








ANXIETY, DEPRESSION AND STRESS IN CAREGIVERS OF CEREBROVASCULAR ACCIDENTS SURVIVORS

ANSIEDADE, DEPRESSÃO E ESTRESSE EM CUIDADORES DE SOBREVIVENTES DE ACIDENTE VASCULAR ENCEFÁLICO

ANSIEDAD, DEPRESIÓN Y ESTRÉS EN LOS CUIDADORES DE SOBREVIVIENTES DE ACCIDENTE VASCULAR ENCEFÁLICO

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ABSTRACT

Objective: to associate anxiety, depression and stress with sociodemographic characteristics, lifestyle, health status and data on the provision of care in caregivers of cerebrovascular accident survivors. **Method:** cross-sectional study conducted with 151 informal primary caregivers in João Pessoa, Paraíba, Brazil. A semi-structured instrument and the Anxiety, Depression and Stress-21 Scale were used, and the data were analyzed using descriptive and inferential statistics. **Results:** caregivers with more years of study had a higher mean of stress. Those who always felt tired had higher means for anxiety, depression and stress, as did those who mentioned their health status as poor and those who devoted more than 10 hours a week to care. Participants who did not practice leisure activities had higher means of depression and stress, those who helped with medication were related to a higher average of anxiety and those who helped with mobility reported higher means of depression and stress. **Conclusions:** it was observed that the levels of anxiety, depression and stress were influenced by some personal characteristics, life habits, health situation and characteristics of the care provided to the family member who suffered a cerebrovascular accident.

Keywords: Stroke; Caregivers; Anxiety; Depression; Stress, Psychological.

RESUMO

Objetivo: associar a ansiedade, a depressão e o estresse às características sociodemográficas, hábitos de vida, situação de saúde e dados da prestação do cuidado em cuidadores de sobreviventes de acidente vascular encefálico. **Método:** estudo transversal realizado com 151 cuidadores informais primários em João Pessoa, Paraíba, Brasil. Foram utilizados um instrumento semiestruturado e a Escala de Ansiedade, Depressão e Estresse-21, sendo os dados analisados por estatística descritiva e inferencial. **Resultados:** os cuidadores com mais anos de estudo tiveram maior média de estresse. Os que se sentiam sempre cansados apresentaram maiores médias para ansiedade, depressão e estresse, bem como aqueles que mencionaram seu estado de saúde como ruim e os que dedicavam mais de 10 horas por semana ao cuidado. Os participantes que não praticavam atividade de lazer obtiveram maiores médias de depressão e estresse, os que auxiliavam na medicação foram relacionados a maior média de ansiedade e os que ajudavam na locomoção relataram maiores médias de depressão e estresse. **Conclusões:** foi observado que os níveis de ansiedade, depressão e estresse sofreram influência de algumas características pessoais, hábitos de vida, situação de saúde e características do cuidado prestado ao familiar vítima de acidente vascular encefálico.

Palavras-chave: Acidente Vascular Cerebral; Cuidadores; Ansiedade; Depressão; Estresse Psicológico.

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RESUMEN

Objetivo: asociar la ansiedad, la depresión y el estrés con características sociodemográficas, hábitos de vida, estado de salud y datos de los servicios prestados en cuidadores de sobrevivientes de accidente vascular encefálico. **Método:** estudio transversal realizado con 151 cuidadores primarios informales de João Pessoa, Paraíba, Brasil. Se utilizó un instrumento semiestructurado y la escala de ansiedad, depresión y estrés-21; los datos se analizaron mediante estadística descriptiva e inferencial. **Resultados:** los cuidadores con más años de estudio tuvieron mayor promedio de estrés. Aquellos que generalmente se sentían cansados tuvieron promedios más altos de ansiedad, depresión y estrés, al igual que aquellos que declararon que su estado de salud era malo y los que dedicaron más de 10 horas semanales a atender a los familiares. Los participantes que no practicaban actividades de ocio tuvieron promedios más altos de depresión y estrés, los que ayudaron con los medicamentos presentaron mayor promedio de ansiedad y los que ayudaron con la movilidad demostraron promedios más altos de depresión y estrés. **Conclusiones:** se observó que los niveles de ansiedad, depresión y estrés fueron influenciados por algunas características personales, hábitos de vida, estado de la salud y características de la atención brindada al familiar que sufrió el accidente vascular encefálico.

Palabras-chave: Accidente Cerebrovascular; Cuidadores; Ansiedad; Depresión; Estrés Psicológico.

INTRODUCTION

Cerebrovascular diseases represent one of the main causes of morbidity and mortality worldwide, among which cerebrovascular accident (CVA) is outstanding. People affected by this problem commonly become dependent on the care of others, which is often performed by informal family caregivers, such as spouses and adult children.¹

The caregiver is a very important figure to provide autonomy, independence and integration, however, if not prepared to assume this role, it may hinder the engagement of healthy behaviors of the patient and delay the rehabilitation.^{2,3} In addition, many claim that they feel unprepared to offer practical support at home and are excluded from discharge and follow-up plans by health professionals, which can cause intense suffering.⁴

In this sense, it is quite common for caregivers to develop processes of physical and psychological illness, especially episodes of anxiety, depression, stress, anger, anguish and thoughts of suicidal ideation, which are due to the lack of support, the patient's level of dependence, chronicity of the disabling situation, the complexity of care activities and the worsening of health status. Because of this, social isolation, the reduction or extinction of leisure activities, the

compromise of professional activity and the lack of time to take care of oneself are frequently observed.⁵⁻⁸

Therefore, it seeks to provide more visibility to the caregiver of people with sequelae of CVA, encouraging the implementation of programs of theoretical and practical interventions, to prepare and adapt caregivers for a new context of life, significantly reducing the burden and, consequently, the levels of depression, anxiety and stress, with an improvement in the sense of competence and quality of life of this population.

Thus, the present study aims to associate anxiety, depression and stress with sociodemographic characteristics, lifestyle, health status and data on the provision of care in caregivers of CVA survivors.

METHOD

This is a cross-sectional study conducted with primary informal caregivers of people with sequelae of cerebrovascular accident registered in family health units (FHU) in João Pessoa, Paraíba, Brazil. The selection was carried out at random, with three units from each health district being drawn, since the health care network of this municipality is composed of 194 family health units, managed in an organizational way by five health districts.

The sample calculation was based on the number of people affected by CVA who were registered with the FHUs in the city, during 2016, totaling 249 individuals. The sample size was defined using the calculation for finite populations with known proportions, based on a margin of error of 5% (error=0.05), with a degree of reliability of 95% ($\alpha=0.05$, which provides $Z_{0.05/2}=1.96$), considering the true proportion as 50% ($p=0.50$) for sequelae, resulting in a sample of 151 caregivers, who were selected proportionally to the quantitative individuals in each unit and district.

Inclusion criteria were defined as: being 18 years of age or older and being a primary informal caregiver of people with sequelae of cerebrovascular accident registered in family health units in the municipality. Individuals who provided care for less than six months were excluded, as this interval does not allow adaptation to changes resulting from the initial impact of care to a person with cerebrovascular accident sequelae, often triggering episodes of anxiety, depression and stress which can improve and/or get worse as the care time increases.

The data were collected between September and December 2017 by previously trained researchers, in a process that involved the presentation, explanation and application of the instruments among the interviewers to standardize data collection. Individual interviews were conducted in the households, with an mean duration of 30 minutes, with the content of the speeches recorded in audio. There were no sample losses throughout the research. The identification of the caregivers occurred through contact with the

nurses of each unit, requesting information about the people who suffered a cerebrovascular accident and had some type of sequel.

For data collection, a semi-structured instrument was used to obtain sociodemographic characteristics, life habits, health situation and related to the provision of care, in addition to the Anxiety, Depression and Stress Scale-21 (DASS-21).⁹ DASS-21 is an instrument composed of 21 items, evaluated on a Likert-type scale with four points, ranging from zero (strongly disagree) to three (strongly agree), which is divided into three subscales formed by seven questions each, aimed at assess emotional states of anxiety, depression and stress during the last week.

The anxiety subscale assesses the excitation of the autonomic nervous system; musculoskeletal effects; situational anxiety; subjective anxiety experiences. The depression subscale evaluates symptoms as inertia; anhedonia; dysphoria; lack of interest and involvement; self-depreciation; devaluation of life and discouragement. And the stress subscale assesses the difficulty in relaxing; nervous excitement; easy disturbance/agitation; irritability/overreaction and impatience.⁹

The calculation of the individual result of anxiety, depression and stress corresponds to the sum of the item scores in each subscale. Scores are classified as follows: normal (anxiety 0-7; depression 0-9; stress 0-14); mild (anxiety 8-9; depression 10-13; stress 15-18); moderate (anxiety 10-14; depression 14-20; stress 19-25); severe (anxiety 15-19; depression 21-27; stress 26-33); very severe (anxiety \geq 20; depression \geq 28; stress \geq 34).⁹

The data were stored in an electronic spreadsheet structured in the Microsoft Excel Program with double typing, in order to guarantee reliability in the data compilation. Then, they were organized, coded, imported and processed by the application Statistical Package for the Social Science for Windows, version 22.0, being analyzed using descriptive and inferential statistics. The association between the variables was performed using the Mann-Whitney and Kruskal-Wallis tests. The level of significance used for the statistical analyzes was 5% ($p\leq 0.05$).

The study was developed in accordance with that recommended by Resolution Nr. 466/2012 of the Brazilian National Health Council and its complementarities. The research was approved by the Research Ethics Committee of the Health Sciences Center of the *Universidade Federal da Paraíba*, under Opinion Report Nr. 2,243,225/17 and Certificate of Presentation for Ethical Appreciation No. 71855817.0.0000.5188, being conducted in accordance with the standard's ethical requirements.

RESULTS

Among the 151 caregivers, the majority were female (78.1%), aged between 56 and 65 years (27.8%), married or in a stable relationship (65.6%), with five to eight years of study (27.2%), practitioners of the Catholic religion (60.9%), with individual income

of up to R\$ 937.00 (44.4%), family income between R\$ 937.00 and R\$ 1,874.00 (41.7%) and who did not consider income sufficient (58.3%). The main caregiver was the spouse (41.1%) who lived with the patient (87.4%), but there was the presence of people who helped with patient care (61.6%), acting as a secondary or tertiary caregiver (51.7%).

An association with statistical significance between stress and the variable years of study (p -value=0.044) was found, in which participants with less than four years of study showed a higher mean of stress (Table 1).

When associating the variables of life habits and health conditions with the means of anxiety, depression and stress, it was found that those caregivers who reported feeling always tired, who did not perform leisure activities and mentioned their health status as bad had an influence statistically significant ($p < 0.05$), as recorded in Table 2.

In the association between data referring to care and DASS-21, it was inferred that caregivers who devoted more than 10 hours per week to care had a statistically significant influence ($p < 0.05$), as shown in Table 3.

Significant associations were found between the medication variable and anxiety (p -value=0.047), showing a higher mean (5.55 ± 7.597) when the patient needed help with medication; the variable movement and depression and stress, with higher means those who needed help to get around (6.84 ± 9.120 ; 9.23 ± 10.257 , respectively) (Table 4).

DISCUSSION

In the relationship between sociodemographic data and the DASS-21 scale, there was statistical significance between having more years of study and a higher mean of stress. People who spend more time in the knowledge acquisition process create expectations of being financially rewarded for the investment made, through more job possibilities.¹⁰ However, when they assume the role of caregiver, their social life is limited, being unable to put into practice all the perspectives created by projects, which can become a stressor.^{4,7,8}

When associating the variables of life habits and health conditions with the means of DASS-21, statistical significance was found among the caregivers who reported feeling always tired and higher means of anxiety, depression and stress. This finding corroborates other studies in which tiredness and physical, emotional, financial and social burden of caregivers were associated with mental disorders,¹¹⁻¹⁶ which, consequently, affects the well-being and quality of life of these individuals.¹⁷

The experience of taking care of dependent people has been presented by family caregivers as a task that causes physical and psychological exhaustion, usually due to the uninterrupted nature of the assistance in the performance of practical tasks

Table 1 - Relationship between the sociodemographic characteristics of caregivers of people with cardiovascular accident sequelae and DASS-21. João Pessoa - PB, Brazil, 2018

| Variáveis | Anxiety | | Depression | | Stress | |
|--------------------------------|---------|--------------------|------------|--------------------|--------|--------------------|
| | Mean | Standard-Deviation | Mean | Standard-Deviation | Mean | Standard-Deviation |
| Gender | | | | | | |
| Female | 5.42 | 7.897 | 6.39 | 9.056 | 8.73 | 10.136 |
| Male | 4.48 | 6.261 | 4.06 | 5.160 | 5.94 | 6.937 |
| p Value* | | 0.757 | | 0.340 | | 0.167 |
| Age range | | | | | | |
| < 65 yearsold | 4.93 | 7.122 | 5.86 | 8.403 | 8.34 | 9.530 |
| > 65 yearsold | 6.62 | 9.428 | 6.00 | 8.560 | 7.08 | 9.931 |
| Valor p* | | 0.315 | | 0.835 | | 0.485 |
| Marital status | | | | | | |
| Single | 5.29 | 7.644 | 7.13 | 9.637 | 8.84 | 9.423 |
| Married or stable relationship | 5.14 | 7.373 | 5.48 | 7.748 | 7.96 | 9.621 |
| Widower | 4.40 | 4.561 | 2.80 | 5.215 | 4.40 | 6.066 |
| Divorced | 6.22 | 11.111 | 6.67 | 11.358 | 8.89 | 12.046 |
| p Value** | | 0.996 | | 0.608 | | 0.706 |
| Education | | | | | | |
| < 4 years of study | 5.65 | 8.104 | 5.23 | 8.733 | 6.85 | 9.590 |
| > 4 years of study | 4.99 | 7.291 | 6.22 | 8.247 | 8.79 | 9.553 |
| p Value* | | 0.497 | | 0.176 | | 0.044 |
| Religion | | | | | | |
| Yes | 5.37 | 7.841 | 6.08 | 8.684 | 8.16 | 9.661 |
| No | 3.60 | 3.239 | 5.00 | 5.437 | 7.60 | 8.208 |
| p Value* | | 0.882 | | 0.987 | | 0.965 |
| Individual income | | | | | | |
| < 2 minimum wages | 5.45 | 7.827 | 5.73 | 8.231 | 8.00 | 9.555 |
| > 2 minimum wages | 3.63 | 5.241 | 6.89 | 9.689 | 8.95 | 9.964 |
| p Value* | | 0.537 | | 0.819 | | 0.762 |
| Family income | | | | | | |
| < 2 minimum wages | 5.41 | 7.457 | 5.96 | 8.558 | 8.37 | 9.343 |
| > 2 minimum wages | 4.91 | 7.778 | 5.76 | 8.217 | 7.72 | 10.014 |
| p Values* | | 0.378 | | 0.462 | | 0.398 |

*Mann-Whitney Test; **Kruskal-Wallis Test.

of daily living and self-care activities and, above all, of the care of great demand with rare support and assistance and the limitation of their social life.¹⁴

In this perspective, the importance of monitoring these caregivers by a multidisciplinary team is perceived, in which Nursing, in addition to assisting the patient, must offer all support to these people and their family, to avoid or mitigate the negative effects of this process, thus ensuring the quality of care provided to the patient.¹⁷

Caregivers who did not have any leisure activity had higher means of depression and stress. Leisure increases the level of

satisfaction with life and the ability to deal with stressful events,¹⁸ in contrast, its lack predisposes to an increase in burden, as a result of the various responsibilities attributed to the caregiver, which impairs their well-being, quality of care, recovery and reintegration of the patient into society.¹⁹

Regarding the self-reported health status, there was a significant relationship with anxiety, depression and stress, especially those who said they perceived their health as bad. The response of family members about their health status is directly proportional to their degree of awareness in recognizing that they also need care.¹⁴ Often,

Table 2 - Association of life habits and health situation of caregivers of people with cerebrovascular accident sequelae and DASS-21. *João Pessoa - PB, Brazil, 2018*

| Activities in which help is needed | Anxiety | | Depression | | Stress | |
|------------------------------------|---------|---------------------|------------|--------------------|--------|--------------------|
| | Mean | Standard- Deviation | Mean | Standard-Deviation | Mean | Standard-Deviation |
| Physicalactivity | | | | | | |
| Yes | 5.74 | 7.958 | 5.66 | 7.383 | 8.26 | 9.531 |
| No | 5.04 | 7.450 | 5.96 | 8.747 | 8.07 | 9.636 |
| pValue* | | 0.737 | | 0.694 | | 0.914 |
| Feeling tired | | | | | | |
| Never | 2.70 | 4.902 | 3.06 | 4.555 | 6.30 | 8.202 |
| Sometimes | 4.01 | 5.555 | 4.65 | 7.735 | 5.64 | 7.325 |
| Often | 9.06 | 10.483 | 10.33 | 10.561 | 13.92 | 11.832 |
| Always | 9.83 | 10.375 | 10.65 | 9.905 | 14.71 | 11.682 |
| pValue** | | 0.001 | | 0.001 | | < 0.001 |
| Leisureactivities | | | | | | |
| None | 6.33 | 8.509 | 6.86 | 9.241 | 9.06 | 10.095 |
| Daily | 0.50 | 0.707 | 3.00 | 4.243 | 2.00 | 2.828 |
| Weekly | 3.60 | 6.298 | 4.20 | 4.813 | 7.60 | 7.461 |
| Biweekly | 3.82 | 5.250 | 2.64 | 3.749 | 6.73 | 9.603 |
| Monthly | 3.00 | 4.681 | 3.08 | 7.003 | 3.25 | 6.509 |
| Annually | 8.75 | 8.509 | 14.75 | 10.794 | 18.25 | 10.714 |
| pValue** | | 0.568 | | 0.010 | | 0.003 |
| Self-reportedhealth status | | | | | | |
| Bad | 11.40 | 12.756 | 7.36 | 7.569 | 10.60 | 14.438 |
| Regular | 6.03 | 7.575 | 6.20 | 9.401 | 9.62 | 9.847 |
| Great | 2.44 | 4.641 | 3.07 | 5.316 | 4.70 | 7.545 |
| Excelent | 0.50 | 1.000 | 0.50 | 1.000 | 3.50 | 5.745 |
| p Value** | | < 0.001 | | 0.005 | | 0.008 |

*Mann-Whitney Test; **Kruskal-Wallis Test.

Table 3 - Association between data referring to the care of people with cerebrovascular accidentsequelae and DASS-21. *João Pessoa - PB, Brazil, 2018*

| Variables | Anxiety | | Depression | | Stresse | |
|--|---------|-------------------|------------|--------------------|---------|--------------------|
| | Mean | Standarddeviation | Mean | Standard-deviation | Mean | Standard-deviation |
| Period that takes care of the patient | | | | | | |
| < 5 years | 4.83 | 7.408 | 5.34 | 7.747 | 7.55 | 9.284 |
| > 5 years | 5.84 | 7.822 | 6.74 | 9.363 | 9.03 | 10.047 |
| p Value* | | 0.642 | | 0.582 | | 0.412 |
| Days/week for care | | | | | | |
| Upto 3 days | 9.00 | 12.702 | 3.50 | 7.000 | 6.50 | 9.434 |
| > 3 days | 5.12 | 7.417 | 5.95 | 8.447 | 8.16 | 9.610 |
| p Value* | | 0.341 | | 0.285 | | 0.721 |
| Hours/week for care | | | | | | |
| < 10 hours | 3.00 | 5.461 | 4.03 | 7.286 | 6.57 | 7.724 |
| > 10 hours | 5.89 | 7.987 | 6.44 | 8.661 | 8.59 | 10.054 |
| p Value* | | 0.037 | | 0.043 | | 0.049 |

*Mann-WhitneyTest; **Kruskal-WallisTest.

Table 4 - Association between activities in which people with cerebrovascular accident sequelae need help from the caregiver and the DASS-21. João Pessoa - PB, Brazil, 2018

| Activities in which help is needed | Anxiety | | Depression | | Stress | |
|------------------------------------|---------|--------------------|------------|--------------------|--------|--------------------|
| | Mean | Standard-Deviation | Mean | Standard-Deviation | Mean | Standard-Deviation |
| Hygiene | | | | | | |
| Yes | 5.15 | 7.453 | 6.04 | 8.630 | 5.88 | 8.402 |
| No | 5.40 | 7.911 | 5.49 | 7.881 | 8.05 | 9.191 |
| pValue* | | 0.496 | | 0.326 | | 0.519 |
| Eliminations | | | | | | |
| Yes | 6.09 | 8.389 | 6.77 | 8.987 | 9.25 | 10.318 |
| No | 4.36 | 6.584 | 5.00 | 7.739 | 7.00 | 8.712 |
| pValue* | | 0.181 | | 0.332 | | 0.170 |
| Medication | | | | | | |
| Yes | 5.55 | 7.597 | 6.10 | 8.466 | 8.54 | 9.835 |
| No | 4.00 | 7.414 | 5.06 | 8.238 | 6.56 | 8.519 |
| pValue* | | 0.047 | | 0.234 | | 0.209 |
| Physicalactivity | | | | | | |
| Yes | 5.64 | 6.412 | 6.33 | 7.147 | 8.97 | 9.112 |
| No | 5.10 | 7.872 | 5.75 | 8.218 | 7.88 | 9.729 |
| pValue* | | 0.202 | | 0.836 | | 0.515 |
| Leisure | | | | | | |
| Yes | 4.77 | 6.057 | 5.75 | 8.125 | 7.96 | 8.776 |
| No | 5.43 | 8.186 | 5.94 | 8.566 | 8.19 | 9.971 |
| pValue* | | 0.842 | | 0.885 | | 0.990 |
| Movement | | | | | | |
| Yes | 5.80 | 8.252 | 6.84 | 9.120 | 9.23 | 10.257 |
| No | 4.04 | 5.820 | 3.94 | 6.371 | 5.88 | 7.650 |
| pValue* | | 0.515 | | 0.049 | | 0.042 |

*Teste Mann-Whitney.

due to the high degree of involvement, the caregiver gives up their health,^{5,17} which in addition to causing damage can interfere with the care that is given to the patient.

Regarding the care time, it was evidenced that those who devoted more than 10 hours a week to this activity exhibited higher levels of anxiety, depression and stress. A similar study carried out in Italy identified a prevalence of 46 hours or more of care, confirming that caregivers devote most of their time to caring for the dependent.²⁰ This reinforces the thought that nurses need to intervene in the family during hospital discharge and immediately after this event, with psychoeducational therapies, skills training and therapeutic counseling, which will help to reduce anxiety and overload, providing a more favorable outcome.^{14,15}

In research on the initial period after discharge, it was shown that caregivers felt they did not have a life of their own and were prisoners in their own home, especially when they received little support and needed to perform other roles, such as in formal work

and home activities.^{21,22} They also felt sad, overwhelmed and guilty for not having enough strength to do everything.²³

As for the association between the activities in which they need help from caregivers and the DASS-21, there was a statistical significance between the medication used by the patient and a higher mean of anxiety. Studies show that medication assistance is one of the activities most performed by informal caregivers²⁴ and that the lack of knowledge and mastery over the various processes that are related to the use of medicines, from purchase, administration, time taken and adherence to therapy, can cause feelings of anxiety in the caregiver and negatively interfere with their health condition.^{11,12}

Another activity that needed help from the caregiver that had statistical significance was movement, with higher means of depression and stress. Providing care in movement of the patient with a cerebrovascular accident sequel results in physical and emotional stress for the caregiver, especially when it comes

to an elderly caregiver, because in addition to the difficulties encountered in movement of the family member, still needs to deal with the physical and functional limitations of the own aging.²⁵ This statement corroborates a study carried out in Brazil, in which older caregivers had worse health-related quality of life in the functional capacity and pain domains, which can cause depression and stress.¹⁷

It is worth mentioning that often the patient with a CVA sequel has physical and cognitive conditions to perform a certain activity of movement, however, the caregiver, afraid of being neglecting the care, overloads and deprives the patient of functional improvement and possible independence.^{14,20} In this perspective, Nursing care should be focused on interventions that aim to improve the quality of life of caregivers, guiding on providing care only for activities that the individual is unable to perform, to promote maximum independence and autonomy to the patient, in addition to reducing the burden and its deleterious effects for the caregiver.¹⁷

CONCLUSION

The participants in this study who declared more years of study had a higher mean of stress, those who always felt tired had higher means of anxiety, depression and stress, as well as those who mentioned their health status as bad and those who dedicated more than 10 years. hours a week to care. Participants who did not perform leisure activities had higher means of depression and stress, those who helped with medication were related to a higher mean of anxiety and those who helped with mobility reported higher means of depression and stress.

It is noticed that informal caregivers have a hard and especially important job for the rehabilitation, social integration and motivation of the person under their care. However, it is difficult to provide qualified care when one experiences negative changes in one own life. In this context, the professional support of nurses is essential, through the provision of a space for sharing doubts and concerns and health education strategies for the importance of self-care as a mechanism for health promotion and disease prevention. When illness processes are present, the care plan must be focused on treatment, rehabilitation and coping strategies.

It is expected that this study will contribute to the understanding of the caregiver's role and that it will encourage health professionals to plan an integrated and individualized care for this population, respecting their profile, their life history, beliefs and the social environment in which the individual is inserted, focusing on tasks related to health promotion, overload prevention and emotional distress.

The study had limitations due to the selection of only primary informal caregivers of people with sequelae of the disease, which

restricts the broader understanding of the negative impacts of care on the lives and health of these individuals. Thus, it is suggested that further research be carried out, mainly with a longitudinal design, that can investigate the repercussions of care on the quality of life of caregivers, as well as the cause and effect relationships between the processes of illness and the care provided.

REFERENCES

- Palacios E, Pinzón D. Sobrecarga, ansiedad y depresión en el cuidador de paciente com enfermedad cerebrovascular. *Repert Med Cir.* 2017[cited 2019 Aug 17];26(2):118-20. Available from: <https://www.sciencedirect.com/science/article/pii/S0121737217300493>
- Capistrant BD. Caregiving for older adults and the caregivers' health: an epidemiologic review. *Curr Epidemiol Rep.* 2016[cited 2019 Aug 17];3(1):72-80. Available from: <https://link.springer.com/article/10.1007/s40471-016-0064-x>
- Plow M, Moore SM, Sajatovic M, Katzan I. A mixed methods study of multiple health behaviors among individuals with stroke. *Peer J.* 2017[cited 2019 Aug 21];5:e3210. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/28560091>
- Lou S, Carstensen K, Jørgensen CR, Nielsen CP. Stroke patients and informal carers experiences with life after stroke: an overview of qualitative systematic reviews. *Disabil Rehabil.* 2017[cited 2019 Aug 19];39(3):301-13. Available from: <https://www.tandfonline.com/doi/abs/10.3109/09638288.2016.1140836>
- Dunbar SB, Khanjou OA, Bakas T, Hunt G, Kirch RA, Leib AR, *et al.* Projected Costs of Informal Caregiving for Cardiovascular Disease: 2015 to 2035. *Circulation.* 2018[cited 2019 Sept 29];137(19):e558-e577. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/29632217>
- Haley WE, Roth DL, Hovater M, Clay OJ. Long-term impact of stroke on family caregiver well-being: a population-based case-control study. *Neurology.* 2015[cited 2019 Sept 29];84(13):1323-9. Available from: <http://www.neurology.org/cgi/pmidlookup?view=long&pmid=25740862>
- Pucciarelli G, Vellone E, Savini S, Simeone S, Ausili D, Alvaro R, *et al.* Roles of changing physical function and caregiver burden on quality of life in stroke a longitudinal dyadic analysis. *Stroke.* 2017[cited 2019 Sept 11];48(3):733-9. Available from: doi: 10.1161 / STROKEAHA.116.014989
- Roth DL, Fredman L, Haley EE. Informal caregiving and its impact on health: a reappraisal from population-based studies. *Gerontologist.* 2015[cited 2019 Sept 17];55(2):309-19. Available from: <https://academic.oup.com/gerontologist/article-lookup/doi/10.1093/geront/gnu177>
- Vignola RC, Tucci AM. Adaptation and validation of the depression, anxiety and stress scale (DASS) to Brazilian Portuguese. *J Affect Disord.* 2014[cited 2019 Sept 30];155:104-9. Available from: <https://www.sciencedirect.com/science/article/abs/pii/S0165032713007738?via%3Dihub>
- Zhang H, Lee DT. Meaning in stroke family caregiving: a literature review. *Geriatr Nurs.* 2017[cited 2019 Sept 12];38(1):48-56. Available from: <https://www.sciencedirect.com/science/article/abs/pii/S0197457216301458?via%3Dihub>
- Arwert HJ, Meesters JJJ, Boiten J, Balk F, Wolterbeek R, Vlieland TPMV. Post stroke depression, a long-term problem for stroke survivors. *Am J Phys Med Rehabil.* 2018[cited 2019 Aug 07];97(8):565-71. Available from: doi: 10.1097 / PHM.0000000000000918
- Brown RM, Brown SL. Informal caregiving: a reappraisal of effects on caregivers. *Soc Issues Policy Rev.* 2014[cited 2019 Aug 06];8(1):74-102. Available from: <https://deepblue.lib.umich.edu/bitstream/handle/2027.42/102687/sjpr12002.pdf?sequence=1&isAllowed=y>
- Camak DJ. Addressing the burden of stroke caregivers: a literature review. *J Clin Nurs.* 2015[cited 2019 Aug 06];24(17-18):2376-82. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/26095074>
- Dou DM, Huang LL, Dou J, Wang XX, Wang PX. Post-stroke depression as a predictor of caregivers burden of acute ischemic stroke patients in China. *Psychol Health Med.* 2018[cited 2019 Aug 22];23(5):541-7. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/28851230>

15. Denno MS, Gillard PJ, Graham GD, DiBonaventura MD, Goren A, Varon SF, *et al.* Anxiety and depression associated with caregiver burden in caregivers of stroke survivors with spasticity. *Arch Phys Med Rehabil.* 2014[cited 2019 Aug 21];94(9):1731-6. Available from: [https://www.archives-pmr.org/article/S0003-9993\(13\)00274-8/fulltext](https://www.archives-pmr.org/article/S0003-9993(13)00274-8/fulltext)
16. Lou Q, Liu S, Huo YR, Liu M, Liu S, Ji Y. Comprehensive analysis of patient and caregiver predictors for caregiver burden, anxiety and depression in Alzheimer's disease. *J Clin Nurs.* 2015[cited 2019 Oct 09];24(17-18):2668-78. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/26108739>
17. Costa TF, Costa KNFM, Fernandes MGM, Martins KP, Brito SS. Quality of life of caregivers for patients of cerebrovascular accidents: association of (socio-demographic) characteristics and burden. *Rev Esc Enferm USP.* 2015[cited 2019 Oct 25];49(2):245-52. Available from: <http://www.scielo.br/pdf/reeusp/v49n2/0080-6234-reeusp-49-02-0245.pdf>
18. Kim D. Relationships between caregiving stress, depression, and self-esteem in family caregivers of adults with disability. *Occup Ther Int.* 2017[cited 2019 Oct 25];2017:1686143. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/29114184>
19. Quinn K, Murray C, Malone C. Spousal experiences of coping with and adapting to caregiving for a partner who has a stroke: a meta-synthesis of qualitative research. *Disabil Rehabil.* 2014[cited 2019 Oct 28];36(3):185-98. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/23597001>
20. Simeone S, Coehn MZ, Savini S, Pucciarelli G, Alvaro R, Vellone E. The lived experiences of stroke caregivers three months after discharge of patients from rehabilitation hospitals. *Prof Inferm.* 2016[cited 2019 Oct 11];69(2):103-12. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/27600551>
21. Barbic SP, Mayo NE, White CI, Bartlett SJ. Emotional vitality in family caregivers: Content validation of a theoretical framework. *Qual Life Res.* 2014[cited 2019 Oct 28];23(10):2865-72. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/24853533>
22. Van Dongen I, Josephsson S, Ekstam L. Changes in daily occupations and the meaning of work for three women caring for relatives post-stroke. *Scand J Occup Ther.* 2014[cited 2019 Oct 28];21(5):348-58. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/24853697>
23. Bastawrous M, Gignac MA, Kapral MK, Cameron JI. Adult daughters providing post-stroke care to a parent: a qualitative study of the impact that role overload has on lifestyle, participation and family relationships. *Clin Rehabil.* 2015[cited 2019 Oct 28];29(6):59-600. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/25258424>
24. Diniz MAA, Melo BRS, Neri KH, Casemiro FG, Figueiredo LC, Gaioli CCLO, *et al.* Comparative study between formal and informal caregivers of older adults. *Ciênc Saúde Colet.* 2018[cited 2019 Sept 11];23(11):3789-98. Available from: http://www.scielo.br/pdf/csc/v23n11/en_1413-8123-csc-23-11-3789.pdf
25. Fuhrmann AC, Bierhals CCBK, Santos NO, Paskulin LMG. Association between the functional capacity of dependant elderly people and the burden of family caregivers. *Rev Gaúcha Enferm.* 2015[cited 2019 Sept 12];36(1):14-20. Available from: <http://www.scielo.br/pdf/rgenf/v36n1/1983-1447-rgenf-36-01-00014.pdf>