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Burden over family caregivers of elderly people with stroke

Sobrecarga de cuidadores familiares de idosos com acidente vascular encefálico

Sobrecarga en los cuidadores familiares de ancianos accidente cerebrovascular

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Abstract

Objective: To investigate the prevalence and association between burden and characteristics of individuals with stroke sequel and of the caregiver. **Methods:** To investigate the prevalence and association between burden and characteristics of individuals with stroke sequel and of the caregiver. **Results:** There was a high prevalence of burden among caregivers (77.2%), which showed a statistically significant association with the following characteristics: individuals with stroke sequel, being 65 old years or older, with very severe degree of dependency, female caregivers, adult age and low level of education. **Conclusion:** It is highlighted the practical importance of interventions carried out by nurses and other health professionals in relation to guidance and supervision of the care given to family caregivers of individuals with stroke sequel.

Keywords: Stroke; Caregivers; Family Relations.

Resumo

Objetivo: Investigar a prevalência e associação da sobrecarga com características do indivíduo com sequela de acidente vascular encefálico e do cuidador. **Métodos:** Estudo descritivo, transversal, com abordagem quantitativa, realizado na cidade de João Pessoa - PB. Os participantes foram 136 cuidadores familiares. Para a coleta de dados, aplicou-se a escala de Barthel e *Zarit Burden Interview*. **Resultados:** Evidencia-se alta prevalência de sobrecarga entre os cuidadores (77,2%), a qual apresentou associação estatisticamente significativa com as seguintes características: indivíduos com sequela de acidente vascular encefálico com 65 anos ou mais, com grau de dependência muito grave, cuidadores do sexo feminino, com faixa etária adulta e com baixo grau de escolaridade. **Conclusão:** Destaca-se a importância prática de intervenções realizadas por enfermeiros e demais profissionais de saúde com relação às orientações e supervisões referentes ao cuidado dispensado ao cuidador familiar de indivíduos com sequela de acidente vascular encefálico.

Palavras-chave: Acidente Vascular Encefálico; Cuidadores; Relações Familiares.

Resumen

Objetivo: Investigar la prevalencia y la asociación de la sobrecarga con características del individuo con secuelas por accidente cerebrovascular y del cuidador. **Métodos:** Estudio descriptivo, transversal, con abordaje cuantitativo, realizado en la ciudad de João Pessoa (PB). Los participantes fueron 136 cuidadores familiares. Para la coleta de datos se aplicó la escala de Barthel y *Zarit Burden Interview*. **Resultados:** Se evidenció una alta prevalencia de sobrecarga entre los cuidadores (77,2%), que se asociaron de forma significativa con las siguientes características: pacientes con secuelas de accidente cerebrovascular de 65 años o más, con un grado muy severo de dependencia, y cuidadores del género femenino, con edad adulta y con bajo nivel educativo. **Conclusión:** Se destaca la importancia práctica de intervenciones realizadas por enfermeros y otros profesionales de salud con respecto a las orientaciones y supervisiones referentes a la atención prestada a los cuidadores familiares de personas con secuelas de accidente cerebrovascular.

Palabras-clave: Accidente Cerebrovascular; Cuidadores; Relaciones Familiares.

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INTRODUCTION

The cerebrovascular accident (CVA) is a clinical syndrome consisting of the rapid development of focal clinical disorders of brain function lasting more than 24 hours or leading to death without other apparent cause other than a vascular origin[1]. It is characterized also as a public health problem that is among the top three causes of death in many countries, and the leading cause of severe neurological disability, resulting in costs, measured both in spending on health care as with lost productivity.

The unexpected event of a disabling illness, such as stroke, is a stressful event for the patient and the family, who initially experiences an imbalance in their normal operating capacity, causing changes dealing with affection and finances that lead to a family reorganization.

In this context, it is necessary to define roles among family members, and in most situations only one member is chosen to take responsibility of care: the primary caregiver or informal caregiver. This person becomes an important part of the actions for maintenance of autonomy, integration and participation of the afflicted individual in the family relations and society[2].

However, the experience of taking care for a dependent person has been placed by family caregivers as an exhaustive and stressful task, due to the emotional involvement and the frequent occurrence of a change from a previous relationship of reciprocity to a relationship of dependency, in which the caregiver, by performing activities related to the physical and psychosocial well-being of the person, starts to experience restrictions regarding their own life[3].

In Brazil, the informal caregiver visibility is still very limited, which is a problem faced by family caregivers who, in their daily lives, have been providing care that the dependency situation demands almost without any formal social support[3,4]. This fact provides the negligence by professionals on the health needs of this population. Thus, the lack of training for the act of caring and the lack of guidance and social support expose the caregiver to a great burden of stress and work overload that can affect their health, their well-being and quality of life.

In this sense, this research is important as it increases the knowledge and the visibility of issues related to family caregivers. It is believed that it can affect the nursing care in primary care, redirecting the look of these professionals to the multidimensional phenomenon involving the dependent patient, the caregiver and the family, so that the assistance is focused on the development of strategies and interventions that minimize the impact of the dependency on the caregiver.

Given the above, this study aimed to investigate the prevalence of burden of family caregivers of elderly with stroke sequel, residents in João Pessoa, Paraíba, and their relationship with the sociodemographic characteristics of the caregivers themselves and with the sociodemographic characteristics and functional disability of individuals.

METHOD

It is a descriptive, cross-sectional research with a quantitative approach, performed in the city of João Pessoa - PB. The study object was family caregivers of elderly patients with sequelae of cerebrovascular accident - CVA. The sample of this study was 136 caregivers calculated from the total of 204 patients seen at health facilities in the city of João Pessoa - PB in 2012.

At first we carried out a random selection with an average of 40 Family Health Units, in which we contacted the supporters and nurses in each unit, who reported through the medical records patients who have suffered stroke and had sequel. We started collecting data in the patients' houses, accompanied by a community health worker.

We adopted as inclusion criteria of individuals with stroke sequel: being 18 years old or older, having at least two Activities of Daily Living (ADL) impaired, and having a family caregiver. Among the inclusion criteria for caregivers, we included: being 18 years old or older; being the primary caregiver.

Data collection was conducted through interviews in the homes of individuals with stroke sequelae and their caregivers from April to June 2013. To this end, we used semi-structured questionnaires with questions regarding sociodemographic characteristics of individuals with stroke sequel (age, sex, marital status, education, employment status, personal income) and of caregivers (age, sex, marital status, education, employment status, personal income, type of income and relationship to the patient). Then, the Barthel index was applied to confirm the inclusion of individuals and caregivers in the research. This index is the most used as a prognostic measure after a stroke; it measures the severity of inability evaluating the functional independence by measuring the individual's ability in developing the ADL. To evaluate and rank the burden among caregivers we used the Zarit Burden Interview[5] which aims to assess the existence of objective and subjective caregiver burden, and it was adapted and validated in Brazil according to the following scores: intense overload (score from 61 to 88), moderate to severe overload (scores from 41 to 60), moderate to mild overload (scores from 21 to 40) and absence of overload (scores lower than 21)[6].

For statistical analysis, we used the SPSS (Statistical Package for Social Science) version 18.0 and we applied the Association Analysis technique using the chi-square test.

Regarding the ethical procedures, we have met with all legal and ethical issues involving human subjects, recommended by Resolution 466/12 of the National Health Council[7]. The project was referred to the Ethics Committee of the Health Sciences Center of the Federal University of Paraíba and approved under protocol number 0279/13 and CAAE: 13778313.3.0000.5188. We also respected the principle of autonomy and privacy, especially regarding the Informed Consent Form, an indispensable tool so that we can conduct research involving human subjects.

RESULTS

Among the sociodemographic characteristics of the elderly with CVA sequel, it was found prevalence of females (51.4%), mean age of 70.43 years, married (48.53%), with from one to four years of education (27.94%), retired (80.88%), personal income between two and three minimum wages (61.76%). With regard to functional disability, it was found that 46 (33.83%) patients had mild dependency; 35 (25.74%), very severe dependency; 28 (20.59%) were severely dependent; and 27 (19.85%) had moderate dependency.

Regarding the characteristics of caregivers, it was found that most were female (84.5%), children (51.47%) had a mean age of 47.34 years, married (57.35%), with from five to nine years of education (51.47%). As for the employment status, there was a predominance of unemployed caregivers (45.59%) with personal income between 1 and 3 minimum wages (58.09%).

Regarding the prevalence of burden among caregivers, it was found by applying the Zarit Burden Interview that 77.2% had work overload. Considering the overload levels, as shown in Table 1, it was found that 79 (58.0%) of family caregivers showed moderate to mild overload, 31 (22.8,%) showed no overload and 26 (19.1%) moderate to severe overload.

Table 1. Assesment according to the Zarit Scale. João Pessoa - PB, 2013

Assesment according to the Zarit Scale	Freq.	%
Moderate to severe overload	26	19.12
Moderate to mild overload	79	58.09
Absence of overload	31	22.79

Analyzing the relationship between caregiver burden and characteristics of individuals with CVA sequel presented in Table 2, there was a statistically significant association among those caring for individuals only in relation to the age group of patients that is significantly associated (*p*-value less than 0.05) to the level of overload.

By establishing the relationship between the measured functional disability of individuals with stroke sequel and the levels of caregiver burden using the Barthel index, we found little correlation through Fisher's exact test, as shown in Table 3. However, when using the correlation coefficient (r = -0.197) between the scores of both scales, there was a significant association (*p*-value less than 0.05) between the highest overload levels with the highest level of dependency (moderate to severe or moderate to mild).

Considering socio-demographic characteristics of caregivers and levels of burden among them, as shown in Table 4, statistically significant differences were found between the highest average overload (*p*-value less than 0.05) of female caregivers, with a tendency to have higher overload than men. In addition, adult caregivers are associated with larger levels of overload than younger caregivers. With regard to the relationship between higher levels of burden and the education level of the caregiver (*p*-value 0.05), there was a higher burden among caregivers with lower education.

DISCUSSION

To evaluate the occurrence of caregiver burden, we applied the Zarit Burden Interview (ZBI), composed of 22 items that evaluate the relationship between the caregiver and the patient, the health condition, the psychological well-being, finance and social life. In this study, it was found that 58.09% of the caregivers expressed moderate to mild overload, 22.79%, absence of overload, and 19.12%, moderate to severe overload.

The dependency of a family member is a situation of crisis that generates stress, threatens the balance of the normal personal, family and social functioning. Given this situation, there may be a psychosocial disorganization, often accompanied by negative feelings such as fear, guilt and anxiety. When this state of uneasiness and tension is not tolerated for a long period, the individual tends to adopt new coping strategies to overcome the crisis, which could lead to an unhealthy adjustment, with negative emotional repercussions that cause overload[2].

Some studies have indicated that the burden on family members results from the tasks arising from the caregiving role and from the changes in their social and professional life, as they prioritize the patients' needs. Moreover, as these studies have shown, the burden is exacerbated by the lack of information regarding the patient's disease, the treatment used and the most appropriate strategies to deal with the problem behaviors of patients and the management of crisis situations[8,9].

In analyzing the characteristics of individuals with stroke sequelae related to caregiver burden we found higher overloads with individuals aged from 65 to 80 years old, male, single and with low level of education. It is noteworthy that only age group was statistically significant ($p = 0.0062$).

Older age itself is not a deficit that can lead to greater burden on the caregiver. However, it is a major risk factor for the emergence of morbidities that influence their level of dependency[10]. It is evidenced in studies that impaired patient's autonomy is directly linked to the type of disabling chronic diseases that they afflict them. In this way, the patient's dependence level is a contributing factor to generate physical and mental stress, and overhead is directly proportional to the level of dependency of the cared being, because the more impaired their autonomy, the greater the demands and the complexity of activities developed by caregivers[11].

As to gender, men have greater difficulties to accept the condition of dependency and the need to be cared, which contributes to the emergence of overload among family caregivers. In addition, they worry less about maintaining their health, which makes them more susceptible to the occurrence of chronic problems that can evolve to functional impairment[11].

Table 2. Relationship between sociodemographic characteristics of the elderly with stroke sequelae and levels of caregiver overload. João Pessoa - PB, 2013

Sociodemographic profile (patients)	Zarit Scale Moderate to severe overload (n = 26)		Moderate to mild overload (n = 79)		Absence of overload (n = 31)		Significance (*p*-value)
	Freq.	%	Freq.	%	Freq.	%	
Sex							
Female	10	38.46	45	56.96	15	48.39	$p^{(1)} = 0.2425$
Male	16	61.54	34	43.04	16	51.61	
Age group							
< 65 years old	5	19.23	31	39.24	8	25.81	$p^{(2)} = 0.0062$
65 - 80 years old	11	42.31	29	36.71	21	67.74	
> 80 years old	10	38.46	19	24.05	2	6.45	
Marital status							
Single/divorced/widowed	14	53.85	39	49.37	14	45.16	$p^{(1)} = 0.8075$
Married/other	12	46.15	40	50.63	17	54.84	
Education							
Illiterate/literate	15	57.69	37	46.84	9	29.03	$p^{(2)} = 0.1652$
Elementary School	7	26.92	21	26.58	10	32.26	
High School	3	11.54	11	13.92	10	32.26	
Higher Education	1	3.85	10	12.66	2	6.45	

$^{(1)}$ Chi-square association test; $^{(2)}$ Fisher's exact test.

Table 3. Relationship between functional disability and levels of caregivers burden. João Pessoa - PB, 2013.

Barthel Index	Zarit Scale Moderate to severe overload (n = 26)		Moderate to mild overload (n = 79)		Absence of overload (n = 31)		Significance (*p*-value)
	Freq.	%	Freq.	%	Freq.	%	
Very severe dependency	11	42.31	23	29.11	3	9.68	
Severe dependency	5	19.23	17	21.52	6	19.35	$p^{(1)} = 0.1753$
Moderate dependency	2	7.69	16	20.25	9	29.03	r = -0.197
Mild dependency	8	30.77	23	29.11	13	41.94	$p^{(2)} = 0.0215$

$^{(1)}$ Fisher's exact test; $^{(2)}$ Correlation coefficients.

The low level of education is also an important factor, which most often is related to low income, resulting in financial losses that significantly burden the caregiver, since, providing care to others may encompass basic needs such as food, the realization of physical activities and even specific needs such as the acquisition and purchase of medicines. Therefore, the limited financial resources can be a stress generating factor to caregiver[10,12].

By establishing a relationship between disability and levels of caregiver burden, it was realized that the greater the level of dependence, the greater the overload. The same results were found in other studies[12,13]. Dependency refers to the state in which the person is unable to exist or live, in a satisfactory manner, without the help of others. The person who has disability or social disadvantage is a person who at some time or situation is dependent to self-care and needs a caregiver[11].

Therefore, promoting safety strategies, such as a simple adaptation of the toilet, removing rugs, adopting a new patient positioning or mobilization technique can help easing the difficulties for the provision of care. In addition, the support of other family members is an important factor to minimize the experience of overload, allowing the caregiver a feeling of not being alone[14].

As regards the characteristics of caregivers, this study revealed an average of greater overload among females. The aforementioned result evidences that described in the literature

Table 4. Relationship between sociodemographic characteristics and levels of caregivers burden. João Pessoa - PB, 2013

Sociodemographic profile (caregivers)	**Zarit Scale** Moderate to severe overload (n = 26)		**Moderate to mild overload (n = 79)**		**Absence of overload (n = 31)**		**Significance (*p*-value)**
	Freq.	**%**	**Freq.**	**%**	**Freq.**	**%**	
Sex							
Female	26	100.00	66	83.54	23	74.19	$p^{(2)} = 0.0124$
Male	0	0.00	13	16.46	8	25.81	
Age group							
< 40 years old	3	11.54	26	32.91	10	32.26	$p^{(2)} = 0.0208$
40 - 60 years old	12	46.15	43	54.43	15	48.39	
> 60 years old	11	42.31	10	12.66	6	19.35	
Marital status							
Single/divorced/widowed	7	26.92	35	44.30	16	51.61	$p^{(1)} = 0.1575$
Married	19	73.08	44	55.70	15	48.39	
Education							
Illiterate/literate	8	30.77	11	13.92	5	16.13	$p^{(2)} = 0.0210$
Elementary School	11	42.31	28	35.44	4	12.90	
High School	5	19.23	24	30.38	16	51.61	
Higher Education	2	7.69	16	20.25	6	19.35	

(1) Chi-square association test; (2) Fisher's exact test.

as to the female sociocultural role of caring, either of the house or of the children, although, currently, changes in society and in family composition have assigned new roles to women. The tendency to care of both household environment as the health of their family members still fall upon women due to the symbolic relationship built by society[3]. From this perspective, the woman commonly takes the responsibility of caring even when they have other work. Thereby, care overload reduces the free time and impairs the social life of the woman[4].

Regarding age, it was shown that caregivers with adult or middle age have a higher level of overload. This refers to the fact that often caregivers at that age have to adjust their daily activities, which are also within their competence, such as work, housework and children, with the care provided to the dependent family member, thus causing an accumulation of roles.

Regarding the relationship between higher levels of burden and the low level of education of caregivers, some authors point out that the lack of knowledge and information for the act of caring, often linked to low levels of education, can trigger the in the caregiver feelings of anxiety and distress that negatively impacts the care provided and the health of the caregiver him/herself[1,15]. As a result, caregivers become more vulnerable to illness[16].

The task of taking care itself leads to health problems such as depression or social isolation for the caregiver. Thus, many caregivers need training and education about the care, rest and care for their physical and mental health. Such programs should provide guidance to help caregivers cope with changes in their daily routine. Added to the caregivers' physical wear arising from the care, there is the emotional impact related to living with the dependent family member, lack of time for leisure, feelings of guilt and fear of the disease to themselves and the financial difficulties imposed by the abandonment of work activities[17].

CONCLUSION

There was a high prevalence of overload between the investigated caregivers (77.2%) and it was found that some sociodemographic characteristics of individuals with stroke sequel and of the family caregivers themselves were related to higher average of overload. Among the established relationships, it was observed statistically significant associations between the caregiver burden and the following characteristics: individuals with stroke sequel, being 65 years old or older, with very severe level of dependency, female caregivers of adult age group and with low level of education.

The values found in this study point to the need to offer support to caregivers of individuals with stroke sequel in order to reduce the burden related to activities related to the provision of care and accessibility to knowledge. Thus, it is highlighted the practical importance of interventions performed by nurses and other health professionals in order to improve the assistance, guidance and supervision for the care given by family caregivers. Moreover, such findings are relevant to awaken the society and government actors on the need to implement public policies and actions with a view to providing formal and emotional support for these people.

In this study limitations were related to the lack of intervention studies in the Brazilian literature aimed at these caregivers, which leads to the need for more research in this area as well as the validation in Brazil of specific scales for application in family members of patients affected by stroke, which could bring more reliable data regarding this population.

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