An evaluation of the burden of Alzheimer patients on family caregivers

Avaliação do impacto no cuidador familiar do doente de Alzheimer

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Abstract

Caregivers are indispensable to persons living with Alzheimer's disease; however, such care involves hard work, and the consequences of this activity on caregivers are often neglected. The objective of this study was to construct a profile for caregivers of Alzheimer patients and to evaluate the burden such care imposes on them. It is a transversal study of 122 caregivers from the metropolitan region of Londrina, Paraná State, Brazil. Socio-demographic data for the caregivers were analyzed, while the Katz scale and Lawton index were used to evaluate the functionality of Alzheimer's patients, and the Burden Interview Scale assessed the burden these patients impose on caregivers. Caregivers are predominantly married, are daughters who have learned to care for the patient on a daily basis, usually with some help, and they do so out of love. The caregiver's age ($p < 0.01$), whether or not the caregiver had help ($p < 0.01$), and the number of hours caring for the patient ($p = 0.01$) were associated with the impact. Results showed that the burden imposed on caregivers by Alzheimer patients is a heavy one.

Caregivers; Alzheimer Disease; Home Nursing

Introduction

Research has shown that caring for a patient with mental problems is a lonely and exhausting task [1,2,3]. The redefinition of family roles added to a caregiver's other activities outside the home can lead to emotional, social and financial problems and many diseases. These may get worse if the caregiver is unprepared or as the patient's condition deteriorates, thus imposing a burden [4,5,6,7].

Alzheimer's disease is the most common type of mental illness. It progressively disables individuals, affecting their memory, behavior, relationships, language and other functional activities; demanding the constant presence of a caregiver [8]. In developed countries, caregivers are extremely important, and public and private networks have been created to help to keep the aging person around his or her family [1,9]. In Brazil, the responsibility lies exclusively with the patient's family which cannot count on effective public support, while private sector support is expensive and available to very few [9,10].

Brazilian studies of the burden that Alzheimer disease patients place on caregivers have mostly been carried out in the Southeast region of the country, and they point out co-residence, time spent caring for the patient, and type of relationship with the patient as important factors associated with the burden [6,11,12]. However, such studies deal with mental diseases from different etiologies, with a small number of samples.

The sample size of this study is larger than any other reported in Brazil for this specific type of mental condition. To evaluate the burden that this type of care poses, very few published instruments have been adapted to the reality of Brazil [13]. Therefore, this study opted for the Burden Interview Scale [14].

The objective of this study was to construct a profile of the family caregiver and to evaluate the burden this activity imposes on his or her personal life, using the Burden Interview Scale.

Method

A transversal observational study was carried out at the Mental Health Outpatient Clinic (AHC-UEL) of the Londrina State University, Paraná State, Brazil, having been approved by the Research on Human Beings Ethics Committee from the same institution, under reference 066/06.

A list of all patients seen by the clinic from January 2005 to December 2006 (total 330) was provided by the Medical Archives and Statistics Sector of the AHC-UEL. All patients' records were evaluated, and 196 of 330 showed a probable clinical diagnosis for Alzheimer's disease, according to the criteria of the National Institute for Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Association (NINCDS-ADRDA) [15]. The search for caregivers was done by phone and/or mail. Family caregivers were characterized as individuals with greater or total responsibility for supervision and care, and for all activities involving the Alzheimer disease patient [16].

Family caregivers of both sexes participated in the study, whether they were living with the patient or not, and were required to be over 16 years of age. Caregivers who were excluded included those of deceased patients (n = 16), those who lived outside the Londrina metropolitan area (n = 16), where they reported that the patient had been institutionalized (n = 4), as well as professional and non-professional paid caretakers (n = 16). In addition, caregivers that were not registered with the phone company, and those who never returned the contact, which was made twice (n = 13), were also excluded.

All in-house interviews were carried out between June 2006 and May 2007, by the researcher, during pre-arranged days and times, when the signature of the free and informed terms of consent was obtained. Socio-demographic data showed how caregivers evaluated the functionality of the patients according to the *Daily Life Activities Scale* [17] and the *Daily Life Instrumental Activities Scale* [18], adapted by Scazufca and published by Almeida [19]. Patients who did not need any help were classified as independent whereas those who needed supervision and help to carry out their daily activities were classified as partially dependent. Dependent patients were those classified as totally dependent on a caregiver for performing basic functional needs.

To evaluate the adverse effects of this type of care on the physical, emotional, social and financial life of caregivers, this study used the Burden Interview Scale translated into Portuguese and adapted to the reality of Brazil by Scazufca [14]. The scale is easy to apply and contains 22 questions with five possible answers ranging from "never" to "always". Possible answers were printed on two cards: one numbered from 0 to 4, to be used with illiterate caregivers, and; another for literate caregivers, showing the graded answers. Global scores were obtained by the sum of all answers, varying from 0 to 88, so that the higher the score, the greater the burden imposed on the caregiver. All caregivers were instructed to estimate the frequency of the problems occurred during the last month.

Although the scale includes self-explanatory statements, the interviewer read the questions and filled out the questionnaire according to the options selected by the interviewees. Examples taken from the caregivers' experience with the patients were used for clarification in case of doubts regarding any of the questions.

Data were fed into the Epi Info program for Windows 2005 (Centers for Disease Control and Prevention, Atlanta, USA). Discrete variables were given as frequency percentiles and continuous variables as means and standard deviations. The Kolmogorov-Smirnov test verified the presence of a Gaussian distribution in the continuous variables. Student's t tests and the analysis of variance (ANOVA) were used to compare means. Later, data were transferred to the SPSS program version 13.0 (SPSS Inc., Chicago, USA) and a multivariate analysis by the stepwise method was conducted to identify independent variables. The Burden Interview Scale score was used as a dependent variable during the multivariate analysis. In the beginning, the variables selected to be included in the model were those that, during the univariate analysis, showed a $p > 0.10$ level of association with the dependent variable. All tests were carried out at the 5% level of significance.

Results

Of the 131 eligible caregivers, nine refused to participate in the study, limiting the sample size to 122 caregivers. The socio-demographic characteristics of the family caregivers are shown in Table 1.

The burden on the caregiver was evaluated using the *Burden Interview Scale*. Total mean was 37.3 ± 13.08 points. The lowest score was 10 and the highest was 66 points. Answers to the *Burden Interview Scale* questions are presented in Table 2. The highest levels of burden were observed in women under 60 years of age, with high school and college degrees, who learned to care for the patient on a daily basis, did not get any extra help, and who cared for the patient for more than 10 hours per week (Table 1). A major burden was also observed among caregivers of patients who were dependent on them to carry out instrumental activities such as using the phone ($p < 0.01$), leaving the house ($p = 0.01$) going shopping ($p = 0.03$) and doing chores around the house ($p = 0.04$) (Table 3). Similarly, a greater burden was verified among caregivers whose patients were dependent on them for basic needs such as bathing ($p < 0.01$) and getting dressed ($p = 0.03$) (Table 4).

Variables such as caregiver sex, age, educational level, income level, professional level, as well as type of help (if any), period during which the caregiver cared for the patient, and number of hours spent caring for the patient were included in the mutivariate analysis. Analysis by the stepwise method highlighted the following as significant and independent variables, using an $r^2 = 0.31$, $p < 0.01$ model: caregiver age ($p < 0.01$), the presence of extra help ($p < 0.01$) and number of care hours ($p = 0.01$).

Table 1

Socio-demographic characteristics and burden evaluated by the *Burden Interview Scale* (BI) of 122 family caregivers for Alzheimer's disease patients at the Mental Health Outpatient Clinic of Londrina State University (AHC-UEL). Londrina, Paraná State, Brazil, 2006.

Characteristics	n *	%	Mean BI	p-value **
Gender				
Male	11	9.0	27.0 (±10.8)	< 0.01
Female	111	91.0	38.3 (±12.8)	
Age (years)				
< 60	72	59.0	40.1 (±12.5)	< 0.01
≥ 60	50	41.0	33.1 (±12.8)	
Marital status				
Married/Partner	90	73.8	36.6 (±12.4)	0.23
Divorced	6	4.9	36.1 (±10.4)	
Single	24	19.7	41.2 (±15.2)	
Widower	2	1.6	24.5 (±12.0)	
Educational level				
Illiterate	11	9.0	34.1 (±11.9)	0.04
Primary school	60	49.2	34.5 (±12.1)	
High school	25	20.5	41.6 (±14.1)	
Higher education/Post	26	21.3	40.8 (±13.4)	
Professional occupation				
Homemaker	47	38.5	39.0 (±13.5)	0.18
Active	36	29.5	39.1 (±12.4)	
Inactive	36	29.5	33.7 (±12.6)	
Other	3	2.5	30.6 (±14.6)	
Type of relationship				
Daughter	66	54.1	38.1 (±13.0)	0.25
Wife	32	26.2	35.4 (±11.9)	
Daughter-in-law	9	7.4	43.5 (±12.2)	
Other	15	12.3	33.6 (±15.2)	

(continue)

Table 1 (continued)

Characteristics	n *	%	Mean BI	p-value **
Income (as a multiple of the minimum wage)				
None	43	35.2	39.6 (±14.1)	0.09
1-5	69	56.6	35.1 (±12.7)	
> 5	10	8.2	42.4 (±14.1)	
Religious				
Yes	78	63.9	36.1 (±13.0)	0.18
No	44	36.1	39.4 (±13.2)	
Living together				
Yes	110	90.2	37.4 (±13.4)	0.65
No	12	9.8	35.6 (± 9.8)	
Patient contributes towards expenses				
Yes	88	72.1	38.4 (±13.0)	0.12
No	34	27.9	34.2 (±12.9)	
Reasons for caring				
Love	70	57.4	36.4 (±12.9)	0.70
Obligation	43	35.2	38.5 (±13.6)	
Other	9	7.4	38.1 (±12.5)	
Learned how to care				
Day by day	76	62.3	39.2 (±13.7)	0.04
Other	46	37.7	34.2 (±11.5)	
Previous experience with this type of caring				
Yes	61	50.0	36.1 (±13.1)	0.32
No	61	50.0	38.4 (±13.0)	
Extra help				
Yes	76	62.3	34.7 (±11.9)	< 0.01
No	46	37.7	41.5 (±13.8)	
Period with the patient (months)				
Up to 36	58	47.6	34.6 (±12.6)	0.06
36-96	44	36.1	40.7 (±12.7)	
More than 96	20	16.3	37.5 (±14.0)	
Diagnosis period (months)				
Up to 12	16	13.1	37.9 (±13.6)	0.44
12-60	87	71.4	38.3 (±13.8)	
More than 60	19	15.5	31.8 (± 6.9)	
Hours of assistance (hours/week)				
Up to 10	16	13.1	30.1 (± 8.8)	0.02
More than 10	106	86.9	38.3 (±13.3)	
Leisure time (hours/week)				
Up to 5	96	78.7	36.9 (±13.8)	0.49
5-10	7	5.8	34.2 (± 6.2)	
More than 10	19	15.5	40.2 (±14.8)	

* Number of participants;

** The statistical analysis was carried out by the t Student test to compare means between the two categories and by the ANOVA where 3 or more categories were compared.

Table 2

Zarit Burden Interview Scale applied to 122 family caregivers of Alzheimer's disease patients at the Mental Health Outpatient Clinic of Londrina State University (AHC-UEL). Londrina, Paraná State, Brazil, 2006.

Elements of the *Burden Interview Scale*	**Never n (%)**	**Rarely n (%)**	**Sometimes n (%)**	**Frequently n (%)**	**Always n (%)**
Do you feel that your relative asks for more help than he/she needs?	46 (37.7)	20 (16.4)	22 (18.0)	14 (11.5)	20 (16.4)
Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	25 (20.5)	28 (23.0)	35 (28.7)	12 (9.8)	22 (18.0)
Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	24 (19.7)	11 (9.0)	42 (34.4)	19 (15.6)	26 (21.3)
Do you feel embarrassed about your relative's behavior?	81 (66.4)	8 (6.6)	30 (24.6)	2 (1.6)	1 (0.8)
Do you feel angry when you are around your relative?	49 (40.2)	17 (13.9)	39 (32.0)	10 (8.2)	7 (5.7)
Do you feel that your relative currently affects your relationships with other family members or friends in a negative way?	63 (51.6)	10 (8.2)	25 (20.5)	15 (12.3)	9 (7.4)
Are you afraid what the future holds for your relative?	12 (9.8)	7 (5.7)	27 (22.1)	29 (23.8)	47 (38.5)
Do you feel your relative is dependent on you?	-	2 (1.6)	8 (6.6)	20 (16.4)	92 (75.4)
Do you feel strained when you are around your relative?	48 (39.3)	13 (10.7)	38 (31.1)	10 (8.2)	13 (10.7)
Do you feel your health has suffered because of your involvement with your relative?	38 (31.1)	12 (9.8)	37 (30.3)	23 (18.9)	12 (9.8)
Do you feel that you don't have as much privacy as you would like because of your relative?	46 (37.7)	10 (8.2)	35 (28.7)	16 (13.1)	15 (12.3)
Do you feel that your social life has suffered because you are caring for your relative?	30 (24.6)	16 (13.1)	31 (25.4)	19 (15.6)	26 (21.3)
Do you feel uncomfortable about having friends over because of your relative?	92 (75.4)	8 (6.6)	10 (8.2)	7 (5.7)	5 (4.1)
Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	15 (12.3)	5 (4.1)	18 (14.8)	20 (16.4)	64 (52.5)
Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	49 (40.2)	13 (10.7)	27 (22.1)	13 (10.7)	20 (16.4)
Do you feel that you will be unable to take care of your relative for much longer?	57 (46.7)	15 (12.3)	33 (27.0)	10 (8.2)	07 (5.7)
Do you feel you have lost control of your life since your relative's illness?	35 (28.7)	17 (13.9)	35 (28.7)	15 (12.3)	20 (16.4)
Do you wish you could leave the care of your relative to someone else?	69 (56.6)	8 (6.6)	31 (25.4)	2 (1.6)	12 (9.8)
Do you feel uncertain about what to do about your relative?	43 (35.2)	16 (13.1)	46 (37.7)	8 (6.6)	9 (7.4)
Do you feel you should be doing more for your relative?	37 (30.3)	10 (8.2)	27 (22.1)	16 (13.1)	32 (26.2)
Do you feel you could do a better job in caring for your relative?	35 (28.7)	19 (15.6)	28 (23.0)	12 (9.8)	28 (23.0)
Overall. How burdened do you feel in caring for your relative? *	16 (13.1)	44 (36.1)	22 (18.0)	35 (28.7)	5 (4.1)

* In this question the answers are: 0 = nothing, 1 = a little, 2 = moderately, 3 = a lot, and 4 = extremely.

Table 3

Alzheimer's disease patients' dependence during daily instrumental activities and its burden on 122 family caregivers seen at the Mental Health Outpatient Clinic of Londrina State University (AHC-UEL). Londrina, Paraná State, Brazil, 2006.

Daily instrumental activities	**Independent**			**Help**			**Dependent**			**p-value ***
	n	**%**	**Mean BI**	**n**	**%**	**Mean BI**	**n**	**%**	**Mean BI**	
Telephone **	14	12.6	26.3	13	11.7	36.0	84	75.7	39.7	< 0.01
Locomotion outside the house	14	11.5	32.1	41	33.6	33.9	67	54.9	40.4	0.01
Shopping	14	11.5	28.9	14	11.5	36.2	94	77.0	38.6	0.03
Meals	14	11.5	30.7	16	13.1	34.5	92	75.4	38.7	0.07
Household chores	15	12.3	32.6	25	20.5	33.3	82	67.2	39.3	0.04
Medication	9	7.4	33.3	22	18.0	32.9	91	74.6	38.7	0.11
Money	13	10.7	30.8	21	17.2	38.3	88	72.1	38.0	0.17

BI: *Burden Interview Scale*.

* The probability described refers to the statistical analysis carried out with ANOVA between the burden assessed by the *Burden Interview Scale* and the respective daily instrumental activity;

** 11 caregivers were excluded from this variable since their patients never used the phone.

Table 4

Alzheimer's disease patients' dependence in carrying out daily basic activities and its burden on family caregivers seen at the Mental Health Outpatient Clinic of Londrina State University (AHC-UEL). Londrina, Paraná State, Brazil, 2006.

Daily basic activities	**Independent**			**Help**			**Dependent**			**p-value ***
	n	**%**	**Mean BI**	**n**	**%**	**Mean BI**	**n**	**%**	**Mean BI**	
Bathing	55	45.1	33.2	24	19.7	41.7	43	35.2	40.0	< 0.01
Dressing	54	44.3	33.8	10	8.2	39.8	58	47.5	40.0	0.03
Going to the bathroom	85	69.7	36.0	17	13.9	37.2	20	16.4	42.4	0.15
Moving	103	84.4	36.9	11	9.0	36.4	8	6.6	43.0	0.45
Urinary continence	69	56.5	35.7	28	23.0	38.7	25	20.5	40.0	0.30
Meals	68	55.7	35.5	37	30.3	39.5	17	14.0	39.5	0.25

BI: *Burden Interview Scale*.

* The probability described refers to the statistical analysis carried out with ANOVA between the burden assessed by the *Burden Interview Scale* and the respective daily basic activity.

Discussion

This study is pioneering in its attempts to construct a profile and to evaluate the burden that Alzheimer disease patients impose on caregivers. It uses patients from AHC-UEL and an expressive sample of 122 caregivers, a number higher than any other found in studies published in Brazil [3,6]. There is no universal benchmark established which allows for the classification of burden measured by the Burden Interview Scale as low or high; however, by comparing the burden index found in this study with other Brazilian studies, we observed that the scores were similar to those found for Porto Alegre, Rio Grande do Sul State [3] and higher than those found for the city of São Paulo [6,11,12]. Compared to international studies, the burden described in this study is greater than those reported in China and India, showing that in cultures where people are devoted to their elderly people and see caring for them as a family (children or spouse) obligation, caregivers have difficulty admitting any suffering, a characteristic that was more readily apparent among Latin caregivers [2,7,10].

Some characteristics of caregivers found in this study such as female, age below 60, and being the patient's relative were the variables most commonly found in many international studies [1,13,16]. For cultural reasons, societies pass on to women the caregiver role, and single daughters are more predisposed to care for the patient due to their emotional and/or financial dependence, for co-residing with the patient and for not yet having started their own family [7,16,20]. However, due to financial needs and the search for equal rights between the sexes, this paradigm is shifting and women are participating in the job market, accumulating skills. Consequently, they are subject to emotional, physical and social problems which can intensify the burden score [21]. Results have also shown that female caregivers are subject to a greater burden than their male counterparts [6,22]. Although, males also act as caregivers, the care they provide to Alzheimer's disease patients is limited to their instrumental needs [6,10,16,22]. Data from this research was insufficient to evaluate the burden on this subgroup due to the small sample size.

Some methodological limitations such as the use of a convenience sample made up of caregivers of patients from a tertiary service do not allow generalizations to other types of chronic-degenerative diseases. Other possible interferences came from estimating the patient's functional and cognitive needs based only on the caregiver's point of view and from adopting instruments developed originally to be self-applicable but which, in this study, were conducted by the interviewer. The instrument stresses subjective data which can be underestimated or overestimated in different populations, thus jeopardizing any comparison among published studies. In addition, patients were not categorized according to their Alzheimer disease stage, and the difference of the burden on caregivers in different phases of the patients' disease were not evaluated. The non-categorization of the deficit levels of patients with Alzheimer disease also makes comparison among studies difficult [3,6,11], since it is not clear whether caregivers were involved with patients with similar levels of the disease.

The incomes of elderly person and of the caregiver were not considered important factors in this study; however, Printz-Feddersen [23] believes that this variable affects burden, since a higher income could provide the caregiver with additional help to ease his or her burden. An outside job to complement family income prevents the social isolation of the caregiver but reduces the time spent with the patient as the disease intensifies and his dependence on the caregiver increases. This task is usually taken over by other family members and indirectly by maids. A study of Brazilian and Japanese family caregivers in the Southeast region of Brazil showed that the help of maids is effective and gives the caregiver more time for his or her other family businesses, spending more time with their family and on personal and professional activities [10].

In this study, the level of education of the interviewees was up to 8 years, a finding similar to those reported by other national publications [3,6,11]. However, higher levels of education had a significant positive impact on the caregiver. Other studies do not show this association, probably due to the lack of standardized data collection instruments and categorization of analyzed variables, which could have prevented comparison between studies , thus making the generalization of findings difficult [6,12,13].

Affection contributed the most to the exercise of caring analyzed in this study. According to the literature, the caregiver carries out his or her role out of love, gratitude, and marital or legal obligations [10,21]. Among the "time spent with the patient" variables, only the "weekly assistance" affected burden, which was greater according to the number of hours spent caring for the patient, a finding corroborated by the literature [6,12]. The influence of time on the caregiver's burden is controversial since this variable is seldom studied, and can be registered without the association of this variable with burden being evaluated [13]. Garcia [24], studying family life and the Alzheimer disease patient, verified that a long period of caring for the patient can work as a protection against burden. Conversely, data from this research show the increasing dependence of the patient to be a strong source of burden on the caregiver, a finding that is supported by Garrido & Menezes [6].

As for the daily activities and the burden they impose on the caregiver, previous research findings are inconsistent [19,25,26]. In this study, instrumental and basic daily activities which had a greater influence on burden were: using the telephone, locomotion, going shopping, carrying out household chores, bathing and getting dressed. The sample size may have been too small to detect the statistical significance of other variables.

Results showed that family caregivers are generally women, 29 to 88 years of age, with 8 years of schooling, who live with the patient and care for him/her with love. The burden that Alzheimer's disease patients place on family caregivers evaluated at AHC-UEL was great and independently associated with gender, the presence of extra help and the number of hours spent caring for the patient.

The provision of structured assistance to caregivers is still lacking in Brazil, and for this reason the attention given to family caregivers needs to be reevaluated by health officials. Support to caregivers through meetings, lectures and home visits with the help of a multiprofessional team will contribute to the planning and implementation of activities for the patient, encouraging caregivers to accept their limitations and to ask for help, promoting the sharing of experiences among them and mutual growth. These strategies can reinforce family and community bonds, reducing the great burden imposed on caregivers. Longitudinal research that investigates the relevance of the variables studied here will provide information on the caregiver burden in different regions around the country, on areas that need intervention and on the best strategy to be adopted, since the well being of the caregiver is essential for good quality care.

Resumo

O cuidador é indispensável ao paciente com doença de Alzheimer, no entanto cuidar é uma tarefa árdua, e as conseqüências dessa atividade em quem cuida são negligenciadas. Estudo transversal realizado na região metropolitana do Município de Londrina, Paraná, Brasil, tem por objetivo caracterizar o perfil e avaliar o impacto da ação sobre 122 cuidadores principais de pacientes com doença de Alzheimer. A escala de Katz e o índice de Lawton foram utilizadas para avaliar a funcionalidade dos pacientes com doença de Alzheimer, e a Burden Interview Scale, *para avaliar o impacto no cuidador. Caracterizaram-se seus dados sócio-demográficos. Os cuidadores foram predominantemente filhas, casadas, que aprenderam o cuidado no dia-a-dia, contavam com auxílio e exerciam a função por afeto. Associaram-se ao impacto de forma independente: idade do cuidador (p < 0,01), contar com auxílio (p < 0,01) e número de horas de cuidado (p = 0,01). Os cuidadores estudados apresentaram impacto elevado.*

Cuidadores; Doença de Alzheimer; Assistência Domiciliar

Contributors

S. R. P. Moraes was responsible for the bibliographic review, data collection, data processing and revision, interpretation of results and the writing of the article. L. S. T. Silva helped with the selection of the instruments, methodology, development of the article and revision of the final draft.

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