BURDEN AND THE EMOTIONAL DISTRESS IN CAREGIVERS OF ELDERLY INDIVIDUALS[1]

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ABSTRACT: This epidemiological and cross-sectional study describes the burdens and emotional distress observed among caregivers of elderly people. It was carried out in 2009 with 124 caregivers living in the city of Ribeirao Preto, SP, Brazil, using the following instruments: the Zarit Burden Scale and the Self-Reporting Questionnaire (SRQ-20) for caregivers. Data analysis was carried out in the SPSS, version 15.0, using descriptive, univariate (frequency tables) and bivariate (contingency tables for qualitative variables) statistics. Among the caregivers, 85.6% were women, with an average age of 56.5 years, spent an average of 12.4 hours daily with care, and 57.6% of them had mild to moderate burdens. Multiple linear regressions revealed that older adults' functional dependence and caregivers' gender and time spent weekly providing daily care were predictors of being burdened (p<0.05). Burden is also a risk factor for emotional distress (p<0.05). It is important for nurses to use protocols based on risk factors to evaluate caregivers in order to prevent burdens from developing.

DESCRIPTORS: Caregivers. Psychological stress. Aged.

SOBRECARGA E DESCONFORTO EMOCIONAL EM CUIDADORES DE IDOSOS

RESUMO: A finalidade deste estudo foi descrever a sobrecarga e o desconforto emocional dos cuidadores de idosos. Estudo epidemiológico e transversal conduzido em 2009 com 124 cuidadores residentes na comunidade de Ribeirão Preto-SP, por meio dos instrumentos: Escala de Sobrecarga de Zarit e *Self-Reporting Questionnaire* (SRQ-20) para o cuidador. A análise dos dados foi realizada no aplicativo SPSS, 15.0, de forma descritiva, univariada (tabelas de frequência) e bivariada (tabelas de contingência para variáveis qualitativas). Os cuidadores, 85,6% do sexo feminino, média de 56,5 anos, utilizaram, em média, 12,4 horas diárias para o cuidar e 57,6% dos cuidadores apresentaram de leve a moderada sobrecarga. Dependência funcional do idoso, sexo do cuidador e tempo em horas para o cuidado, foram preditores da sobrecarga (p<0,05). Encontrou-se, também, que a sobrecarga é fator de risco para desconforto emocional (p<0,05). Cabe aos enfermeiros utilizarem protocolos de avaliação, com base nos fatores de risco, para prevenir a sobrecarga.

DESCRITORES: Cuidadores. Estresse psicológico. Idoso.

LA SOBRECARGA Y DESÁNIMO EN LOS CUIDADORES DE ADULTOS MAYORES

RESUMEN: La finalidad del estudio fue describir la sobrecarga y desánimo de los cuidadores de adultos mayores. Estudio epidemiológico y transversal realizado en el 2009 con 124 cuidadores que viven en la ciudad de Ribeirão Preto, SP, por medio de los instrumentos de: Escala de Sobrecarga de Zarit y Self-Reporting Questionnaire (SQR-20) para el cuidador. El análisis de los datos fue ejecutado en el sistema SPSS, 15.0, de forma descriptiva, univariada (tablas de frecuencia) y bivariada (las tablas de contingencia para las variables cualitativas). Con respecto a los cuidadores, 85,6% fueron del sexo femenino, con edad promedio de 56,5 años, utilizaron en promedio 12,4 horas diarias para el cuidado de los adultos mayores y 57,6% de los cuidadores presentaron de una leve a moderada sobrecarga. La dependencia funcional del adulto mayor, sexo del cuidador y el número de horas para el cuidado fueron factores predictivos de sobrecarga (p<0,05). Se encontró que la sobrecarga es el factor de riesgo para el desánimo (p<0,05). Compete a los enfermeros utilizar protocolos de evaluación, con base en los factores de riesgo, para prevenir la sobrecarga en el cuidador.

DESCRIPTORES: Cuidadores. Estrés psicológico. Anciano.

INTRODUCTION

The results from the last Census conducted in Brazil revealed that most elderly individuals live with family, which is considered their main source of care.[1] Given the importance of the social position assigned by the elderly to the family and the Brazilian culture itself, the family has become the focus of studies and interventions.

'Caregiver' is defined as an individual responsible for caring for a sick or dependent individual, who helps this individual to perform daily tasks such as eating and personal hygiene, in addition to administering routine medication and accompanying the individual to health care services or other services, necessary in their daily routine, excluding techniques or procedures identified as being exclusive to other legally established professions. [2-3]

When assuming the responsibility for and providing care to an elderly person, caregivers generally do it in an uninterrupted fashion, that is, without rest. The caregiver works for many hours in a row, mainly with activities related to bodily care, feeding, elimination, environment, health control and other situations, which leads caregivers to experience stressful situations and burdens. [4]

Burdens generated in caregivers can lead to the development of psychiatric symptoms, fatigue, the use of psychotropic medication, in addition to a worsened health condition, depleting a caregiver's suitable condition to care elderly individuals. The caregiver activity can also affect the caregivers' social and economic spheres, hurting all aspects of their lives.[5]

The conception of the term 'burden' includes physical, psychological or emotional, social or financial problems experienced by family caregivers, represented by both subjective and objective aspects, arising from the caregiver role. [6]

Burden can be expressed by physical problems such as multiple somatic complaints, among them mechanical pain in the limbs, tension headaches, asthenia, chronic fatigue, changes in the sleep-wake cycle, as well as psychological problems manifested by disorders such as depression, anxiety and insomnia, which are routes through which emotional discomfort manifests.[7]

Study in this field is crucial for health workers to carefully evaluate and care for this population affected with the problems this activity may cause. Hence, considering this theme, we opted to conduct a study with the objective to evaluate burden and emotional distress among caregivers of elderly individuals living in the community in Ribeirão Preto, SP, Brazil.

SUBJECTS AND METHODS

This epidemiological, descriptive and cross-sectional study was conducted in the urban area of Ribeirão Preto, SP, Brazil with elderly individuals, both genders, living in the community, and their respective caregivers.

Two-stage cluster sampling was used. In the first stage, we considered the Census Sectors* to be the Primary Sampling Unit (PSU). Therefore, 30 census sectors were randomly drawn from the 600 sectors in the city, with a probability proportional to the number of households. The second stage included visiting a fixed number of households in order to ensure a self-weighted sampling; the street and block where the process began were randomly drawn. A minimum of 110 households in each sector was visited in order to reach the expected number of elderly individuals in each sector.

After the sectors were drawn, they were identified on a map of the city of Ribeirão Preto, SP, Brazil and the visited neighborhoods and streets were visualized. The streets of each drawn sector were listed so a new random drawing would be performed in order to determine which streets would be visited by the interviewers. Concomitantly, maps of each drawn sector were printed and the interviewer teams were assigned. Elderly individuals were excluded from the sample if interviewers were not received after three visits.

Interviews were held in the drawn sectors following a clockwise direction. If at the end of the 110 households interviewed in each sector, interviewers were not able to reach the proposed intra-house density, visits continued until the expected number of elderly individuals per sector was achieved. Sampling errors were fixed around 10%. Regarding confidence intervals for prevalence, estimated post-strata defined ac-

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* T.N. These sectors are defined by the Brazilian Census Bureau according to operational criteria and include from 250 and 300 households in urban areas.

cording to age and gender, 10% was considered the upper limit for tolerated error. Only 164 of the 574 interviewed elderly individuals had a caregiver. There was 24% loss due to moves and individuals who did not agree to participate in the interview.

During visits in each household, elderly individuals and their respective caregivers were invited to participate in the study. Those who consented and met the inclusion criteria signed two copies of free and informed consent forms.

Inclusion criteria were: elderly individuals 65 years old or older, either gender; living in the community by themselves or with family members; and having family caregivers. Exclusion criteria were institutionalized individuals and paid caregivers.

Data collection was conducted from January to July 2009 after approval was obtained from the Ethics Research Committee at the University of São Paulo at Ribeirão Preto, College of Nursing (protocol No. 0884/2008). The following instruments were used to collect data from the caregivers:

Instrument to characterize the caregiver: the instrument addressed the caregivers' gender, age, marital status, kinship, knowledge concerning the disease, whether the caregiver had attended a formal course to learn how to care, how many hours were spent providing care, care activities and support received. It was developed by the researcher together with her advisor and submitted to the analysis of three experts in the field of gerontology. Suggestions were provided and some items were changed.

The Zarit Burden Interview: developed in 1987[6], translated and validated for the Brazilian culture in 2002. [8] This scale, with 22 items, assesses the perceived impact of the caregiver role on one's physical and emotional health. The 22 items are answered according to a five-point scale that describes the degree of each statement. The total score is obtained by totaling all the items and ranges from 0 to 88. The higher the score, the greater the caregiver's perceived burden. Cut-off points were used to diagnose burden: scores between 61 and 88 were considered to describe intense burden; scores between 41 and 60 express moderate to severe burden; scores between 21 and 40 are considered to express moderate to mild burden; and scores below 21 points characterize an absence of burden. [4,9]

Self-Reporting Questionnaire (SRQ-20): this instrument was developed in 1980[10] and validated in Brazil 1986[11]. It detects emotional distress in the population in general. Scores range from 0 to 20 and the cut-off point used of 7/8 is based on a Brazilian study to discriminate cases in which there are emotional disorders.

Data concerning the elderly individuals receiving care were collected through a social profile identification instrument, the Mini Mental State Exam (MMSE). This scale was developed in the United States, [12] translated and validated in Brazil in 1994.[13] It is used to aid the investigation of potential cognitive deficits. The Functional Independence Measure (FIM), developed in 1986,[14] and translated and validated in Brazil in 2004,[15] was used to evaluate the individuals' functional impairment.

Data analysis was performed using the Statistical Package for the Social Science (SPSS) version 15.0. Descriptive, univariate (frequency tables) and bivariate (contingence tables for qualitative variables) statistics were performed. The averages of categorical variables were statistically analyzed by Student's t test and the one-factor ANOVA was utilized to compare more than two groups. Spearman's correlation was computed between ordinal and quantitative variables while Pearson's correlation was used for quantitative variables. Correlations were considered weak ($r<0.3$), moderate ($0.3 \leq r \square 0.7$) or strong ($r \geq 7$).

RESULTS

A total of 124 caregivers were interviewed: 107 (85.6%) were women and 17 (14.4%) were men. The average age of caregivers was 56.6 (±13.4), while male caregivers were older (61.8; ±18) than female caregivers (55.7; ±55.7).

The analysis of the caregivers' characteristics related to burden (Table 1) revealed that age was statistically correlated to being burdened in the same way gender was correlated to emotional distress (SRQ).

Table 1 – Distribution of the caregivers' characteristics according to the averages of burden and emotional distress. Ribeirão Preto, SP, Brazil 2009

Caregivers characteristics	Zarit-Average (SD) 27.8 (17.5)	p-value	SRQ-Average (SD) 6.0(4.4)	p-value
Gender		0.691*		0.042*
Female	28.1(17.5)		6.3(4.6)	
Male	26.2(16.4)		4.0(2.8)	
Age		0.049*		0.810*
60 years or younger	29.9(17.6)		5.8(4.6)	
60 + years old	30.8(17.2)		6.2(4.1)	
Educational Level		0.100		0.054
Illiterate	26.1(16.9)		4.9(3.2)	
1 to 4 years	31.1(19.6)		7.0(4.2)	
5 to 8 years	26.7(14.2)		6.2(4.9)	
9 to 11 years	21.6(14.9)		4.1(3.2)	
12 years or more	31(22.3)		6.1(6.1)	
Kinship		0.647		0.256
Spouse	31.7(18.1)		6.9(3.7)	
Child/child-in-law	27.3(14.7)		6.1(4.6)	
Siblings/brother- sister-in-aw/grand-child	21.9(13.7)		5.6(4.6)	
	24.7(11.4)		7.4(5.1)	
Live with the elderly person?		0.273		0.062
Yes	28.8(15.8)		6.4(4.5)	
No	24.4(23.6)		4.7(3.7)	
Has knowledge concerning care delivery?		0.398		0.341
Yes	27.5(17.8)		5.9(4.5)	
No	31.7(13.2)		6.9(2.5)	

*t= Student's t test.

Pearson's correlation showed that the age of caregivers ($p<0.05$) and daily hours spent with care during the week and weekends ($p<0.05$), an average of 12.4 hours and 12.3 hours respectively, were significantly related to burden. A positive correlation with hours spent with daily care during the week and weekends was observed in relation to emotional distress ($p<0.05$) (Table 2).

Table 2 – Pearson's correlation concerning burden and emotional distress related to age, and hours spent and number of days care is provided. Ribeirão Preto, SP, Brazil 2009

Pearson's correlation	Caregiver age	Hours/week (Average=12.4horas)	Hours/Weekend (Average=12.3 hours)	Day/week (A=4.95)	Day/weekend (A=1.94)
Burden	0.178*	0.252*	0.260*	-0.018	0.040
SRQ	-0.022	0.237*	0.227*	-0.043	0.019

*$p<0.05$.

The multiple linear regressions to explain the total scores obtained on the Zarit scale and SRQ when using as predictors the caregivers' variables 'gender', and 'hours spent daily during the week

and during weekends' and also the SRQ values as predictors of burden, showed that the caregiver's gender was a good predictor of emotional distress (β=-0.161; p=0.042) as were the hours spent daily providing care (β=-0.237; p=0.009) for burden. These findings reveal statistically significant data, adjusting for the remaining variables. Caregiver's burden was a strong and revealing predictor of emotional distress (β=-0.454; p<0.001).

In analyzing the characteristics of elderly individuals as determinants of caregiver burden and emotional distress, a statistically significant difference was observed only when burden was associated with cognitive deficit and FIM score. Emotional distress presented significant association only with FIM (Table 3).

Table 3 – Distribution of the socio-demographic characteristics of elderly individuals in relation to the averages of burden and emotional distress for caregivers. Ribeirão Preto, SP, Brazil 2009

Elderly individuals' characteristics	Burden average (SD)	p-value	Average SRQ (DP)	p-value
Age range		-		-
65–69	30.0(16.6)		5.2(2.9)	
70–74	21.3(11.6)		5.1(4.1)	
75–79	26.6(17.2)		6.6(4.6)	
80 years old or older	30.7(18.7)		6.1(4.7)	
Gender		0.876*		0.243*
Female	27.5(18)		5.6(4.4)	
Male	28.1(16.3)		6.7(4.6)	
Marital status		0.692		0.880
Married	27.1(16.9)		5.7(4.1)	
Widowed	28.1(18.2)		6.2(4.6)	
Single	24.5(15.5)		5.0(4.9)	
Divorced/separated	39.0(19.9)		6.3(5.0)	
Education Level		0.812		0.087
Illiterate	27.1(15.6)		6.7(4.6)	
1 to 4 years	27.7(18.9)		5.6(4.4)	
5 to 8 years	36.8(13.9)		7.4(3.9)	
9 to 11 years	17.8(22.1)		3.2(2.9)	
12 years old	27.7(12.3)		3.3(4.2)	
Cognitive deficit (MMSE)		0.035*		0.137*
Yes	29.9(18.6)		6.1(4.3)	
No	24.8(15.8)		5.8(4.7)	
Functional Independence Measure (FIM)		0.004		0.014
Complete dependence	33.3(9.2)		6.9(2.7)	
Moderate dependence	32.5(16.8)		6.7(5.3)	
Minimum dependence	29.9(19.3)		6.8(4.7)	
Modified/complete independence	22.3(15.2)		4.5(3.6)	

*t = Student's t test.

According to the diagnosis of burden (Table 4), caregivers diagnosed with intense burden are those caring for older elderly individuals (average = 91 years old), with lower educational levels, and those who obtained lower scores on the MMSE. Elderly individuals with lower averages obtained in the global, motor and cognitive FIM are cared for by caregivers diagnosed with moderate burden.

Table 4 – Distribution of averages presented by the elderly individuals in terms of age, MMSE, Global FIM, Motor FIM, Cognitive FIM related to the ordinal categories of burden. Ribeirão Preto, SP, Brazil 2009

Elderly individuals' data	Absence of burden	Mild burden	Moderate burden	Intense Burden
Age	82(8.0)	81(8.3)	82.9(8.7)	91.3(11.1)
Educational level	3.2(4.9)	3.2(4.1)	2.8(8.7)	2.3(2.1)
MMSE	17.1(7.6)	15(8.8)	12.8(8.5)	12.7(6.4)
Global FIM	96.9(27.3)	84.9(33.8)	81.7(29.7)	91.3(16.7)
Motor FIM	70.6(20.5)	61.4(25.7)	61(23.6)	69.7(17.2)
Cognitive FIM	26.4(8.5)	23.4(10.2)	20.7(10.0)	21.7(2.%)

The linear regression analysis to explain the total scores of the Zarit Burden Scale and SQR and the elderly individuals' predictor variables, such as global FIM and cognitive performance, showed that the dependency of the elderly individuals was statistically associated (β=-0.179, p=0.046), and is a predictor of burden when adjusted for the remaining variables. Associated with emotional distress, the regression analysis showed marginally significant values. Data suggest that the dependency of elderly individuals is a risk factor for caregiver burden.

DISCUSSION

The analysis of the characteristics of the caregivers related to burden showed that female caregivers older than 60 years of age obtained a higher average compared to male caregivers. Such a result is in agreement with studies addressing caregivers of elderly individuals with dementia[16-18] and depression.[7]

Older caregivers seem to be more vulnerable to burden, though younger individuals may suffer more with isolation and greater social restrictions, proportional to the greater possibilities of social activities and leisure available for their age range.[19]

The social inclusion of women, who have progressively participated in the job market, characterizes changes in current society. For this reason, women add to their caregiver role, work outside the home and domestic tasks inherent to the role of mother, wife and often, the role of grandmother, generating an accumulation of work at home and burden in various domains of life, such as the social, physical, emotional, and spiritual domains. Altogether, these factors contribute to their neglect of their own health.[5]

Data related to educational level revealed greater averages of burden for those who studied from one to four years and those who studied more than 12 years. Therefore, a negative linear association was not observed between these variables. The caregivers' educational level did not indicate a strong association related to burden in a study addressing caregivers of demented elderly individuals.[20]

The greatest burden was also observed in caregivers who are the spouses of the elderly individuals requiring care. Studies show that the spouse often manifests distress and feelings of loneliness when s/he assumes the care of the elderly individual at home alone.[4] Thus, the importance of other family members providing support to the caregiver is evident, even if such support is provided only during visits. A study evaluating the population of elderly individuals 80 years old or older in the city of Ribeirão Preto, SP, Brazil showed that the older elderly individuals (26.5%), especially those aged between 80 and 84 years old, lived with their spouses only, which may indicate reduced family support.[21]

This study showed intense and uninterrupted hours of care delivery, with an average of 12.3 hours/day and 4.95 days/week. Such averages, however, were below those reported in another study[22]: an average of 15.6 hours/day, though this result refers to care provided to demented individuals, who present greater care demands. Often, the caregivers' feelings of burden or exhaustion are associated with symptomatology characterized in individuals who suffer burdens resulting from the great dedication and effort exerted in the care activity in which the caregiver neglects his/her own needs, and constitutes a psychosocial problem.[6]

The general average obtained by caregivers on the SRQ was 6.0 (±4.4), indicating they are at the risk of experiencing emotional distress. Other studies report that caregivers of demented elderly

individuals obtained an average of 6.7 on the SRQ.[23] This study's results indicate that emotional distress experienced by caregivers is strongly associated with burden while being burdened is indicated as a risk factor for emotional distress. It is important to prevent caregiver burden because, in addition to causing numerous problems in the lives of caregivers, symptoms of emotional distress may also manifest, such as headaches, insomnia, poor appetite, sadness, and anxiety, among others.

Similar to burden, emotional distress was potentially associated with time spent daily providing care, in agreement with other Brazilian studies.[7,23] It is common to find family caregivers with depression as a response to prolonged exposure to a situation of physical and emotional exhaustion, a potential generator of stress.[4]

When analyzing the characteristics of elderly individuals, we observed that caregivers of older elderly individuals experience greater burden than those caring for younger elderly individuals, though the data were not statistically significant. These results are similar to those reported by another study indicating greater burden for caregivers of older elderly individuals. Elderly individuals usually have specific demands of care due to the decline of some of their abilities experienced over the years.[19] In contrast, other researchers show some divergence concerning decreased levels of burden over the years, possibly explained by an adaptive process. During the adaptive process and with experience gained over time in care activities, caregivers report more confidence with experiences, which reduce feelings of burden.[20]

No significant differences were observed in this study concerning averages of burden between female and male caregivers, the elderly individual's marital status, education or income. Another study addressing caregivers of elderly individuals with depression[7] does not report any statistically significant association, either, between burden and socio-demographic characteristics (age, gender, educational levels and income) of the elderly individuals.

The comparison of the cognitive ability of the elderly individuals with caregiver burden resulted in variables inversely proportional, that is, the lower the individual's cognitive ability, the greater the burden. Researchers defend the view that the responsibility for caring for an elderly individual with cognitive deficit caused by dementia generates physical and psychological changes in caregivers, making them potentially sick individuals and constantly putting their functional capacity at risk.[4,15-16,23]

Functional ability was the only factor statistically significant to the caregiver's burden, also with inversely proportional averages: the lower the score obtained in FIM, the greater the burden. Such a result reveals that the greater the dependence of the elderly individual, the greater the chances of the caregiver being burdened, similar to the results found in other studies.[7,17,21,23]

According to the burden diagnosis based on the cut-off points previously mentioned, 72 (57.6%) caregivers presented mild to moderate burden. A study describing the burden of 36 caregivers of elderly individuals with Alzheimer's disease in Alegre, RS, Brazil reported that 20 (55.6%) of the caregivers presented moderate burden.[4] We did not identify other Brazilian studies comparing the scores of caregiver burden with the characteristics of elderly individuals. Therefore, we consider these findings to be essential to planning care delivered to elderly individuals and support provided to caregivers.

The task of caring for an elderly individual requires from caregivers almost exclusive dedication, especially in the case of elderly individuals with a disabling disease. Caregivers are oftentimes required to leave their jobs and occupations, and put aside their own lives, while only a few can depend on the help of others to share the care task. .[23]

Society, composed of social actors, government and non-governmental organizations, needs to jointly promote effective social participation, in order to improve the condition of the lives of caregivers of elderly individuals to prevent or even reduce the burden they experience. The Government Action Plan sets the guidelines for care, however, state and city health care services, universities, NGOs and other networks should coordinate their efforts and devise formal and informal interventions for family caregivers of elderly individuals.

CONCLUSIONS

This study contributed to improving knowledge concerning symptoms arising from burden and emotional distress experienced by the caregivers of elderly individuals living in the community, showing that 72 (57.6%) of the caregivers experience mild to moderate burden.

Analyzing the characteristics of the family caregivers with burden we observed that most

were adult female caregivers, when women have numerous social roles: mother, spouse, and homemaker, among others. Often the female caregiver has other social responsibilities, such as work outside the home, in addition to providing care to already elderly parents.

The study also shows that care activities led caregivers to experience emotional distress in addition to burden, associated with impairment of elderly individuals in the performance of daily life activities, revealing that the dependence of elderly individuals was an important predictor of caregiver burden.

Time spent daily providing care was frequently uninterrupted while many caregivers provided care without pausing for rest or leisure. The variables concerning caregivers, such as being a woman and spending an average of 12 hours daily, correlated with the variables related to the elderly individuals, such as functional dependence. These are factors that should draw the attention of health workers to the possibility that caregivers may experience burden. Hence, the role of health workers is to use assessment protocols based on risk factors to diagnose and prevent this problem.

Further studies are suggested in the field regarding interventions with caregivers living with elderly individuals that use assessment tools validated for the Brazilian population, since research conducted in the field usually focuses on caregivers of elderly individuals with dementia. Such work will benefit not only caregivers but also patients, since caregivers can provide more efficient care when not experiencing burden or distress.

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