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Original Article

Quality of life and burden of informal caregivers of post-stroke individuals

Qualidade de vida e sobrecarga de cuidadores informais de indivíduos acometidos por Acidente Vascular Encefálico

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Abstract

Introduction: Assistance to post-stroke individuals is usually provided by family caregivers, but with a great burden and negative impact on their quality of life (QoL). **Objective:** To identify the population that currently takes care informally for individuals with sequelae resulting from stroke in Araranguá/SC (Brazil) and to assess the relationship between QoL and the level of burden in this population. **Method:** A cross-sectional study that evaluated 60 individuals: 30 informal caregivers of 30 chronic post-stroke individuals enrolled in Basic Health Units in Araranguá, SC. The following assessment instruments were used: *Zarit Burden Interview* Scale to assess burden and *World Health Organization Quality of Life Questionnaire* (WHOQOL-BREF) to assess caregiver QoL; Functional Independence Measure (FIM) to assess functional independence and the Modified Rankin Scale to assess the individual's level of disability post-stroke. **Results:** Some level of burden was observed in 71.67% of the caregivers evaluated, with the majority (46.67%) having mild to moderate burden. The caregivers' QoL was altered, with lower levels of satisfaction on the physical and environment domains. A significant correlation was observed between burden and QoL ($\rho=-0.60$; $p<0.01$) of caregivers. **Conclusion:** The population of caregivers of post-stroke individuals residing in Araranguá proved to be overloaded with the care function, with changes in their QoL. The findings suggest the need for health interventions aimed not only at post-stroke individuals, but also at their family caregivers.

Keywords: Caregiver Burden, Quality of Life, Stroke.

Resumo

Introdução: A assistência ao indivíduo pós-acidente vascular encefálico (AVE) geralmente é prestada por cuidadores familiares, mas com grande sobrecarga e

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impacto negativo em sua qualidade de vida (QV). **Objetivo:** Identificar a população que atualmente cuida de maneira informal de indivíduos com sequelas decorrentes de AVE em Araranguá/SC (Brasil) e avaliar a relação entre a QV e o nível de sobrecarga nessa população. **Método:** Estudo transversal que avaliou 60 indivíduos: 30 cuidadores informais de 30 indivíduos pós-AVE crônicos inscritos nas Unidades Básicas de Saúde de Araranguá, SC. Os seguintes instrumentos de avaliação foram utilizados: Escala *Zarit Burden Interview* para avaliar a sobrecarga e Questionário *World Health Organization Quality of Life* (WHOQOL-BREF) para avaliar a QV do cuidador; Medida de Independência Funcional (MIF) para avaliar a independência funcional e a Escala de Rankin Modificada para avaliar o nível de incapacidade do indivíduo pós-AVE. **Resultados:** Foi observado algum nível de sobrecarga em 71,67% dos cuidadores avaliados, sendo que a maioria (46,67%) apresentou sobrecarga leve a moderada. A QV dos cuidadores mostrou-se alterada, com menores índice de satisfação com os domínios físico e meio ambiente. Foi observada correlação significativa entre a sobrecarga e a QV (ρ=-0,60; p<0,01) dos cuidadores. **Conclusão:** A população de cuidadores de indivíduos pós-AVE residentes em Araranguá mostrou-se sobrecarregada com a função de cuidar, com alteração na sua QV. Os achados sugerem a necessidade de intervenções de saúde dirigidas não só aos indivíduos pós-AVE, mas também a seus cuidadores familiares.

Palavras-chave: Fardo do Cuidador, Qualidade de Vida, Acidente Vascular Cerebral.

Introduction

Stroke has high levels of morbidity and mortality and, in cases of non-death, can generate temporary or permanent functional disabilities (Araújo et al., 2017). The injury mechanism can cause various motor, sensory, cognitive and language deficits, depending on the area involved and the extent of the injury, which also influences on the recovery capacity of these individuals (Rissetti et al., 2020).

Disability levels can influence levels of care dependency. Thus, upon being discharged from the hospital, individuals often return to their homes with physical, cognitive and behavioral sequelae that commonly compromise their functional capacity, independence and autonomy, which makes them dependent on other people (Caro et al., 2018; Costa et al., 2015a, 2020a). Functional dependence is directly related to worse quality of life (QoL) of post-stroke individuals and to caregiver burden (Cerniauskaite et al., 2012; Costa et al., 2015b).

The experience of caring for someone with stroke sequelae has become increasingly frequent in the daily lives of families (Araújo et al., 2017; Sedrez-Celich et al., 2016). The various tasks assigned to the caregiver add to the lack of support, of preparation to take care, the degree of dependence of the patient, the chronicity of the disabling situation, the complexity of care activities, the worsening of health status and the uncertainty of the future, which can, in many cases, lead the caregiver to social isolation, reduction or extinction of leisure activities, compromise of professional activity, loss of job and lack of time for self-care (Araújo et al., 2017; Oliveira et al., 2017; Faria et al., 2017; Caro et al., 2018). Thus, with imbalance or difficulties in the aforementioned aspects, the caregiver begins to suffer from overload, which can significantly affect their health, well-being and QoL (Costa et al., 2015b).

The QoL and the burden of family caregivers of post-stroke individuals have been the object of studies in recent years. Costa et al. (2015b) analyzed the burden of caregivers of individuals affected by strokes and observed that 77.2% of them were overloaded and that the sociodemographic characteristics and the level of involvement of individuals with post-stroke symptoms were related to this fact. Health-related QoL is fundamental in the context of health status or the variation in the impact that the disease causes on the individual's life; therefore, it is an effective tool in the assessment of changes regarding the caregiver's health, particularly in situations of burden (Caro et al., 2017).

The identification of QoL and caregiver burden in a given region allows identifying the common needs of these individuals. This, in turn, makes it possible to better guide the care offered to people who live in the same area and who have similar conditions, as well as the identification of possible improvements or changes in intervention strategies, both for patients and family members. Thus, the objective of this study was to identify the population that currently informally cares for individuals with sequelae resulting from stroke in Araranguá/SC and to assess the relationship between QoL and the level of burden in this population.

Method

This is a cross-sectional analytical study that evaluated the burden and QoL of caregivers of post-stroke individuals enrolled in Basic Health Units (UBS) in the city of Araranguá/SC. The study was carried out between August 2017 and October 2018.

This research is based on ethical principles, based on Resolution No. 466 of December 12, 2012 of the National Health Council. The study was approved by the Research Ethics Committee of the Federal University of Santa Catarina (UFSC) under the number CAAE: 67843317.3.0000.0121.

All participants signed a Free and Informed Consent Form before the beginning of the collection procedures.

Participants

The population consisted of individuals with sequelae resulting from stroke and their caregivers, who had a family bond with them, registered at the Basic Health Unit in Araranguá/SC. The sample consisted of 30 caregivers and 30 post-stroke individuals selected in an intentional non-probabilistic manner.

In this study, adults (>18 years) of both sexes who were currently acting as primary informal caregivers of chronic post-stroke individuals (more than six months) with a minimum classification of level 2 on the Modified Rankin Scale (Ovando et al., 2016), residents of the city of Araranguá/SC, who agreed to participate in the research.

Caregivers of post-stroke individuals who had disabilities resulting from other associated neurological or orthopedic pathologies, such as amputation, Parkinson's disease, Alzheimer's disease, severe osteoarthritis of the hip or knee, were excluded.

Data collection procedure

After screening the medical records at the UBS, individuals diagnosed with stroke or their family members were contacted by telephone or address. In a first conversation, the objectives of the study were exposed, the importance of their participation, the instruments used, the confidentiality of the information and, if the patient and the caregiver fit the inclusion criteria, they were invited to participate in the evaluations. After acceptance, a visit to the individual's residence was previously scheduled with date, time and place. At the time of the evaluation, the signature of the Free and Informed Consent Form was requested. The assessments were answered by the caregivers. Care was taken so that people affected by post-stroke were not in the same place of the interview with the caregiver to avoid embarrassment and bias when answering the questions. Two trained evaluators applied the collection instruments.

Assessment instruments

Socio-demographic data were collected from post-stroke individuals and their caregivers, such as age, sex, marital status, type of stroke (ischemic or hemorrhagic), time elapsed since the stroke, most compromised hemibody (right or left), associated diseases, number of medications used, educational and socioeconomic level, type of paid activity, monthly family income, caregiver's degree of kinship, work situation, scholarity, division of care and living or not at the same address as the post-stroke individual. Therefore, the researchers created a questionnaire about this information.

The Modified Rankin Scale was used to measure the disability of post-stroke individuals. This scale has six categories ranging from 0 (no symptoms) to 5 (severe disability), eventually adding a score of 6 (death). (Carmo et al., 2016). It is a systematic method of assessing the patient's ability, identifying skills or deficiencies in self-care and needs related to activities of daily living (ADL). The Modified Rankin Scale is a simple instrument with good acceptability to measure the level of functional recovery of post-stroke individuals (Ovando et al., 2016).

The Functional Independence Measure (FIM) was used to assess the disability experienced by post-stroke individuals. This is a multidimensional instrument that assesses a person's performance in the motor and social cognition domains (Riberto et al., 2004). It contains 18 items, grouped into six dimensions, and each item can receive a score from 1 to 7, corresponding, respectively, to total dependence and complete independence. Each dimension is analyzed by the sum of the items that compose it. The FIM total score is given by the sum of the scores of each dimension and can vary from 18 to 126 points. Dependency levels are classified according to the total MIF score: 18 points, complete dependence; 19 to 60 points, modified dependency (up to 50% assistance in tasks); 61 to 103 points, modified dependency (up to 25% assistance in tasks); 104 to 126 points, complete/modified independence

(Riberto et al., 2004). In this study, the FIM was answered through interviews with caregivers.

For information on the caregiver's perception of QoL, the World Health Organization Quality of Life (WHOQOL-BREF) questionnaire was used. This instrument consists of four domains and aims to verify psychological well-being, physical capacity, social relationships and the environment where the individual is inserted, containing a total of 24 questions. It also presents two more general questions about QoL. The WHOQOL-BREF questions provide information about the last two weeks experienced by the respondents. The instrument is easy and quick to apply, with an average filling time of 10 minutes. The domain scores are presented in percentage, and the closer to 100, the better the QoL (Fleck, 2000).

To assess the burden of the main caregiver, the Zarit Burden Interview (ZBI) scale was used, which is composed of 22 questions that encompass health areas, such as social and personal life, financial situation, emotional well-being and interpersonal relationships. This scale can be used to assess the burden of caregivers of individuals with mental and physical disabilities, and has been translated and validated for the Brazilian population (Scazufca, 2002). For each item, caregivers indicate how often they feel that way. Each answer is scored on a Likert-type scale ranging from 0 to 4 points. Questions referring to items 1 to 21 are scored as: 0) never, 1) rarely, 2) sometimes, 3) often and 4) always; and item 22 as: 0) not at all, 1) a little, 2) moderately, 3) a lot and 4) extremely. The sum of all responses can range from 0 to 88. The caregivers' burden level is classified as follows: score ≤20, no burden; 21-40, mild to moderate overload; 41-60, moderate to severe overload; 61-88, severe overload. The higher the final score, the higher the level of caregiver burden (Scazufca, 2002).

Statistical analysis

The study variables were descriptively analyzed using absolute and relative frequencies and measures of central tendency and dispersion. Spearman's correlation coefficients were calculated to assess the magnitude, direction and significance of the correlations between the variables QoL and caregiver burden, disability generated by stroke and caregiver burden and disability generated by stroke and functional independence. The inferential analyzes were described using the SPSS statistical package version 20.0 for Windows at a significance level of 5% ($p<0.05$).

Results

Figure 1 presents the results of the screening of the study subjects. Of the 529 individuals screened, 30 informal caregivers and their respective post-stroke individuals were included in the assessment.

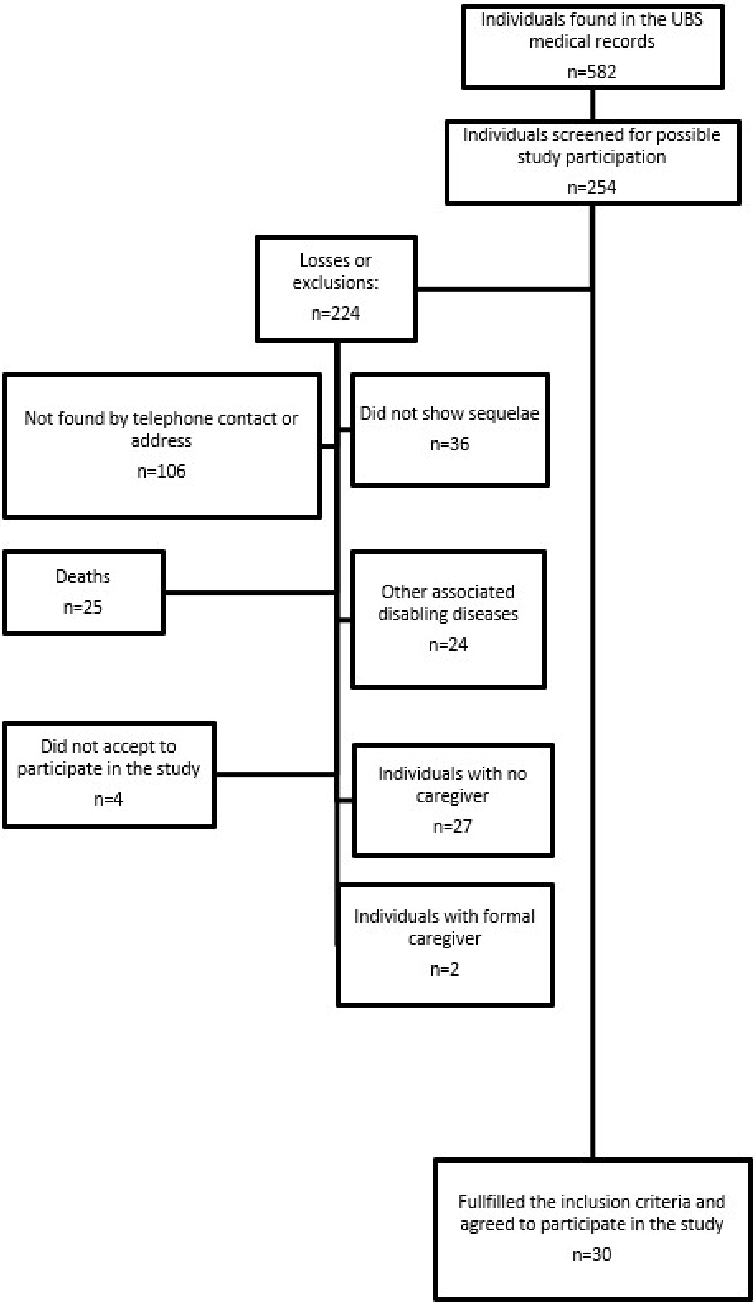

Figure 1. Study recruitment flowchart. *Source*: Elaborated by the authors.

Table 1 presents the sociodemographic and clinical characteristics of post-stroke individuals. It is observed that most participants were male, the left hemibody was more affected, there was a predominance of ischemic stroke, most individuals were married, and the mean age was 70.4 ± 11.09 years.

Table 1. Clinical and sociodemographic characteristics of post-stroke individuals.

VARIABLE	CATEGORY	RESULTS	
		N	%
Modified Rankin Scale	Slight disability (score 2)	3	10
	Moderate disability (score 3)	17	56.67
	Moderately severe disability (score 4)	6	20
Functional Independence Measure	Severe disability (score 5)	4	13.33
	Full dependency	1	3.33
	Modified dependency (50%)	6	20
	Modified dependency (25%)	21	70
	Complete independency	2	6.67
Sex	Male	21	70
	Female	9	30
Type of brain stroke	Ischemic	21	70
	Hemorrhagic	6	20
	Could not specify	3	10
Affected hemibody	Right	14	46.77
	Left	16	53.33
Scholarity	Incomplete primary education	24	80
	Complete primary education	3	10
	Complete high school	2	6.67
	Illiterate	1	3.33
Marital status	Married	24	80
	Widow/Widower	5	16.67
	Divorced	1	3.33
Time since stroke	Years (mean ±SD)	5.4 ±4.6	
Associated diseases	Number of diseases (mean ±SD)	1 ±2.0	
Medication	Number (mean ±SD)	5 ±2.4	
Monthly Family Income	Minimun wage (mean ±SD)	2.81 ±1.39	

Table 2 presents the sociodemographic characteristics of the evaluated caregivers. The average age of caregivers was 59.5 ± 15.91 years, with the majority being women (90%).

The caregivers' QoL was altered in all domains of the questionnaire. There was a lower rate of satisfaction with the aspects that make up the physical domain (53.2%) and a higher rate of satisfaction in the domain of social relationships (69.83%), followed by the psychological (67.7%) and environmental (58.47%) domains.

Table 3 presents the results of questions 1 and 2 of the questionnaire that are not included in the total score of the WHOQOL-BREF. In question 1, QoL is evaluated in general, and in question 2, satisfaction with one's own health is evaluated.

Table 2. Description of caregivers' sociodemographic characteristics.

Variable	Category	N	%
Degree of kinship	Spouse	19	63
	Daughter/Son	6	20
	Sibling	3	10
	In-law	1	3
	Granddaughter/Grandson	1	3
Work situation	From home	12	40
	Retired	9	30
	Employed	6	20
	No income/Unemployed	2	6.67
	Sickness allowance	1	3.33
Lives at the same address	Yes	27	90
	No	3	10
Stopped working to take care (n=14)	Yes	7	50
	Did not work before	7	50
Scholarity	Incomplete primary education	17	56.67
	Complete high school	6	20
	Complete primary education	5	16.67
	Illiterate	1	3.33
	University education	1	3.33
Interleave care with someone else	Yes	6	80
	No	24	20

Table 3. Questions 1 and 2 of WHOQOL-BREF.

Questions	Category	N	%
How would you rate your quality of life (QoL)?	Neither bad, nor good	13	43.33
	Good	13	43.33
	Really bad	3	13.33
	Bad	2	6.68
	Very good	1	3.33
How satisfied are you with your health?	Neither bad, nor good	12	40
	Good	10	33.33
	Bad	7	23.34
	Really bad	1	3.33
	Very good	0	0

Regarding the presence of burden among caregivers, it was verified through the application of the ZBI that 71.67% of the individuals had some level of burden. The following numbers of caregivers and levels of burden were observed: 7 (28.33%), no burden; 14 (46.67%), mild to moderate overload; 6 (20%), moderate to severe overload; 3 (10%), intense overload.

Table 4 presents the significant correlations between caregiver burden and the total QoL score on the WHOQOL-BREF. The analysis of correlations between caregiver burden and the QoL domains of the WHOQOL-BREF show correlations with the social, physical and psychological domains. No significant correlations were found between post-stroke functional independence and caregivers' burden and QoL. In post-stroke subjects, the Modified Rankin Scale correlated strongly with functional independence (ρ=-0.74; p<0.01).

Table 4. Correlations between quality of life (QoL) domains assessed by the WHOQOL-BREF and caregiver burden.

WHOQOL-BREF domains	Correlation value
Social relationships	ρ=-0.54*
Physical	ρ=-0.48*
Psychological	ρ=-0.64*
Final score	ρ=-0.6*

*=p<0.01.

Discussion

This study showed that most post-stroke individuals evaluated are male, elderly and with a greater predominance of ischemic stroke. In view of this, the literature states that the occurrence of stroke is more frequent in men, with arterial hypertension, diabetes and dyslipidemia as a risk factor (Barker-Collo et al., 2015). Age is also an important factor in the occurrence of stroke, as the risk increases twice every 10 years after age 55 (Melgaard et al., 2014).

Regarding the Modified Rankin Scale, more than half of the individuals (56.67%) had moderate disability, corroborating the results of a previous study conducted with a similar population that used the same instrument (Carmo et al., 2016). The functional independence examined in this study through the FIM showed that 70% of the sample presented modified dependence, requiring assistance of up to 25% in carrying out their ADL. Similar results were obtained by Carvalho et al. (2013), who observed that 52.6% of post-stroke individuals reached a characteristic dependency score. In general, dependence for performing ADL after stroke is due to hemiparesis, which is characterized by weakness in the hemibody contralateral to the lesion (Rissetti et al., 2020). Up to 85% of post-stroke individuals have hemiparesis, and between 55 and 75% of survivors continue to experience associated motor deficits that can limit autonomy and functionality in ADLs and instruments, directly affecting their QoL and health condition (Baumann et al., 2011).

Regarding the caregivers evaluated, there was a predominance of females, with a mean age of 59.5 years, most of them daughters or wives, revealing that it is common for women to take on caring chores even though they have another job, reducing their free time and bringing consequences for their social life (Costa et al., 2020b). Culturally, it is also expected that the care of dependents be the responsibility of close family members due to factors such as emotional relationships and living with or close to the post-stroke individual (Souza et al., 2015; Padilha et al., 2017). In this study, 90% of caregivers lived with the post-stroke individual.

When considering marital status, being married seems to favor the individual affected by a stroke being cared for by their spouse, as observed in this study, where there was a higher percentage of spouses who do not work outside the home and who take care of their partners. In addition, it was observed that 50% of caregivers who fit the category of unemployed or houseworkers stopped working to take care of their family member, evidencing a change in their occupational role. Thus, even if the caregiver is designated informally, the kinship relationship ends up being greater, especially in relation to the spouse (Padilha et al., 2017).

It was found that a large percentage of post-stroke individuals and caregivers had a lower level of education and family income, similar to what was observed in other studies (Costa et al., 2020a; Araújo et al., 2017; Silva et al., 2016). Low education leads to lower socioeconomic income, less knowledge about health risk factors and, consequently, less disease prevention (Boaventura et al., 2016). Family conflicts arising from financial issues can also arise, especially when the caregiver needs to use the dependent's income for their needs. In addition, decisions regarding expenditures are also considered potential generators of burden (Nardi et al., 2011).

It was observed that 71.67% of the evaluated caregivers had some level of burden, with a predominance of the mild to moderate category. Stroke can be highly disabling, since the individual has motor impairment with movement difficulties in the affected hemibody. These difficulties limit the performance of ADL, their return to work and social life, impacting their QoL and that of their families (Faria et al., 2017). Dependence on a family member represents a stressful circumstance that threatens the balance of personal, family and social functioning, with negative emotional consequences that generate overload (Pereira et al., 2013). In addition, it is noted that the sequelae of the disease bring to the affected individual an emotional fragility that causes insecurity and increases their dependence on the family member, aggravating the caregiver’s burden (Caro et al., 2017).

This study found that, despite some caregivers interspersing care with another person, 80% of them did not have any kind of help, which may have contributed to the levels of overload that were found. The help and support of family members can determine a reduction in the burden.

In relation to the caregivers' QoL, impairment was observed in all domains of the questionnaire, with a lower level of satisfaction with the aspects that make up the physical and environment domains. Similar results were found in a study carried out with caregivers of post-stroke individuals (Carleto & Caldana, 2014), where the domains of personal and psychological relationships were the least affected, while the physical and environment domains were the most affected. The worst QoL values found in the environment domain in this study may point to a greater burden in relation to aspects that encompass physical safety and protection, home environment, financial resources, health and social care (availability and quality), opportunity to acquire new information, participation and opportunities for leisure and physical environment (pollution, noise, traffic, climate and transport) - issues that are not necessarily related to caring for a sick person, but which can be explained by the socioeconomic status of individuals (Fleck, 2000).

In the physical domain, it is likely that the physical effort when caring for an individual with disabilities and some level of dependence for ADL results in compromises for the caregiver, with increased burden, which can impair the QoL of these subjects (Caro et al., 2017). In addition, most caregivers (40%) considered their QoL “neither good nor bad”, classifying their health in the same way. However, there is an expressive number of caregivers who classify their health as poor (23.34%).

A significant correlation was found between caregiver burden and QoL. These results corroborate those of other studies conducted with similar samples, indicating that burden is associated with a decrease in QoL in terms of caregivers' health (Caro et al., 2017; McCullagh et al., 2005).

In this study, the post-stroke dependency level did not show a significant correlation with caregivers' burden and QoL. Such correlations were expected, since changes in ADL performance result in an increased need for physical and emotional support resources and, consequently, in caregivers' overload (Ogunlana et al., 2014). In these circumstances, the time spent at home by the caregiver increases, there is less time for leisure activities and social isolation occurs, which is associated with low QoL scores. A possible explanation for this result would be the presence of other variables related to QoL that may have influenced the burden, such as advanced age, female gender, low levels of income and scholarity, deficits in social relationships and poor health conditions of the caregiver (Sprangers et al., 2000). In addition, the unexpected change in routine that these family members were suddenly subjected to, starting to do an activity for which they had not planned or prepared, can be, in itself, an overloading factor. The literature also points to sphincter control, advanced age and gender as mediators of burden and decrease in caregivers' QoL (Rigby et al., 2009).

There was a statistically significant correlation between functional independence and the Modified Rankin Scale, suggesting that individuals with greater disability have higher levels of dependence - findings that have already been widely described in the literature (Rissetti et al., 2020).

Considering the results of the caregiver's overload and their QoL and health, the importance of an education relationship is noted so that the family caregiver who assumes responsibility for the care of the post-stroke individual is guided by a health professional. Thus, an educational relationship is interconnected between both, because the caregiver must understand techniques and knowledge in order to take care of the patient, without harming them or themselves. In addition, health professionals must understand that the focus of health care must go beyond the care of the post-stroke individual. These findings suggest the need for health interventions aimed not only at post-stroke individuals, but also at their family caregivers.

Conclusion

This study showed that individuals affected by brain strokes in Araranguá/SC have a moderate degree of functional disability, which requires the presence of a caregiver; in these cases, informal and mostly women. These caregivers showed themselves to be overloaded with the care function and with compromised QoL. It is believed that the results found here may contribute to a better understanding of the relationship between the changes caused by a stroke episode and the QoL and burden of family caregivers.

As a limitation of this study, we can mention the small sample of individuals screened and evaluated, due to the difficulty of locating them. However, to the best of our knowledge, this is the first study carried out with this population in Araranguá/SC.

Further research is suggested that may bring more knowledge about the difficulties faced by the population of people who care for a family member in such peculiar conditions, such as those affected by brain stroke. It would be of great importance to design studies that help to understand the changes in the lives of caregivers of post-stroke individuals, such as changes in their occupational roles, in the use of their time and in their ADL, and the possible influence of these changes on the levels of overload and Qo. In addition, future studies could assess the effects of specific interventions aimed at improving the health of informal caregivers.

References

Araújo, J. B., Cirne, G. N. M., Lima, N. M. F. V., Cavalcanti, F. A. C., Cacho, Ê. W. A., & Cacho, R. O. (2017). Sobrecarga de cuidadores familiares e independência funcional de pacientes pós-acidente vascular encefálico. *Revista Ciência Médica*, *25*(3), 107-113.

Barker-Collo, S., Bennett, D. A., Krishnamurthi, R. V., Parmar, P., Feigin, V. L., Naghavi, M., Forouzanfar, M. H., Johnson, C. O., Nguyen, G., Mensah, G. A., Vos, T., Murray, C. J., Roth, G. A., GBD 2013 Writing Group, & GBD 2013 Stroke Panel Experts Group (2015). Sex differences in stroke incidence, prevalence, mortality and disability-adjusted life years: results from the global burden of disease study 2013. *Neuroepidemiology*, *45*(3), 203-214. http://dx.doi.org/10.1159/000441103.

Baumann, M., Lurbe-Puerto, K., Alzahouri, K., & Aïach, P. (2011). Increased residual disability among poststroke survivors and the repercussions for the lives of informal caregivers. *Topics in Stroke Rehabilitation*, *18*(2), 162-171. http://dx.doi.org/10.1310/tsr1802-162.

Boaventura, L. C., Borges, H. C., & Ozaki, A. H. (2016). Avaliação da sobrecarga do cuidador de pacientes neurológicos cadeirantes adultos. *Ciência & Saúde Coletiva*, *21*(10), 3193-3202. http://dx.doi.org/10.1590/1413-812320152110.15202016.

Carleto, G. N., & Caldana, L. M. (2014). Correlation between quality of life of the aphasic patient and his family. *Revista Distúrbios da Comunicação*, *26*(4), 630-640.

Carmo, J. F. D., Oliveira, E. R. A., & Morelato, R. L. (2016). Functional disability and associated factors in elderly stroke survivors in Vitória, Brazil. *Revista Brasileira de Geriatria e Gerontologia*, *19*(5), 809-818. http://dx.doi.org/10.1590/1809-98232016019.150215.

Caro, C. C., Costa, J. D., & Cruz, D. M. C. (2018). O uso de dispositivos auxiliares para a mobilidade e a independência funcional em sujeitos com Acidente Vascular Cerebral. *Cadernos Brasileiros de Terapia Ocupacional*, *26*(3), 558-568. http://dx.doi.org/10.4322/2526-8910.ctoAO1117.

Caro, C. C., Mendes, P. V., Costa, J. D., Nock, L. J., & Cruz, D. M. (2017). Independence and cognition post-stroke and its relationship to burden and quality of life of family caregivers. *Topics in Stroke Rehabilitation*, *24*(3), 194-199. http://dx.doi.org/10.1080/10749357.2016.1234224.

Carvalho, J. C., Gusmão, C. A., Matos, M. A., Matias, A. C., & Santos, N. A. (2013). Avaliação dos desfechos de funcionalidade e mobilidade pós-acidente vascular encefálico. *Revista da Faculdade de Ciências Médicas de Sorocaba*, *15*(4), 100-104.

Cerniauskaite, M., Quintas, R., Koutsogeorgou, E., Meucci, P., Sattin, D., Leonardi, M., & Raggi, A. (2012). Quality-of-life and disability in patients with stroke. *American Journal of Physical Medicine & Rehabilitation*, *91*(Suppl. 13), 39-47.

Costa, T. F., Costa, K. N. F. M., Fernandes, M. G. M., Martins, K. P., & Brito, S. S. (2015a). Qualidade de vida de cuidadores de indivíduos com acidente vascular encefálico: associação com características e sobrecarga. *Revista da Escola de Enfermagem da USP*, *49*(2), 245-252. http://dx.doi.org/10.1590/S0080-623420150000200009.

Costa, T. F., Costa, K. N. F. M., Martins, K. P., Fernandes, M. G. M., & Brito, S. S. (2015b). Burden over family caregivers of elderly people with stroke. *Escola Anna Nery*, *19*(2), 350-355. http://dx.doi.org/10.5935/1414-8145.20150048.

Costa, A. F. D., Lopes, M. C. B. T., Campanharo, C. R. V., Batista, R. E. A., & Okuno, M. F. P. (2020a). Qualidade de vida e sobrecarga de cuidadores de idosos. *Texto & Contexto Enfermagem*, *29*, 1-11. http://dx.doi.org/10.1590/1980-265X-TCE-2019-0043.

Costa, T. F., Pimenta, C. J. L., Nóbrega, M. M. L., Fernandes, M. G. M., França, I. S. X., Pontes, M. F. L., & Costa, K. N. F. M. (2020b). Burden on caregivers of patients with sequelae of cerebrovascular accident. *Revista Brasileira de Enfermagem*, *73*(6), e20180868. http://dx.doi.org/10.1590/0034-7167-2018-0868.

Faria, A. C. A., Martins, M. M. F. P. S., Schoeller, S. D., & Matos, L. O. (2017). Percurso da pessoa com acidente vascular encefálico: do evento à reabilitação. *Revista Brasileira de Enfermagem*, *70*(3), 520-528. http://dx.doi.org/10.1590/0034-7167-2016-0579.

Fleck, M. P. A. (2000). O instrumento de avaliação de qualidade de vida da Organização Mundial da Saúde (WHOQOL-100): características e perspectivas. *Ciência & Saúde Coletiva*, *5*(1), 33-38. http://dx.doi.org/10.1590/S1413-81232000000100004.

McCullagh, E., Brigstocke, G., Donaldson, N., & Kalra, L. (2005). Determinants of caregiving burden and quality of life in caregivers of stroke patients. *Stroke*, *36*(10), 2181-2186. http://dx.doi.org/10.1161/01.STR.0000181755.23914.53.

Melgaard, L., Rasmussen, L. H., Skjøth, F., Lip, G. Y., & Larsen, T. B. (2014). Age dependence of risk factors for stroke and death in young patients with atrial fibrillation: a nationwide study. *Stroke*, *45*(5), 1331-1337. http://dx.doi.org/10.1161/STROKEAHA.114.004903.

Nardi, T., Rigo, J. C., Brito, M., Santos, E. L. M., & Bós, Â. J. G. (2011). Sobrecarga e percepção de qualidade de vida em cuidadores de idosos do Núcleo de Atendimento à Terceira Idade do Exército (Natiex). *Revista Brasileira de Geriatria e Gerontologia*, *14*(3), 511-519. http://dx.doi.org/10.1590/S1809-98232011000300011.

Ogunlana, M. O., Dada, O. O., Oyewo, O. S., Odole, A. C., & Ogunsan, M. O. (2014). Quality of life and burden of informal caregivers of stroke survivors. *Hong Kong Physiotherapy Journal*, *32*(1), 6-12. http://dx.doi.org/10.1016/j.hkpj.2013.11.003.

Oliveira, E. C., Ferreira, W. F. S., de Oliveira, E. C., & Dutra, D. A. (2017). Cuidados pós-alta em pacientes idosos com sequelas de acidente vascular cerebral: planejamento de alta hospitalar. *Revista Saúde e Desenvolvimento*, *11*(9), 172-197.

Ovando, A. C., Peres, D., Michaelsen, S. M., & de Noronha, M. A. (2016). Processo de tradução, propriedades de medida e classificação de acordo a CIF dos instrumentos de avaliação pós-AVE disponíveis em Português falado no Brasil. *Fisioterapia Brasil*, *17*(4), 400-414. http://dx.doi.org/10.33233/fb.v17i4.513.

Padilha, B. W., Carrasco, A. C., Binda, A. C., Fréz, A. R., & Bim, C. R. (2017). Qualidade de vida e sobrecarga de cuidadores de deficientes físicos. *Revista Brasileira de Qualidade de Vida*, *9*(1), 3-16. http://dx.doi.org/10.3895/rbqv.v9n1.5078.

Pereira, R. A., Santos, E. B. D., Fhon, J. R. S., Marques, S., & Rodrigues, R. A. P. (2013). Sobrecarga dos cuidadores de idosos com acidente vascular cerebral. *Revista da Escola de Enfermagem da USP*, *47*(1), 185-192. http://dx.doi.org/10.1590/S0080-62342013000100023.

Riberto, M., Miyazaki, M. H., Jucá, S. S. H., Sakamoto, H., Pinto, P. P. N., & Battistella, L. R. (2004). Validação da versão brasileira da Medida de Independência Funcional. *Acta Fisiátrica*, *11*(2), 72-76. http://dx.doi.org/10.5935/0104-7795.20040003.

Rigby, H., Gubitz, G., Eskes, G., Reidy, Y., Christian, C., Grover, V., & Phillips, S. (2009). Caring for stroke survivors: baseline and 1-year determinants of caregiver burden. *International Journal of Stroke*, *4*(3), 152-158. http://dx.doi.org/10.1111/j.1747-4949.2009.00287.x.

Rissetti, J., Feistauer, J. B., Luiz, J. M., da Silveira, L. D. S., & Ovando, A. C. (2020). Independência funcional e comprometimento motor em indivíduos pós-AVE da comunidade. *Acta Fisiátrica*, *27*(1), 27-33. http://dx.doi.org/10.11606/issn.2317-0190.v27i1a169615.

Scazufca, M. (2002). Versão brasileira da escala Burden Interview para avaliação de sobrecarga em cuidadores de indivíduos com doenças mentais. *The British Journal of Psychiatry*, *24*(1), 12-17. http://dx.doi.org/10.1590/S1516-44462002000100006.

Sedrez Celich, K. L., Maschio, G., da Silva Filho, C. C., Gaffuri da Silva, T., & Silva de Souza, S. (2016). Influência do apoio familiar na sobrecarga do cuidador de indivíduos com sequelas de acidente vascular cerebral. *Investigacion y Educacion en Enfermeria*, *34*(3), 544-550. http://dx.doi.org/10.17533/udea.iee.v34n3a14.

Silva, I. F. G., Neves, C. F. S., Vilela, A. C. G., Bastos, L. M. D., & Henriques, M. I. S. (2016). Viver e Cuidar Após o Acidente Vascular Cerebral. *Revista de Enfermagem Referência*, *4*(8), 103-111. http://dx.doi.org/10.12707/RIV15047.

Souza, L. R. D., Hanus, J. S., Dela Libera, L. B., Silva, V. M., Mangilli, E. M., Simões, P. W., Ceretta, L. B., & Tuon, L. (2015). Sobrecarga no cuidado, estresse e impacto na qualidade de vida de cuidadores domiciliares assistidos na atenção básica. *Cadernos Saúde Coletiva*, *23*(2), 140-149. http://dx.doi.org/10.1590/1414-462X201500020063.

Sprangers, M. A., de Regt, E. B., Andries, F., van Agt, H. M., Bijl, R. V., de Boer, J. B., Foets, M., Hoeymans, N., Jacobs, A. E., Kempen, G. I., Miedema, H. S., Tijhuis, M. A., & de Haes, H. C. (2000). Which chronic conditions are associated with better or poorer quality of life? *Journal of Clinical Epidemiology*, *53*(9), 895-907. http://dx.doi.org/10.1016/S0895-4356(00)00204-3.

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