



**PROFILE OF ELDERLY FAMILY CAREGIVERS AFTER A STROKE**  
**PERFIL DE CUIDADORES FAMILIARES DE IDOSOS APÓS O ACIDENTE VASCULAR CEREBRAL**  
**PERFIL DE CUIDADORES FAMILIARES DE ANCIANOS DESPUÉS DE UN ACCIDENTE VASCULAR CEREBRAL**

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**ABSTRACT**

**Objective:** to describe the profile of Family Caregivers (FCs) of elderly surviving a Stroke and the care burden level. **Method:** a Cross-sectional study with 13 FCs living with the elderly after a stroke. Data were collected through questionnaires and scales from September to November 2015 at their residence. The variables were analyzed using Microsoft Excel 2010, calculating the relative and absolute frequency. **Results:** FCs are women (100%), usually daughters and wives (76.9%), aged between 41 and 60 years old (76.9%), white and brown (77.0%), low education (64.3%), with no labor activity (84.6%), with diseases (69.2%) and moderate burden care (69.2%). **Conclusion:** it is important to develop health education strategies to raise awareness among caregivers regarding the of care without causing harm to their health, both the caregiver and the elderly. **Descriptors:** Family; Caregivers; Stroke; Health Care; Home Care.

**RESUMO**

**Objetivo:** descrever o perfil dos Cuidadores Familiares (CFs) de idosos sobreviventes ao Acidente Vascular Cerebral (AVC) e o nível de sobrecarga de cuidado. **Método:** estudo de corte transversal, realizado com 13 CFs que residem com idosos após AVC. Os dados foram coletados através de questionário e escalas de setembro a novembro de 2015 na residência da diáde. As variáveis estudadas foram analisadas pelo Microsoft Excel 2010, com cálculos de frequência relativa e absoluta. **Resultados:** as CFs são mulheres (100%), geralmente filhas e esposas (76,9%), com idade entre 41 e 60 anos (76,9%), brancas e pardas (77,0%), baixa escolaridade (64,3%), sem atividade laboral (84,6%), apresentam patologias (69,2%) e sobrecarga moderada de cuidado (69,2%). **Conclusão:** é importante desenvolver estratégias de educação em saúde para sensibilizar os cuidadores quanto à realização do cuidado sem acarretar danos à saúde da diáde. **Descritores:** Família; Cuidadores; Acidente Vascular Cerebral; Cuidados de Saúde; Assistência Domiciliar.

**RESUMEN**

**Objetivo:** describir el perfil de los cuidadores familiares (CFs) de ancianos sobrevivientes al accidente vascular cerebral (AVC) y el nivel de sobrecarga de cuidado. **Método:** estudio de corte transversal, realizado con 13 CFs que residen con ancianos después AVC. Los datos fueron recogidos a través de un cuestionario y escalas de septiembre a noviembre de 2015 en la residencia. Las variables estudiadas fueron analizadas por Microsoft Excel 2010, con cálculos de frecuencia relativa y absoluta. **Resultados:** las CFs son mujeres (100%), generalmente hijas y esposas (76,9%), con edad entre 41 y 60 años (76,9%), blancas y pardas (77,0%), baja escolaridad (64,3%), sin actividad laboral (84,6%), presentan patologías (69,2%) y sobrecarga moderada de cuidado (69,2%). **Conclusión:** es importante desarrollar estrategias de educación en salud para sensibilizar los cuidadores para la realización del cuidado sin causar daños a la salud del anciano y de su cuidador. **Descriptors:** Familia; Cuidadores; Accidente Vascular Cerebral; Cuidado de la Salud; Cuidado en el Hogar.

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## INTRODUCTION

The Stroke (CVA) is a chronic degenerative disease that can lead to death or trigger functional and cognitive impairment, temporary or permanent, usually due to a stroke or rupture of cerebral vessels.<sup>1-3</sup> The main malfunctions are those that cause physical and neurological disorders such as muscle weakness, disturbances in language and dysphagia that can harm locomotion, communication, and power, respectively.<sup>4</sup> In this sense, the elderly who is already weakened due to the aging process,<sup>5</sup> becomes more vulnerable to reduced functional capacity and more exposed to risk factors for a stroke.<sup>6</sup>

These changes impact negatively on the performance of basic Activities of Daily Living (ADL), and the person who survived the stroke requires constant help in his daily lives. This degree of dependence can be assessed by the Katz scale in six ADL: food, sphincter control, transfers, personal hygiene, ability to dress and bathe.<sup>7</sup>

Katz score ranges from 0 to 6 points in which one point is to each "Yes" answer. The person will be classified as independent in all six functions when obtaining score 6. The moderate dependency occurs if the score is 4 and 5 are it is considered as very dependent if the score is less or equal to 3. Thus, the smaller the numerical value, the greater the degree of dependence.<sup>8</sup>

The person who survived the stroke usually requires constant care in the home environment after discharge. In this scenario, there is the caregiver usually represented by a family member who has or not consanguineous ties, usually women, chosen by ties of affinity or greater availability of time for the care.<sup>7</sup>

By providing direct assistance and almost uninterrupted to the person who survived a stroke, the family caregiver (FC) tends to develop care burden that can be evaluated by the Zarit Burden Interview Scale (ZBI), in 22 items and ranging from 0 to 88. That is, the higher the value, the more burden they have. The score 0-20 indicates no burden; 21 to 40 is a moderate burden; 41 to 60 - is moderate to severe burden, and 61 to 88 is a severe burden.<sup>9</sup>

This scale evaluates the problems or changes in the physical, psychological, emotional, social and financial aspects of the primary caregiver and the relationship with the patient quantitatively.<sup>9</sup> Therefore, the task of caring for dependent elderly who survived the stroke is not easy because the FCs play various care activities, besides those

personal, which contributes to an increased burden of care.<sup>10</sup>

These changes in physical, social and emotional burden generate negative impacts on the quality of life of elderly's FCs, especially those surviving of a stroke.<sup>6,10</sup>

Knowing the characteristics of these FCs is important to track and consolidate public policy strategies that help the health care network, offering the formal and emotional support to FCs because there are not consolidated policy instructional courses in Brazil that help families in this home care stage.<sup>11-12</sup>

In this sense, this study aims to describe the profile of family caregivers of elderly surviving to a stroke and care burden level.

## METHOD

Cross-sectional descriptive and exploratory study with FCs of people who survived the stroke, after hospitalization in a public hospital located in Bahia, between January 2012 to December 2013.

To identify the FCs, it was necessary to analyze the personal identification data, address, and telephone of 115 hospital records. The inclusion criteria of the FCs were: age  $\geq 18$  years old, be the main FC from the survivor to a stroke with dependent care (score  $\leq 5$  evaluated by Katz scale) and have moderate, moderate to severe and severe burden, according to scale ZBI, those having score 21-88.

After reading the 115 records, there was a residential collection from September to November 2015, through a form prepared by the researchers. There were 74 people excluded, 61 of them died with a diagnosis of stroke, 12 were FCs survivors from a stroke regarding the care, and one person had no care burden. There were 28 losses for the lack of residential location. In the end, there were 13 FCs identified survivors of a stroke who wanted to participate.

Data were tabulated in Excel Program 2010 version, with calculations of standard deviation, relative, and absolute frequency. All participants had their identity protected and signed the free and Informed Consent Form (ICF) in two copies, one for the FC and the other for the researchers.

This research was approved by the Ethics Committee in Research of the Bahia State University under the opinion number 996,193 and CAEE 41625015.7.0000.0057. It is a subproject of a larger study entitled "Disability after a stroke and caregiver burden: barriers for home care."

RESULTS

Through a form, it was possible to trace the profile of FCs of the survivors to a stroke as the sociodemographic characteristics (gender, age, kinship, race/skin color, educational level and marital status), economic (income and employment status), information related to care provided and caregiver health.

All FCs are women (n=13, 100%) adults aged between 38 and 64 years old (mean 50.5,

SD=7.8), considered as brown and white, respectively (n=5; 38.5%, n=5, 38.5%) and with study time ≤ nine years (n=9; 69.2%).  
Usually, they are daughters (n=7; 53.8%) and partners (n=3; 23.1%), but others also assist in the care even with the lack of consanguineous family ties. Although most women are married (n=9, 69.2%) and constitute another family, they care their family. The sociodemographic characteristics of the family caregivers are described in Table 1.

Table 1. sociodemographic characteristics of elderly family caregivers of Guanambi/BA, Brazil, 2015.

Characteristics	n=13	%
Gender		
Female	13	100
Age (years old)		
31 to 40	1	7.7
41 to 50	6	46.1
51 to 60	4	30.8
>60	2	15.4
Kinship		
Son/Daughter	7	53.8
Partner	3	23.1
Grandchildren	1	7.7
Brother/Sister	1	7.7
Other	1	7.7
Race/Skin color		
White	5	38.5
Brown	5	38.5
Black	2	15.3
Do not know	1	7.7
Education		
<1year	1	7.7
>1year	4	30.8
5 to 9 year	4	30.8
10 to 12 years	1	7.7
>12 years	3	23.1
Marital status		
Married	9	69.2
Single	3	23.1
Widow	1	7.7

The monthly income of the FC ranged from R\$ 233.00 to 2108.00 (Brazilian currency), with an average of R\$ 852.10 (SD=473.1). Regarding the employment situation, most of them (n=11; 84.6%) has no salary, and the money they receive is from their retirement benefits or sporadic informal activities (“extra jobs”). Moreover, the benefit of the retirement of the older people who survived to a stroke is used as the family’s economic supplement.

All FCs are continually assisting the elderly in the ADL from the moment they received the hospital discharge and returned to the home whose care ranged from 1 to 30 years (mean=4 years and 5 months; SD=9.6).

Usually, it was necessary to live with the elderly surviving the stroke to ensure comprehensive care. This continuous assistance generated carefully moderate burden (n=9; 64.3%) and moderate to severe burden (n=4, 28.6%) as assessed by the ZBI

scale. There was not a severe burden. It is noted that when the burden is moderate, the FCs are women aged 38-61 years old, married, daughters and low level of education.  
It is also pointed out that the FCs reported they spend an average of 20 hours of their day taking care of the elderly who survived to the stroke. Thus, they feel unable to meet their personal needs and participate in social events at various times.  
This care burden can worsen because all FCs have no training by health staff to perform home care. Thus, most of them need to develop their skills for this assistance and rely on the help of other family members (n=8; 61.5%), given that the majority (n=9, 69.2%) have chronic diseases (diabetes, hypertension, joints and neurological disorders) which may be aggravated by the continuous care. The economic characteristics, information related to care

and health conditions of family caregivers are described in Table 2.

Table 2. Economic characteristics, information, related to the care provided in health conditions of elderly family caregivers. Guanambi/BA, Brazil, 2015.

Characteristics	n=13	%
Income		
780,00	7	53,8
233,00	1	7,7
2,108.00	1	7,7
720.00	1	7,7
Without income	3	23,1
Labor situation of the caregiver		
Working	2	15,4
Working remunerable job	4	30,8
Suspending labor activity due to care	3	23,1
Without working	4	30,8
Age of the elderly surviving a stroke		
60 to 70 years	3	23,1
71 to 80 years	4	30,7
81 to 90 years	3	23,1
>90 years	3	23,1
Gender of the elderly surviving a stroke		
Male	8	61,5
Female	5	38,4
Time the caregiver takes to care of the elderly		
≥1 years	1	7,6
≥2 years	5	38,5
≥3 years	5	38,5
≥4 years	2	15,4
Caregivers' Burden		
Moderate (21 a 40)	9	69,2
Moderate to Severe (41 a 60)	4	30,7
Social support of the caregiver		
Yes	8	61,5
No	5	38,5

DISCUSSION

After returning home, the elderly who survived to the stroke needs constant care provided mainly by family members. This act of caring is still represented in society as a culturally feminist activity<sup>1,11</sup> highlighting the activities that occur in the home environment.<sup>7</sup>

The FC has been one maintaining the largest bonding and closer kinship such as daughters and wives.<sup>12-13</sup> It was possible to identify a significant number of women aged over 50 years old in the care process. Thus, the FCs who are in the aging process are taking care of the dependent elderly. This may reflect in higher physical, functional and psychological losses, impairing care delivery and the health of the caregiver.<sup>5,13-14</sup>

A significant part of the participants described race/skin color as brown (n=5, 38.5%). Similar results were found in another study that found that 65.5% of FCs were brown.<sup>15</sup> Both results are similar possibly because they were made in Bahia, which concentrates a population of African descent. Therefore, the variable race/skin color may differ according to the location of the study, when considering miscegenation.

About education, most of them (n=; 69.2%) had less or equal to nine years. This finding is

supported by another national research conducted in the Southeast to demonstrate that the education of up to eight years of study represented 67.7%.<sup>6</sup> The low level of education can be an important factor in choosing the FC since the person usually does not have any professional relationship. This criterion of choice can have negative impacts on the care concerning the understanding of complex technical care to the elderly survivor to a stroke.<sup>16</sup> However, another study shows that dedication to care together with feelings such as the kind and love has contributed to a better recovery of the elderly surviving the stroke, where the provision of such assistance is carried out by people with lower education levels.<sup>17</sup>

About income and economic situation, it was noted that most of the study participants exercise care with an average of 20 hours and assistance dedication to his family member that is dependent. Care of this extensive workload prevented some FCs remaining in their job or spend time looking for work for an extra source of income. Thus, the retirement of the elderly has been the main economic income used to supply, albeit precariously, basic needs, resulting in negative impacts on health and well-being of the elderly and the caregiver.<sup>17</sup>



Care for dependent older people for a long period after hospital discharge contributed to 100% of FCs develop care burden. Studies show that this burden increases proportionately with the dependence of the elderly surviving the stroke, as they often have irreversible consequences from the disease, such as loss or reduction of functional capacity to perform ADL.<sup>18-19</sup> Since most FCs are daughters and wives, this care burden intensifies, as well as direct assistance to surviving these people still perform household chores and at various times vanishing their needs.<sup>19</sup>

## CONCLUSION

The current study contributes to knowing the profile of FCs of elderly residents in an interior municipality of Bahia, women in the process of senescence, with low levels of education and income, which performs care for a long time and, in most times in full time. This profile resembles that distributed throughout the country, respecting the diversity of some regions and cultures.

Knowledge of this profile can guide the multidisciplinary health care team, which belongs to the network of care, improving health education strategies to raise awareness of the essential care at home and how this care should be carried out, considering the low level of education as a positive factor and/or aggravating during care.

It is important to pay attention to the early onset of the guidelines from the hospital because the FCs returned with his family at home with questions that have not been rectified by primary health units, possibly by the vast demand service. In this sense, it is necessary that those units of primary health care formally communicate this care gap to municipal managers, with a view to creating extension, regular and continuous courses, with the main purpose to reduce rehospitalization, disease prevention for the survivors and reducing the care burden associated with better quality of life for caregivers, especially those in the aging process.

Also, it is important to create mechanisms of joint assistance network to allow active participation of other professionals such as social workers, regarding the direction of granting the 25% increase in disability benefits, which occurs in some diseases causing dysfunctionalities such as stroke.

This study has a limitation regarding the number of participants, especially the severity of the illness that caused high mortality rate in two years after discharge (53.04%) and lack

of complete data in the study of hospital records for location residential address for collection of the scales (24.34%), representing a total loss of 77.38% of potential participants.

It is suggested in the next study the need to extend the time and/or conducting follow-up studies of these caregivers over the years to assess the burden and possible factors associated with this burden.

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