers who lived with the patients, in others studies(21,39) they found higher burden when caregiver and patient lived together.

The level of patient’s dependence for the realization of the basic activities of daily living influences the level of burden of caregivers; some studies detected a positive correlation between caregiver’s burden and patient’s dependence(9, 15). By contrast, we found a negative correlation between burden and dependence when comparing burden between caregivers of patients with severe dependence and caregivers of patients with total dependence.

Social loneliness experienced by caregivers is an important variable to take into account because, as we found, it presents associations with others such as the presence of depression. Despite this, it is a variable hardly studied, and future projects should focus on its development and study.

As main contributions to the literature, it can be highlighted the association found between the higher level of caregiver studies and the higher level of burden, especially within the female gender, which predominates at this level of studies. It should also be noted that women live in a worse way the experience of care and they are more affected than men by the disturbances that derive from it.

Knowledge of how burden interferes with caregivers with high educational levels implies that Nurses help to these people, to allow them to continue their careers. These professionals should develop interventions oriented to the intellectual area: decision making, self-help groups… as well as studies to know if decision making is the reason that overload them.

The study has some limitations, the willingness of caregivers to participate in the study and complete the questionnaires. It has been a cross-sectional so it is not possible to stablish causal relationships. Another limitation is the sample size, it would be better a bigger one for generalizing the results; and only one center as setting of the study.

CONCLUSIONS

Finally, we can conclude that women become victims of caring Alzheimer' patients. They experience greater burden (higher when they have high levels of academic studies), anxiety, social loneliness and lower quality of life. As it has been said, caregivers of people with Alzheimer's disease who have a higher educational level suffer a greater deterioration in their quality of life. It is a serious impediment to their personal and professional development, which can have repercussions at other levels and may cause them to take decisions as giving up their professional careers.

These data have relevance to the health field (Clinical Implications), Nurses must know if caregivers are overload by decision making and in this case they should implementing individual adequate interventions.

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ISSN 1695-6141