



Revista da Escola de Enfermagem da USP

ISSN: 0080-6234

reeusp@usp.br

Universidade de São Paulo

Brasil

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Revista da Escola de Enfermagem da USP, vol. 47, núm. 1, febrero, 2013, pp. 185-192

Universidade de São Paulo

São Paulo, Brasil

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Burden on caregivers of elderly victims of cerebrovascular accident*

SOBRECARGA DOS CUIDADORES DE IDOSOS COM ACIDENTE VASCULAR CEREBRAL

SOBRECARGA DE LOS CUIDADORES DE ANCIANOS CON ACCIDENTE CEREBROVASCULAR

Roberta Amorim Pereira¹, Emanuella Barros dos Santos², Jack Roberto Silva Fhon³, Sueli Marques⁴, Rosalina Aparecida Partezani Rodrigues⁵

ABSTRACT

The aim was to assess the burden on caregivers of elderly victims of cerebrovascular accident (CVA) and to correlate it with care hours, the elderly people's age and functional independence. This cross-sectional study counted the participation of 62 elderly individuals with CVA and their caregivers. The instrument used contained socio-demographic and economic variables, the Mini-Mental Status Examination, the Functional Independence Measure (FIM) and the Zarit Scale. The possible correlations between the Zarit scale scores and the other variables were assessed using Pearson's Correlation Coefficient. Most caregivers were adults, children of the victims, married, and female. The mean Zarit score was 34.92(15.8). The FIM showed a negative correlation with caregiver burden, but no correlation with age and number of care hours. The burden on most of the caregivers ranged from moderate to severe and seems to be related to the level of functional independency of the elderly.

DESCRIPTORS

Aged
Stroke
Caregivers
Geriatric nursing

RESUMO

O objetivo deste estudo foi avaliar a sobrecarga dos cuidadores de idosos com acidente vascular cerebral (AVC), assim como correlacioná-la com as horas de cuidado, a idade e a independência funcional dos idosos. Trata-se de estudo transversal feito com 62 idosos com AVC e seus cuidadores. O instrumento continha variáveis sociodemográficas e econômicas, Mini-Exame do Estado Mental, Medida da Independência Funcional (MIF) e a Escala de Zarit. A possível correlação entre os escores da escala de Zarit e as outras variáveis foi avaliada por meio do Coeficiente de Correlação de Pearson. A maioria dos cuidadores era adultos, filhos, casados e do sexo feminino. A média do escore de Zarit foi 34,92 (15,8). A MIF apresentou correlação negativa com a sobrecarga do cuidador, porém, não houve correlação com a idade e as horas de cuidado. A sobrecarga da maioria dos cuidadores variou de moderada a severa e parece estar relacionada ao nível de independência funcional dos idosos.

DESCRITORES

Idoso
Acidente vascular cerebral
Cuidadores
Enfermagem geriátrica

RESUMEN

Se objetivó evaluar la sobrecarga de cuidadores de ancianos con accidente cerebrovascular (ACV), y correlacionarla con horas de cuidado, edad e independencia funcional de los ancianos. Estudio transversal con 62 ancianos con ACV y sus cuidadores. El instrumento contenía variables sociodemográficas y económicas, Mini-Examen del Estado Mental, Medida de la Independencia Funcional (MIF) y la Escala de Zarit. La posible correlación entre los puntajes de la escala de Zarit y las otras variables fue evaluada por Coeficiente de Correlación de Pearson. La mayoría de los cuidadores eran adultos, hijos, casados y de sexo femenino. El promedio de puntaje de Zarit fue 34,92 (15,8). La MIF presentó correlación negativa con la sobrecarga del cuidador, sin embargo no hubo correlación con edad y horas de cuidado. La sobrecarga de la mayoría de los cuidadores varió entre moderada y severa, y parece relacionarse con el nivel de independencia funcional del anciano.

DESCRIPTORES

Anciano
Accidente cerebrovascular
Cuidadores
Enfermería geriátrica

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INTRODUCTION

Among non-transmissible chronic illnesses, cerebrovascular accident (CVA) is a frequent neurological syndrome in adults and the elderly and represents one of the primary causes of morbidity and mortality in the world⁽¹⁾. Its incidence levels increase after the age of 65 years, and the risk rates increase with age and double every decade after the age of 55 years. CVA is the primary cause of functional disability, preceded only by cardiovascular illnesses and cancer⁽²⁾.

Because CVA provokes sequelae and relevant limitations in survivors, it is the most common cause of functional disability in the Western world⁽²⁾. Its global prevalence in the general population ranges from 0.5% to 0.7%⁽²⁾. Approximately 50% of the CVA population survives and requires nursing supervision after hospital discharge, often in primary healthcare, which demands orientation and care to adapt to the new lifestyle that the disease imposes. However, approximately 20% of CVA victims die within one month after the accident. An additional 30% survive and, despite certain neurological deficits, they remain able to live independently⁽²⁻³⁾.

Statisticians estimate that approximately two million people survive CVA and have a disability, 40% of whom need help with daily activities⁽⁴⁾. After hospitalization, elderly CVA victims often return home with physical, cognitive and behavioral sequelae that compromise their functional abilities, independence and autonomy. These social and economic limitations affect all aspects of their lives⁽⁵⁾.

After hospitalization, 80% of CVA survivors return to the community. However, they continue to demand special care. The family generally provides this care in Brazil, given Brazilian culture and socioeconomic conditions⁽⁶⁾.

Changes in the dynamics of these patients' lives can occur as a result of the disabling sequelae of CVA. These changes include restrictions in daily activities such as those related to physical movement, cognition and decision-making concerning the lives of one's self and one's family.

In this context, caregivers emerge as important people with regard to care delivery and patient rehabilitation. The caregiver is responsible for performing the tasks that the patient injured by CVA is no longer able to do. Moreover, they compensate for the patient's temporary or permanent functional disability. Two types of caregivers exist. *Formal caregivers* are hired by the elderly, their family or both to give care. These caregivers establish a job contract. *Informal caregivers* are family members or acquaintances (e.g., friends, neighbors or church members among others) of the elderly who provide care⁽⁷⁾.

Most caregivers of elderly CVA victims are informal because the family is historically responsible for caring for itself⁽⁷⁾. Due

to the increased number of chronic illnesses in the elderly, this circumstance is enhanced by a lack of financial resources to hire a homecare company or a private professional.

The prolonged illness of a family member is a stressful situation and threatens the normal balance of personal, family and social functioning. Informal caregivers (IC) are subject to problem situations due to adverse conditions and a lack of immediate problem-solving abilities, which can lead to a state of psychosocial disorganization that is frequently accompanied by negative feelings such as fear, guilt and anxiety. When this state of discomfort and tension occurs over a long period, these individuals tend to adopt new response modes to overcome the crisis, which can lead to an unhealthy adjustment to negative emotions, thereby causing caregiver burden⁽⁸⁾.

IC burden is a disorder that results from coping with the physical dependence and mental disability of the individual receiving attention and care. The care process for an elderly or dependent family member, which is continuous and almost always irreversible, includes five crisis situations: the awareness of degeneration, unpredictability, time limitations, the affective relationship between the caregiver and the target of care and the lack of alternative options⁽⁹⁾.

Due to increased life expectancy and, consequently, the greater number of disabling conditions (and the omnipresence of caregivers), knowledge of IC burden must guide nursing action planning that is focused on the caregivers of elderly patients.

Thus, this study assessed the relationship between the burden of the ICs of elderly CVA victims and care hours, patient age and functional independence.

METHODS

This cross-sectional and quantitative study examined elderly CVA victims and their ICs. These participants (62 elderly adults and their respective ICs) were recruited between January and December 2010 at the Emergency Unit of the Ribeirão Preto Medical School *Hospital das Clínicas* (HCFMRP) using the registers of the Medical Filing Service (SAM). Next, the elderly victims were contacted by telephone to schedule interviews at their homes. Nurses collected data at the patients' homes using an interview between January and June 2011.

The inclusion criteria for the elderly participants were an age of 60 years or older, a medical diagnosis of (ischemic or hemorrhagic) CVA, a return home after hospital discharge, residence in Ribeirão Preto, SP and care from an IC. The inclusion criteria for the caregiver were an age of 18 years or older and being the elderly patient's IC.

The instrument consisted of four sections. The first section identified participant sociodemographic and economic variables (i.e., age, gender, family income, marital status and education) using a standardized questionnaire.

The second section used the Mini-Mental State Examination (MMSE) to evaluate the patient's cognitive status. This scale consists of questions grouped in seven cognitive domains, such as time orientation, spatial orientation, three-word register, attention and calculation, remembering three words and language and visual constructive capacity. The cut-off points were based on education level, with 12 denoting illiterate participants, 18 representing low (1-3 years) and average (4-7 years) education levels and 16 denoting a high education level (8 years or more)⁽¹⁰⁾.

The third section used the Functional Independence Measure (FIM) to assess patient functional independence. This scale measures the level of assistance that the patient requires to accomplish daily motor and cognitive activities. The scale consists of 18 items distributed across the following domains: self-care, sphincter control, transfers, locomotion, communication and social cognition. Each item is scored between 1 and 7, where 1 denotes complete dependence, 2 represents maximum dependence, 3 is moderate dependence, 4 is minimum dependence, 5 represents supervision, 6 denotes modified independence (technical help), and 7 denotes complete independence. The total score, which characterizes the patient independence level, ranges between 18 and 126 points⁽¹¹⁾.

The final section of the instrument uses Zarit's Caregiver Burden Scale to evaluate the IC's burden. This scale includes 22 items that assess the health as well as the psychological and socioeconomic wellbeing of the primary caregiver and his or her relationship with the patient. Each item consists

of a statement that is scored according to the frequency of its occurrence: 0 (never), 1 (hardly ever), 2 (sometimes), 3 (almost always), and 4 (always). The total score is calculated by adding all the items, and it ranges from 0 to 88. High scores denote large caregiver burdens⁽¹²⁾.

The data collection procedures began after the project received approval from the Ethics Committee at the Ribeirão Preto Medical School Hospital das Clínicas (HCFMRP) in August 2010 (process 7735/2010). This approval was in compliance with National Health Council Resolution 196/1996, which sets the guidelines for human subject research.

The data were compiled in an Excel worksheet using double entry to validate the scores and detect inconsistencies. Next, the data were imported into the Statistical Package for Social Sciences (SPSS) for Windows version 15.0. Descriptive statistics were determined for all variables, including the means and standard deviations of the quantitative variables. The relationships among the Zarit scale scores, FIM, patient age, care hours per week, and care hours during the weekends were evaluated using Pearson's correlation coefficient. Significance was set at 5%.

RESULTS

Table 1 presents the patient sociodemographic characteristics. Elderly individuals aged 75 years or older (51.6%) predominated. The age of the sample ranged between 60 and 87 years, and the mean age was 73.9 (7.70) years. The majority of patients had between 1 and 4 years of education, with an overall mean of 3.95 years (2.50). Most patients were female and married. Thirty-nine patients (62.9%) presented cognitive deficits according to the MMSE cognitive status evaluation.

Table 1 - The age, education, gender, marital status and domestic structure of elderly CVA victims who had attend a public hospital - Ribeirão Preto, 2011

Variable	N	%	Mean (SD*)	Median	Observed Variation
Age			73.9 (7.70)	74.7	60 – 87
60 – 64	7	11.3			
65 – 69	13	21.0			
70 – 74	10	16.1			
75 – 79	17	27.4			
80 or older	15	24.2			
Education (years)			4.0 (2.5)	4.0	0-10
Illiterate	10	16.1			
1 – 4 years	36	58.1			
5 – 8 years	13	21.0			
9 years or more	3	4.80			
Gender					
Male	30	48.4			
Female	32	51.6			
Marital status					
Single	4	6.50			
Married	32	51.6			
Widowed	26	41.9			

*SD = Standard Deviation

Note: (n= 62)

The social profile of the ICs is displayed in Table 2. Despite the predominance of young adult caregivers, it is noteworthy that many caregivers were elderly. The family relationship

between the caregivers and the patients was equally distributed between children and partners, and most caregivers were female. The mean caregiver age was 56.3 (12.5) years.

Table 2 - The age, education, gender, marital status and family relationship of elderly CVA victims at a public hospital - Ribeirão Preto, 2011

Variable	N	%	Mean (SD*)	Median	Observed Variation
Age (in years)			56.3 (12.5)	57	27 – 79
27 – 59	33	53.2			
60 or older	29	46.8			
Education (years)					
Illiterate	1	1.60			
Able to read and write	1	1.60			
1 - 4 years	21	33.9			
5 - 8 years	19	30.6			
9 - 12 years	11	17.7			
13 years or older	9	14.5			
Gender					
Male	10	16.1			
Female	52	83.9			
Marital status					
Never married or lived w/ partner	13	21.0			
Married	42	67.7			
Separated/divorced	5	8.10			
Widowed	2	3.20			
Family relationship					
Husband/wife	25	40.3			
Son/daughter	26	41.9			
Sibling	3	4.80			
Grandchild	1	1.60			
Son-/daughter-in-law	5	8.10			
Others	2	3.20			

*SD = Standard Deviation
Note: (n= 62)

Figure 1 displays the distribution of Zarit Scale caregiver burden scores, which ranged between 5 and 67 points, with a mean of 34.9 and a standard deviation of 15.8. Approximately 40% of the caregivers scored 44 or higher, which denotes a moderate to high burden.

Table 3 displays the correlations between caregiver burden and the patient variables. The functional independence of the patients with regard to the motor and cognitive domains was negatively correlated with caregiver burden, which suggests that higher levels of burden are associated with elderly patients with greater dependence. However, no correlation was observed between caregiver burden and either patient age or care hours.

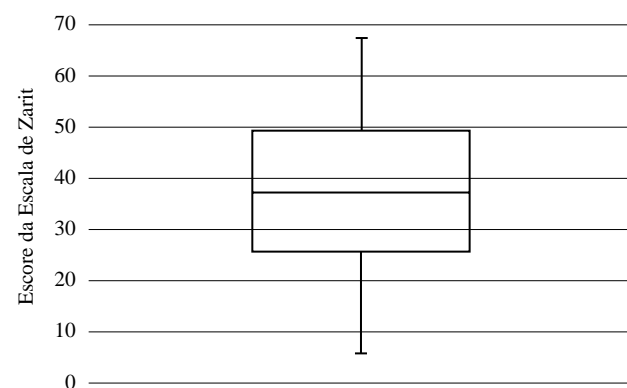


Figure 1 - Box-plot of caregiver's Zarit Caregiver Burden Scale scores - Ribeirão Preto, 2011

Table 3 - Pearson's correlation coefficients between caregiver burden and age, total FIM score and care hours - Ribeirão Preto, 2011

	Patient age	Total FIM	Motor FIM	Cognitive FIM	Weekly care hours	Care hours at weekends
Zarit	- 0.008	-0.466**	-0.444**	-0.496**	0.216	0.223

**p < 0,01

DISCUSSION

The data collected with regard to the age, gender and marital status of most elderly CVA victims in this study are in line with another study⁽¹³⁾ that emphasized that advanced age is a risk factor for CVA because the incidence of this morbidity more than doubles over decades and affects more women than men. Being married predicts that the partner will serve as the caregiver to elderly CVA victims.

Most of the elderly patients in that previous study were illiterate⁽¹³⁾; however, in a different study⁽⁵⁾, 45.4% of the elderly patients could read and write. In this study, an education level between 1 and 4 years predominated, which characterizes a sample with a low education level. This finding, which is associated with socioeconomic and cultural factors, might contribute to the appearance of the disease because it hampers an awareness of healthcare needs, treatment adherence, the maintenance of a healthy lifestyle and the prevention of risk factors.

In addition to education, cognitive status is of fundamental importance to the understanding, adherence and self-care abilities of elderly patients. The MMSE data revealed that most elderly patients (62.9%) suffered cognitive deficits. This result is in line with the findings of a study⁽¹⁴⁾ that found a high prevalence of cognitive deficits in patients up to three years after the CVA. Hence, the high percentage cognitive deficits observed in this study might derive from CVA sequelae, which commonly involve memory, orientation, language and attention. Another factor that contributes to cognitive deficits is advanced age; in this study, 51.6% of the patients were at least 75 years old.

All interviewed caregivers were ICs who usually identified themselves as the primary caregivers (i.e., they were responsible for the elderly and most of their daily tasks). In general, the IC was a relative or friend, which is a common practice in 80% to 90% of the situations in which the self-care abilities of an elderly patient have been compromised. One cross-sectional study with a qualitative approach⁽⁶⁾ described the predominance of these characteristics in the caregiver profiles.

A significant number of caregivers were elderly (75 years or older). A similar situation was observed in another study⁽⁶⁾. Advanced age can be a cause for concern in the care process because these caregivers can experience physical and functional limitations due to the advanced aging process.

The majority of caregivers was female, underlining the caregiving role of women in Brazilian culture. Historically, women have been responsible for care, whether for the home or the children, whereas the role of men is to work and provide the family's income. Despite recent social and

family composition changes and the new roles that women have assumed (including a greater participation in the job market), women are still expected to serve as caregivers. Hence, women commonly take charge of care even when they have another job. This practice reduces their free time and affects their social life. In general, men participate in care secondarily through financial help or external tasks such as transporting the patient and paying bills⁽⁶⁻⁷⁾.

Caregiver marital status also requires attention. The current findings revealed that most caregivers, whether they were the children or partners of the patients, were married. This factor can be positive and facilitate and support certain caretaking activities, or it can be negative when it causes a burden for the caregiver due to an accumulation of roles.

The caregiver education level is relevant because they receive information and orientation from the health team and accompany the elderly patients to health services. Education level can influence caregiver feelings; specifically, a low education can hamper an understanding of what is happening to the patient. However, caregiver feelings derive from a complex interaction of factors that extend beyond information⁽⁶⁾.

In line with the present findings, other authors⁽¹⁶⁾ have emphasized that the responsibility for care is transferred to the children when the partner passes away or is unable to perform this role. Those authors add that a relationship of obligation exists that derives from the values imposed by family culture; that is, caregiving is a moral obligation. When the caregivers are children, their parents take care of them; thus, when parents become dependent, children should take care of their parents. This feeling continues across generations. When children serve as their parents' caregivers, a feeling of obligation is often combined with retribution of care and affection⁽¹⁶⁾.

When partners assume the caregiver role, a relationship of obligation is perceived; however, this situation refers to the *marital obligation* of a common life project that is assumed through marriage and the commitment to be together *in sickness and in health*⁽¹⁵⁻¹⁶⁾.

Thus, disease (especially a chronic condition) is always a stressful event that affects patients and families. When experiencing this crisis, families initially experience disequilibrium in their normal functioning ability, thereby provoking changes in affection, finance and power relationships that lead to a family reorganization process. Family caregivers then emerge as an important part of the plan to maintain elderly patients' autonomy, integrity and participation in family relationships and society.

These data also reinforce the need to give continued attention to family caregivers because the social and

economic changes that are transforming the family structures in Brazilian cities can affect caregivers' positions and traditional roles. Furthermore, the presence of disabled individuals in families can lead to structural, socioeconomic and emotional changes and affect all family members, who react by using welcoming strategies and care.

A deep, affective involvement enhances caregiver familial bonds with the elderly, thus justifying the intensity and diversity of responses observed on the Zarit scale. This result was also found in a study⁽¹⁷⁾ in which the different feelings and behaviors of caregivers were presented across the development of the disease. That study also considered caregivers' perception of the investments they had made in the cure and treatment, their physical and social losses, and the change in their lives as a whole.

Another possible justification for the great variation found in the Zarit Scale scores relates to the different dependence levels of the elderly patients. Previous studies^(7, 18) have found that caregiver burden is frequently associated with dependence level, and a significant correlation exists between this burden and the functional ability of the elderly.

The functional disability of the elderly is related to not only the CVA and its sequelae but also the natural aging process. Although aging is not an illness, the structural and bodily functional changes that occur (primarily in the musculoskeletal, bone and nervous systems) reduce the functional ability of individuals to perform daily activities. Hence, aging increases the losses in functional ability that derive from the CVA and reinforces the need for continuous care.

Aging can increase caregiver burden not only because it reduces functional ability but also because it hampers the perception of improvements in the elderly^(3, 15). The caregivers attempt to accomplish the activities that are necessary to help the patient recover and expect actual results in terms of convalescence. When the caregiver does not perceive such improvement, care can become a tiresome and frustrating routine.

In addition, caregivers feel anxious, nervous, and impatient when the elderly patient cannot accomplish certain activities. These feelings also make the caregivers feel tired and overburdened.

Caregiver burden not only is related to the functional dependence of the elderly but also is associated with a

lack of judgment concerning the level of care needed (i.e., complete, maximum, minimum care or mere supervision) when the elderly perform certain activities. The elderly often have the physical and cognitive conditions necessary to practice activities; however, due to fear, a lack of knowledge, and the feeling of being neglectful, caregivers do not allow patients to perform such tasks, thereby depriving the patients of functional improvements and possible independence.

Judgment concerning when caregivers need to assist or allow the elderly patient to perform an activity derives from knowledge regarding the patient's potential, strategies to facilitate the patient's performance, and how to perform activities safely. This knowledge is not gained arbitrarily; rather, nurses provide this information through orientations upon discharge or when the patients return to the community, including follow-up visits at health services. Effective nursing orientations that are appropriate to the patient's potential and the family's lives are needed.

CONCLUSIONS

Assuming a solo caregiving role for a relative is not an easy task because caregivers not only deal with a range of feelings but also add new activities to their daily routines. Consequently, taking care of an elderly patient with CVA sequelae causes physical, emotional and social burdens for the caregiver.

The results of this study suggest that caregivers of elderly CVA victims experience a moderate to severe burden that is related to the functional level of these patients. These data emphasize the need to plan and practice nursing actions that provide caregivers with directions to accomplish inherent care activities, thus minimizing the burden that caregivers experience.

Due to the present study's limitations in terms of sample size and design, additional research is needed to enhance knowledge and identify other possible factors that trigger or increase caregiver burden. Furthermore, longitudinal studies should identify the form that this burden assumes over time.

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