









## ANXIETY, DEPRESSION, STRESS AND WELL-BEING IN CAREGIVERS OF PEOPLE WITH STROKE SEQUELAE

ANSIEDADE, DEPRESSÃO, ESTRESSE E BEM-ESTAR EM CUIDADORES DE PESSOAS COM SEQUELAS DE ACIDENTE VASCULAR ENCEFÁLICO

ANSIEDAD, DEPRESIÓN, ESTRÉS Y BIENESTAR EN CUIDADORES DE PERSONAS CON SECUELAS DE ACCIDENTE CEREBROVASCULAR

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**Funding:** No funding.

**Submitted on:** 2020/12/16

**Approved on:** 2021/05/24

### Responsible Editors:

-  Janaina Soares
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### ABSTRACT

**Objective:** to correlate anxiety, depression, and stress with well-being in caregivers of people with stroke sequelae. **Method:** cross-sectional and quantitative study carried out with 151 informal primary caregivers of people with stroke sequelae. Data collected through interviews carried out in households, using a structured instrument for surveying sociodemographic information and the Scale of Anxiety, Depression and Stress-21 and Subjective Well-Being. Descriptive and inferential analysis was performed with a significance level of 5%. **Results:** most caregivers had normal levels of anxiety (n=115), depression (n=116) and stress (n=120). The highest average of subjective well-being was on negative experiences, reflecting negative overall well-being. Significant correlations ( $p \leq 0.05$ ) were observed between positive and negative subjective well-being and anxiety, depression, and stress. **Conclusion:** it was evidenced that the subjective well-being of the analyzed caregivers was correlated with the emotional states of anxiety, depression, and stress.

**Keywords:** Stroke; Caregivers; Family Relations.

### RESUMO

**Objetivo:** correlacionar a ansiedade, a depressão e o estresse com o bem-estar em cuidadores de pessoas com sequelas de acidente vascular encefálico. **Método:** estudo transversal e quantitativo realizado com 151 cuidadores informais primários de pessoas com sequela de acidente vascular encefálico. Dados coletados por meio de entrevistas realizadas em domicílios, utilizando-se instrumento estruturado para levantamento de informações sociodemográficas e as Escala de Ansiedade, Depressão e Estresse-21 e Bem-Estar Subjetivo. Realizou-se análise descritiva e inferencial com nível de significância de 5%. **Resultados:** a maioria dos cuidadores apresentou níveis normais de ansiedade (n=115), depressão (n=116) e estresse (n=120). A maior média de bem-estar subjetivo foi sobre as experiências negativas, refletindo bem-estar total negativo. Observaram-se correlações significativas ( $p \leq 0,05$ ) entre o bem-estar subjetivo positivo e negativo e a ansiedade, depressão e o estresse. **Conclusão:** evidenciou-se que o bem-estar subjetivo dos cuidadores analisados apresentou correlação com os estados emocionais de ansiedade, depressão e estresse.

**Palavras-chave:** Acidente Vascular Cerebral; Cuidadores; Relações Familiares.

### RESUMEN

**Objetivo:** correlacionar la ansiedad, la depresión y el estrés con el bienestar de los cuidadores de personas con secuelas de accidente cerebrovascular. **Método:** estudio transversal y cuantitativo realizado con 151 cuidadores primarios informales de personas con secuelas de accidente cerebrovascular. Datos recolectados a través de entrevistas realizadas en hogares, utilizando un instrumento estructurado de relevamiento de información sociodemográfica y la Escala de Ansiedad, Depresión y Estrés-21 y Bienestar Subjetivo. Se realizó análisis descriptivo e inferencial con un nivel de significancia del 5%. **Resultados:** la mayoría de los cuidadores presentaron niveles normales de ansiedad (n = 115), depresión (n = 116) y estrés (n = 120). El promedio más alto de bienestar subjetivo se registró en experiencias negativas, lo que refleja un bienestar general negativo. Se observaron correlaciones significativas ( $p \leq 0.05$ ) entre el bienestar subjetivo positivo y negativo y la ansiedad, depresión y estrés. **Conclusión:** se evidenció que el bienestar subjetivo de los cuidadores analizados se correlacionó con los estados emocionales de ansiedad, depresión y estrés.

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

### How to cite this article:

Costa TF, Viana LRC, Silva CRR, Bezerra TA, Pimenta CJL, Ferreira GRS, Santos EMB, Costa KNFM. Anxiety, depression, stress, and well-being in caregivers of people with stroke sequelae. REME - Rev Min Enferm. 2021[cited \_\_\_\_];25:e-1383. Available from: \_\_\_\_\_  
DOI: 10.5935/1415.2762.20210031

## INTRODUCTION

Stroke is a morbidity that has a high incidence in the world population, especially among the elderly.<sup>1</sup> It is estimated that one case occurs every five seconds, characterized as the second cause of death and the first of disability.<sup>2</sup> In Brazil, between 2010 and 2016, 695,521 admissions for stroke were recorded, with a high number of cases in people aged between 70 and 79 years.<sup>2</sup>

The occurrence of stroke is a serious event, in which most survivors acquire neurological sequelae, manifesting difficulties in speech, walking, vision and other senses, which cause the dependence on care to perform daily activities, due to the limitations imposed by the disease, arising, then, the figure of the caregiver.<sup>3</sup> This individual performs activities related to the care of the person affected by stroke, with frequent cases in which the caregiver neglects their own health, resulting in illness processes that interfere with the quality of life and the role of caregiver of the other.<sup>4,5</sup>

The daily burden of care for the person with stroke varies according to the level of dependence, being generally intense and exhausting, as caregivers deal with individual, interpersonal and organizational aspects related to the disease.<sup>4</sup> Furthermore, while caring for the disease Dependent family members need to reconcile activities such as work, housework and childcare.<sup>5</sup> In this sense, the lack of preparation to exercise the function of caring and the lack of guidance and social support make the caregiver vulnerable to stress and overload, causing physical and emotional exhaustion.<sup>6</sup>

It is evident that, given the situation of dependence, the psychological dimension of the caregiver is often the first to be affected, subsequently compromising the physical condition. The psychological impact caused by the new reality represents, in most cases, a stressful factor and a potential cause of anxiety and depression, generating mental and physical damage during the process of care and rehabilitation, which can affect health and well-being.<sup>5,6</sup>

The psychological distress of these caregivers was proven in a study conducted in Sweden, and it was observed that the well-being of caregivers of people with stroke sequelae was lower when compared to a group of non-caregivers.<sup>7</sup> The devaluation of the informal caregiver is another aspect that causes negative feelings, such as anger, fear, sadness, guilt, anguish, despair, loneliness, and suicidal ideation, which directly affect the health-disease process.<sup>4,8</sup>

In developed countries, the caregiver's visibility has been greater than in developing countries,<sup>9</sup> such as Brazil. The implementation of planned intervention programs, in order to prepare and adapt to a new context of life, has had an impact on the caregiver's life and significantly reduced the burden and depression, in addition to improving their sense of competence and quality of life. individuals.<sup>10,11</sup>

In this sense, research that assess the relationship between psychological distress and the well-being of these caregivers at the national level are still incipient, especially with a quantitative approach, using scales with adequate psychometric properties. The proximity of the authors to the theme emerged from studies and academic works developed within the research group, which highlighted the need to investigate the psychological damage caused by the role of caregiver and its influence on the lives and health of these individuals, seeking alternatives to promote well-being and implement effective actions.

Therefore, the relevance of this study is centered on the possibility of positively influencing the development of strategies aimed at the health of these caregivers and stroke survivors, given that the caregiver's health-disease process directly reflects on the quality and safety of care provided to the patient. In addition, there is the possibility of subsidizing Nursing care for this population, developing care plans aimed at the individual needs of each caregiver.

Thus, the objective was to correlate anxiety, depression, and stress with the well-being of caregivers of people with stroke sequelae.

## METHOD

This is a cross-sectional and exploratory research, with a quantitative approach, carried out in the homes of people with stroke sequelae, registered in the family health units (USF) in the city of *João Pessoa, Paraíba*, Brazil. The study population consisted of informal primary caregivers of CVA survivors.

Informal caregivers are individuals who provide unpaid care, often characterized by close family members, such as spouses, adult children or grandchildren, who may or may not live in the same household as the patient.<sup>12</sup> There are three types of informal caregivers: the primary or principal, who assumes full responsibility for care; the secondary, which helps occasionally and is usually supported by the primary caregiver; and the tertiary, the one who helps sporadically, without major responsibilities with care activities.<sup>9,13</sup>

The following were defined as inclusion criteria: being 18 years old or older and being informal primary caregiver of people with stroke sequelae, registered in the USFs of the city, since this individual is the one who exercises the greatest responsibility for the care of people with sequel to CVA. Caregivers who provided care for a period of less than six months were not included in the study.

The sample calculation was based on the number of people affected by stroke who were registered at the USFs in *João Pessoa* 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.

Data were collected through individual interviews carried out in households between September and December 2017. The health care network in this municipality consisted of 194 USFs managed in an organizational manner, through five health districts. The selection of UBS was carried out in a simple random way, with three being drawn from each health district.

For the selection of caregivers, a meeting was scheduled with the nurses of each USF, with a list of patients who suffered a stroke and who had sequelae being requested. Subsequently, a previous contact was made with the selected individuals, together with the community health agent, to schedule the best time to apply the instruments in the participant's own home, as the study population had physical limitations that hindered mobility.

One day before the date set for the meeting, there was confirmation by phone. On the scheduled day, the objectives, risks, and benefits of the study were first explained and then, participants were asked to participate in the research and to sign the Informed Consent Form.

Data were collected by previously trained researchers, in a process that involved the presentation, explanation and application of the scale among the interviewers to standardize data collection. A structured instrument was applied to obtain sociodemographic data, containing the variables gender, age, marital status, education, religion, and individual and family income. In addition, the Depression, Anxiety, and Stress Scale-21 (DASS-21)<sup>14</sup> and the Subjective Well-Being Scale (SWBS) were also used.<sup>15</sup>

The DASS-21 is an instrument adapted and validated for Brazil in 2014, consisting of 21 items, evaluated on a four-point Likert-type scale, ranging from zero (strongly disagree) to three (strongly agree). It is divided into three subscales, each consisting of seven questions designed to

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 experiences of anxiety. The depression subscale assesses symptoms such as inertia, anhedonia, dysphoria, lack of interest and involvement, self-depreciation, devaluation of life and discouragement. And the stress subscale checks difficulty in relaxing, nervous excitement, easy disturbance/agitation, irritability/overreaction, and impatience.<sup>14</sup>

The calculation of the individual result of depression, anxiety and stress corresponds to the sum of the item scores in each subscale. The classification of scores is performed as follows: normal (depression 0-9; anxiety 0-7; stress 0-14); mild (depression 10-13; anxiety 8-9; stress 15-18); moderate (depression 14-20; anxiety 10-14; stress 19-25); intense (depression 21-27; anxiety 15-19; stress 26-33); very intense (depression  $\geq 28$ ; anxiety  $\geq 20$ ; stress  $\geq 34$ ).<sup>14</sup>

Well-being was assessed by SWBS, an instrument adapted and validated in 2014, consisting of 24 questions, with Likert-type answer options, ranging from one (totally disagree) to five (totally agree). It is divided into four factors: positive affects – PAP, negative affects – NA, positive experiences – PE, negative experiences – NE. The calculation of the total score is obtained by the formula: GSWBS = (AP - NA) + (PE - NE), as well as specifying the negative (NA - NE) and positive (PA - PE) well-being, where the higher is the score, the higher is the well-being.<sup>15</sup>

Data were stored in an electronic spreadsheet, structured in the Microsoft Excel Program, with double entry, in order to ensure reliability in data compilation. Then, they were organized, coded, imported, and processed using the Statistical Package for Social Science (SPSS) for Windows, version 22.0, and analyzed using descriptive and inferential statistics. To verify the normality/symmetry of the numerical data, the Kolmogorov-Smirnov test was used, and it was found that the variables well-being, anxiety, depression, and stress were not normally distributed. In the correlation, Spearman's correlation coefficient was applied, as these are non-parametric variables. The significance level used for statistical analysis was 5% ( $p \leq 0.05$ ).

The study was developed in accordance with Resolution No. 466/2012, of the Brazilian National Health Council (*Conselho Nacional de Saúde-CNS*) and complementarities, which describes the ethical and moral standards of research involving human beings, guaranteeing the participant's rights and the research duties related to the community scientific. The research project was approved by the Research Ethics Committee.

## RESULTS

One-hundred fifty-one informal primary caregivers participated in this study, with three or more years of care (65.6%), in which the majority were female (78.1%), aged between 56 and 65 years (27.8 %), married or living in a stable relationship (65.6%), with between five and eight years of study (27.2%), practitioners of the Catholic religion (60.9%), with an individual income of up to R\$ 880 (44.4%) and family income between R\$881 and R\$1,760 (41.7%). 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 the patient's care (61.6%). Most caregivers had normal levels of anxiety (76.2%), depression (76.8%) and stress (79.5%), as shown in Table 1.

Table 1 - Classification of the Anxiety, Depression and Stress Scale-21. João Pessoa-PB, Brazil, 2017

Classification	Anxiety		Depression		Stresse	
	n	%	n	%	n	%
Normal	115	76.2	116	76.8	120	79.5
Mild	4	2.6	10	6.6	10	6.6
Moderate	19	12.6	14	9.3	8	5.3
Intense	2	1.3	4	2.6	9	6.0
Very intense	11	7.3	7	4.7	4	2.6
<b>Total</b>	<b>151</b>	<b>100.0</b>	<b>151</b>	<b>100.0</b>	<b>151</b>	<b>100.0</b>

In the analysis of the SWB scale, a higher mean was observed related to negative experiences (20.74) by caregivers, which reflected in total well-being, with a negative mean (-1.13) (Table 2).

Table 2 - Classification of the Subjective Well-Being Scale. João Pessoa-PB, Brazil, 2017

Well-being	Mean	Standard Deviation
Positive	0.30	7.28
Positive affects	16.60	3.91
Positive experiences	16.30	4.60
Negative	-7.46	4.89
Negative affects	13.28	3.28
Negative experiences	20.74	3.78
<b>General SWBS</b>	<b>-1.13</b>	<b>5.93</b>

Table 3 - Correlation between the DASS-21 and the Subjective Well-Being Scale. João Pessoa-PB, Brazil, 2017

Correlation	Anxiety		Depression		Stresse	
	r	p*	r	p*	r	p*
Subjective Well-being	-0.082	0.335	-0.061	0.472	0.019	0.825
Positive	-0.354	<0.001	-0.555	<0.001	-0.477	<0.001
Negative	0.188	0.024	0.290	<0.001	0.241	0.003

\*Spearman's correlation test.

The correlations between the DASS-21 and the SWBS scales were statistically significant ( $p < 0.05$ ), and it was observed that the means of positive well-being decrease in the same proportion as the levels of anxiety, depression, and stress increase (Table 3).

## DISCUSSION

In the present study, most caregivers had normal levels of anxiety, depression, and stress, which could be related to longer patient care and the presence of other people to help with these activities. Studies have identified higher depression and burden scores between the first and second day before the patient's discharge and up to three weeks later<sup>16</sup> and higher anxiety and depression scores at the beginning of the event, decreasing progressively until nine months later.<sup>9</sup>

Feelings of apprehension and uncertainty on the part of caregivers are greater in the moments before discharge and, soon after, when they assume the initial role of providing care at home, which, in most cases, occurs without the support of any health professional. In this sense, as the time of care increases, the caregiver becomes more familiar with the role assumed, in addition to receiving more support from other family members, which can reduce psychological symptoms and burden.<sup>16</sup>

Although this scenario is quite common in countries where the dependent person and their caregivers are supported by the State, through political actions in the macro and microsocial spheres, this does not represent a reality in Brazil, as there are no protection and support initiatives family caregivers,<sup>17</sup> in addition to the State's omission about the care of the most vulnerable elderly.<sup>18</sup>

Associated with this, there are other problems in the country that go beyond the government sphere and directly impact the care of people with dependence, such as the existence of a sexist division of care attributions, the lack of family support and the lack of political awareness of this group about the existence of their social protection and health rights, as well as the absence of articulated movements to claim them.<sup>17</sup>

In patients with stroke sequelae, one of the most stressful events for the caregiver is the time of hospital discharge. A study found that right after leaving the hospital, the main needs of caregivers were information about the disease, highlighting risk factors, the probability of other episodes, the action of effective drugs to prevent recurrence and help in recovery and time for rehabilitation.<sup>4</sup> In addition, a few weeks after discharge, there is a need to manage the patient's emotions and behaviors, such as negative feelings, personality changes, impairments in cognition and communication and social activities, causing overload and stress.<sup>19</sup>

The quality of care provided by the caregiver at home is proportional to the health education actions carried out in the hospital.<sup>3</sup> In this sense, during the hospitalization period, the nurse must clarify doubts and alleviate fears and difficulties presented by the person affected by stroke and by their caregiver, seeking to enable them to face the new reality.<sup>5</sup>

During the first months after the stroke, the caregiver often manifests anxiety, which may be the result of uncertainty about the patient's condition, doubt about being able to leave him alone, fear of another episode and insecurity about the future.<sup>21</sup> Furthermore, if caregivers do not find effective coping mechanisms, the accentuated stress exposes them to the risk of developing health problems, such as high blood pressure, coronary heart disease, changes in the immune system, among others.<sup>8</sup>

The complexity involved in the task of caring predisposes individuals to the development of health problems, such as symptoms of depression or social isolation, causing damage to family dynamics.<sup>6,19</sup> Thus, caregivers with depressive symptoms have more difficulties with tasks and life changes than those without these symptoms.<sup>10</sup> Therefore, it is essential to implement training and education programs for caregivers, seeking to promote physical and mental health and provide guidance to adequately face changes in daily routine.<sup>6</sup>

With regard to well-being, there was a higher average of negative experiences on the part of caregivers, which reflected in total negative well-being. A similar result was evidenced in a research carried out with caregivers of people affected by stroke in India, in which losses in emotional and physical well-being were observed, due to the uncertainty and unpredictability of the length of care, in addition to expectations and needs not understood by other family members.<sup>21</sup>

In another study, caregivers of family members who suffered a stroke did not know how to define the role of caregivers, had little or no information about the disease, cared for a long daily period and had no time to take care of themselves, to perform leisure activities or make plans, showing negative feelings about the situation they found themselves in.<sup>22</sup>

The care provided to a person affected by stroke is highly stressful and can affect the caregivers' biopsychosocial well-being. Thus, as they play a fundamental role in the lives of dependent family members, there is a need to maintain individual well-being and adopt a healthy lifestyle, so that it is possible to offer quality care.<sup>5</sup>

The responsibilities assigned to the caregiver often go beyond the helping relationship in carrying out activities of daily living, especially in stroke survivors, since the number of sequelae determines the level of dependence. In these cases, negative effects on their well-being may occur, as many are unable to efficiently manage their personal activities, such as study/work routine, household activities, leisure, affective relationships, self-care, among others.<sup>4,13</sup>

The condition of caring for a person with addiction is naturally stressful and causes damage to the individual's life and health. Even in different contexts, such as those experienced in countries where there are effective policies to support the caregiver or in family environments where support, equal division of activities and recognition is available, wear and tear and stressful situations still occur. This is because there is damage related to economic and social aspects, restriction of opportunities, lack of perspectives, confinement due to daily care needs and many other elements that have a unique impact on the routine of each person.<sup>17</sup>

Faced with this scenario of overload, many caregivers end up neglecting their own life, due to the role of caring, even if involuntarily. In opposition to this, there

are cases in which the family itself allocates all care to a single individual, which increases stress, generates tension, and favors the emergence of negative feelings, such as anguish, sadness, despair, and suicidal ideation.<sup>23</sup>

The correlation between the scales was statistically significant, showing that the means of positive well-being can be influenced by high levels of anxiety, depression, and stress in caregivers. This result is similar to that found in a survey conducted in the United States, where caregivers of people with stroke sequelae who presented depressive symptoms were at high risk for reduced self-esteem, less ability to deal with stress and damage to physical health and well-being.<sup>9</sup>

Behavioral aspects and emotional changes, such as anxiety, depression, and changes in the patient's mood, are the main triggers for the caregiver's emotional changes, such as irritability, cognitive and emotional problems, depression, and anger. These feelings can result in exhaustion, with negative consequences for the caregiver-patient relationship, such as maltreatment and institutionalization, as, without help in managing problematic behaviors, caregivers can become depressed and unable to care for patients.<sup>23</sup>

Therefore, it is necessary to establish a support network for caregivers, which includes professionals and other family members, in order to minimize the impact that the new role can bring and assist in the development of effective coping mechanisms. However, when this network is not effectively consolidated, the caregiver experiences intense physical and mental exhaustion, which can result in stress and anxiety and, in the long term, progress to depression.<sup>23,24</sup>

Thus, professionals who work in the hospital and in the Family Health Strategy must be aware of the needs faced by caregivers. Therefore, it is urgent to train them to assist the person with stroke sequelae and guide them according to their own reality, in order to provide security to the caregiver, increasing their well-being.<sup>25</sup>

Some measures could be implemented to reduce levels of anxiety, depression and stress and promote well-being, highlighting, among these, the early investigation and monitoring of these symptoms, so that a care plan can be developed, seeking to promote the longitudinal follow-up of caregivers. Associated with this, biopsychosocial support can be offered, through multidisciplinary care, in order to reduce negative repercussions on the well-being and quality of life of these individuals.<sup>4,6</sup>

In the broader sphere of care, some changes would also be needed to help improve this scenario, such as the creation of a health and social assistance policy that clearly establishes the protection of the caregiver, the change in existing policies in the country to specify the forms of care and the attributions/responsibility of each social actor in relation to people with dependence, being integrated into health care networks and complementary to routine practices aimed at the elderly population.<sup>17,18</sup>

The limitations of the study are related to the cross-sectional design, as it does not allow establishing a cause-and-effect relationship between the investigated variables. In addition, the results are restricted to a geographic region of Brazil, which present specific culture and customs that can influence the responses to the instruments.

## CONCLUSION

It was found that most caregivers of people with stroke sequelae had normal levels of anxiety, depression, and stress, however, it is noteworthy that 12.6% had moderate anxiety and 9.3% moderate depression. Regarding subjective well-being, a negative total mean was identified.

In the correlation of variables, statistical significance was observed with inversely proportional values, indicating that positive well-being increases as anxiety, depression and stress values are reduced. Thus, measuring these variables quantitatively allows for a quick and effective assessment of the caregiver's mental health condition, supporting early interventions by nurses and the multidisciplinary team, seeking to improve the well-being and quality of life of these individuals.

Informal caregivers work hard, but it is extremely important for rehabilitation, social integration, and motivation of the person under their care. However, it is difficult to provide qualified care when negative changes in life are experienced, such as the appearance of psychic alterations and consequent reduction in well-being, as found in this study.

In view of the findings, it is necessary for the caregiver to be included in the care plan of the health team. Thus, the Nursing team can act by providing support to the caregiver, according to the demands, providing comprehensive and humanized care. Primarily, it is essential that this problem is recognized, with a view to the development and implementation of effective health policies, aimed at the caregiver, considering the maintenance of their physical and mental health.

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