

Factors associated with suicidal ideation in caregivers of stroke survivors

Fatores associados à ideação suicida em cuidadores de sobreviventes de acidente vascular encefálico

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ABSTRACT

Objective: to identify factors associated with the presence of suicidal ideation in caregivers of stroke survivors. **Methods:** cross-sectional survey conducted with 151 primary informal caregivers. The Depression Anxiety and Stress Scale-21 and a questionnaire were used to evaluate the presence of thoughts of suicidal ideation, whose data were analyzed by descriptive and inferential statistics. **Results:** most caregivers had normal levels of depression (76.8%), anxiety (76.2%) and stress (79.5%), and showed no thoughts of suicidal ideation (70.9%). The correlation between scales showed that thoughts of suicidal ideation rise proportionally to the increase of anxiety, depression and stress levels. **Conclusion:** it was observed that high levels of depression, anxiety and stress favored the increased frequency of suicidal thoughts among caregivers of stroke survivors. **Descriptors:** Caregivers; Anxiety; Depression; Stress, Psychological; Suicidal Ideation.

RESUMO

Objetivo: identificar os fatores associados à presença de ideação suicida em cuidadores de sobreviventes de acidente vascular encefálico. **Métodos:** pesquisa transversal, realizada com 151 cuidadores informais primários. Utilizaram-se da Escala de Depressão, Ansiedade e Estresse-21 (*Depression Anxiety and Stress Scale*) e de questionário para avaliação da presença de pensamentos de ideação suicida, cujos dados foram analisados por estatística descritiva e inferencial. **Resultados:** a maior parte dos cuidadores apresentou níveis normais de depressão (76,8%), ansiedade (76,2%) e estresse (79,5%), assim como a ausência de pensamentos de ideação suicida (70,9%). A correlação entre as escalas evidenciou que à medida que os níveis de ansiedade, depressão e estresse aumentam, os pensamentos de ideação suicida se elevam de maneira proporcional. **Conclusão:** observou-se que níveis elevados de depressão, ansiedade e estresse favoreceram o aumento da frequência de pensamentos de ideação suicida entre os cuidadores de sobreviventes de acidente vascular encefálico. **Descritores:** Cuidadores; Ansiedade; Depressão; Estresse Psicológico; Ideação Suicida.

Introduction

Noncommunicable chronic diseases are the leading causes of morbidity and mortality in the world, generating impacts that go beyond the individual sphere and affect families, communities and society. Among these, stroke is the most common cerebrovascular disorder, representing one of the leading causes of death and disability worldwide⁽¹⁾.

Stroke is considered a sudden onset syndrome caused by the interruption of blood flow to the brain, in which clinical manifestations include a wide variety of motor, auditory, visual, intellectual and neurological deficits that may be temporary or permanent⁽²⁾. Due to scientific advances in the medical field, experienced in recent decades, there has been an increasing number of people who survive the stroke. Since the degree of impairment of bodily functions caused by the episode, many need high-complexity hospital care and long-term home care, with the caregiver becoming relevant⁽³⁾.

There are two types of caregivers: formal caregivers, those who have some kind of training and/or qualification and are paid to perform the service; and the informal, whose care is usually provided by a close relative, especially spouse and children, who do not have the knowledge to provide such care⁽⁴⁾. Due to the sudden nature of the stroke, the family is unprepared to deal with the consequences of this event, which has a great impact on the patient and caregiver, who assumes a new role and needs to adapt to a new routine⁽⁵⁾.

The experience of caring for a dependent person is referred in the literature as an exhausting task that causes harm to the caregiver's health and quality of life, since many abdicate routine activities to care for the stroke survivor⁽¹⁻³⁾. Therefore, caregivers are often exposed to high stress situations, becoming vulnerable to diseases, especially to the development of mental problems⁽⁵⁻⁶⁾.

Similar data were evidenced with 115 caregivers of stroke survivors in Nigeria, with a high preva-

lence of depression among participants, corresponding to 46.0%⁽⁷⁾. In Peru, caregivers stated they were constantly experiencing situations of suffering as a result of caring for dependent family members, presenting mainly depressive symptoms such as tiredness, sadness, mood swings, insomnia, anxiety, demotivation, despair, anguish and suicidal ideation⁽⁴⁾.

In this sense, although care for patients with stroke sequelae is essential for rehabilitation and improvement of their health, this activity has negative repercussions for the caregiver, and it is necessary to develop strategies to prevent overload, depression and suicide, reduce stress and provide them a better quality of life⁽⁸⁾.

Thus, the aim is to identify factors associated with the presence of suicidal ideas in caregivers of stroke survivors.

Methods

This is a cross-sectional study, conducted with primary informal caregivers of people with stroke sequelae, registered in the family healthcare units of João Pessoa, Paraíba, Brazil. Inclusion criteria were the following: being 18 years old or older and being the primary informal caregiver of people with stroke sequelae, registered at the family healthcare units of the municipality. Individuals who provided care for less than six months were excluded.

The selection of family healthcare units was performed randomly, with three units from each health district being drawn. The healthcare network of this municipality is composed of 194 family healthcare units, managed in an organizational manner, through five health districts.

The sample calculation was based on the number of people affected by stroke who were registered in the family healthcare units of João Pessoa, during 2016, totaling 249 individuals. The sample size was defined using the finite population calculation with known proportions, based on a 5% margin of error

(error = 0.05), with a 95% confidence level ($\alpha=0.05$, which corresponds to $Z_{0.05/2}=1.96$), considering the true proportion as 50% ($p=0.50$) for the presence of sequelae, resulting in a sample of 151 caregivers, who were selected proportionally to the quantity of individuals in each unit and district.

Data were collected between September and December 2017, by previously trained researchers, in a process that involved the presentation, explanation and application of instruments among interviewers to standardize data collection. Individual interviews were conducted at home, with an average duration of 30 minutes, and the speech content was audio recorded.

The identification of caregivers occurred through contact with the nurses of each unit, requesting information about people who suffered stroke and had some kind of sequelae. An instrument was used to obtain sociodemographic data and aspects related to the care provided, containing the variables gender, age, conjugality, education, family income, degree of relatedness, survivor's age, residence in the same place where the care recipient lives, number of days per week and daily hours dedicated to this activity, amount of time caring for the patient, care provided and sequelae presented by the patient. In addition, the Depression Anxiety and Stress Scale-21⁽⁹⁾ and a questionnaire to assess presence of thoughts of suicidal ideation were used.

The scale is composed of 21 items evaluated in a four-point Likert scale ranging from 0 (strongly disagree) to 3 (strongly agree). The scale is divided into three subscales, each consisting of seven questions designed to assess the emotional states of anxiety, depression and stress over the past week. The anxiety subscale assesses autonomic nervous system arousal; musculoskeletal effects; situational anxiety; subjective experiences of anxiety. The depression subscale assesses symptoms as inertia; anhedonia; dysphoria; lack of interest and involvement; self-depreciation; devaluation of life and discouragement. The stress subscale analyzes the difficulty in relaxing; nervous

excitement; easy disturbance/agitation; irritability/overreaction and impatience⁽⁹⁾.

Calculation of the individual result of depression, anxiety and stress corresponds to the sum-scores of the items in each subscale. Scores are classified 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); severe (depression 21-27; anxiety 15-19; stress 26-33); very severe (depression ≥ 28 ; anxiety ≥ 20 ; stress ≥ 34)⁽⁹⁾.

Suicidal ideation was assessed by four questions aimed at investigating how many days in the last week the subject had the following thoughts: I couldn't move on, I wanted to give up everything; I have thoughts about death; I felt my family would be better if I was dead; I thought about killing myself. The instrument was classified according to the total thoughts of suicidal ideation presented in the last week, ranging from 0 to 28, where 0 corresponds to none, 4 - 8 (1 to 2 times/week), 12 - 16 (3 to 4 times/week) and 20 - 28 (5 or more times/week). It was defined as the presence of suicidal ideation when the individual had a score of 12 or higher.

The questionnaire was elaborated from search in the national and international literature and passed face validation for possible corrections and adaptations. Face and content validation is a subtype of content validation, used to verify the appropriateness of the instrument in measuring what applies⁽¹⁰⁾. In this sense, the validation was performed by three PhD teachers in Nursing, who made suggestions for improving the instrument. After this stage, a pilot test was performed with 20 patients to analyze the existence of incongruities in the understanding of the questions.

Data were stored in a spreadsheet, structured in the Microsoft Excel software, with double typing, in order to ensure the reliability of data compilation. As follows, results were organized, coded, imported and processed by the Statistical Package for Social Science for Windows application, version 22.0, and analyzed

using descriptive and inferential statistics. To verify the normality/symmetry of the numerical data, the Kolmogorov-Smirnov test was adopted. Correlation between scales was performed using the Spearman correlation coefficient. The significance level used for statistical analysis was 5% ($p \leq 0.05$).

The study was developed according to the National Health Council Resolution nº 466/2012, and its complementarities. The research was approved by the Research Ethics Committee of the Health Sciences Center of the Federal University of Paraíba, according to Opinion nº 2.243.225/17 and Certificate of Presentation for Ethical Appraisal nº 71855817.0.0000.5188, and was conducted according to ethical standards required.

Results

A total of 151 caregivers participated in this study, of which 118 (78.1%) were female, 42 (27.8%) were aged 56 to 65 years, 99 (65.6%) were married or living in stable union, 41 (27.2%) had between five and eight years of schooling, 63 (41.7%) had family income between R\$ 881 and R\$ 1,760. Regarding aspects related to the care of stroke survivors, 62 (41.1%) were spouses and 58 (38.4%) children, 116 (76.9%) cared for the elderly and 135 (89.4%) lived in the same residence, 129 (85.4%) provided care every day of the week, 76 (50.3%) stated that such care occurred daily for 19 hours or more, and 41 (27.2%) took care of the care recipient for a period of three to five years.

Among the main care measures provided, 119 (78.8%) reported medication; 106 (70.2%), body hygiene; 103 (68.2%), locomotion; 103 (68.2%), the return for consultations; 81 (53.6%), skin care; and 75 (49.7%), urinary and fecal eliminations. Among the stroke survivors, 123 (81.5%) had sequelae related to motor disorders, 102 (67.5%) muscle weakness, and 57 (37.7%) dysphagia. Most caregivers had normal levels of anxiety (76.2%), depression (76.8%) and stress (79.5%) (Table 1).

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

Classification	Depression	Anxiety	Stress
	n (%)	n (%)	n (%)
Normal	116 (76.8)	115 (76.2)	120 (79.5)
Mild	10 (6.6)	4 (2.6)	10 (6.6)
Moderate	14 (9.3)	19 (12.6)	8 (5.3)
Severe	4 (2.6)	2 (1.3)	9 (6.0)
Very severe	7 (4.6)	11 (7.3)	4 (2.6)
Total	151 (100.0)	151 (100.0)	151 (100.0)

Most caregivers showed no thoughts of suicidal ideation (70.9%). However, 23.2% of the participants reported having these thoughts once or twice a week (Table 2).

Table 2 - Thoughts of suicidal ideation. João Pessoa, PB, Brazil, 2017

Classification (times/week)	n (%)
None	107 (70.9)
1 or 2	35 (23.2)
3 or 4	7 (4.6)
≥ 5	2 (1.3)
Total	151 (100.0)

The correlation between the DASS-21 scale and thoughts of suicidal ideation was statistically significant ($p \leq 0.05$); thoughts of suicidal ideation increased proportionally to levels of anxiety, depression, and stress (Table 3).

Table 3 - Correlation between depression, anxiety, stress and thoughts of suicidal ideation. João Pessoa, PB, Brazil, 2017

Correlation	Suicidal ideation	
	r	p*
Depression	0.395	<0.001
Anxiety	0.437	<0.001
Stress	0.385	<0.001

*Spearman correlation coefficient

Discussion

The limitations of the present study were related to the investigation of primary formal caregivers only, hindering a more accurate understanding of the impact of care on the life and health of these individuals. In addition, the use of the cross-sectional method makes it impossible to identify cause and effect relationships between the variables analyzed.

However, the data from this research have the potential to contribute to the development and/or improvement of health care programs for caregivers, which could be based on the early investigation of disease processes, the analysis of excessive exposure to activities overload and the performance of health care interventions to promote greater support to this individual through family support and professionals from the multidisciplinary team.

Among the caregivers investigated, most exhibited normal values of depression, anxiety and stress, which could be related to the time elapsed since the stroke episode, since most care for the patient for a period of three to five years, providing greater adaptation to the care routine. A study conducted with 60 relatives of stroke survivors in Taiwan showed that the needs of caregivers regarding the care provided progressively decreased with the duration of the disease, given that during hospitalization, these individuals experienced high stress and anxiety loads, due to the uncertain clinical status and misinformation about the disease and its prognosis⁽³⁾.

Associated with this, the experience of positive feelings related to care could favor the reduction of anxiety, stress and depression levels, highlighting the affection for the family member, happy moments of interaction, solidarity, gratitude, appreciation, commitment, well-being and the perception of the importance of activities performed for another person's life⁽⁶⁾.

In contrast, the care of dependent people is related to the presence of overload and physical and mental disorders, especially in the absence of family support, in which all responsibilities fall on a single in-

dividual, who tries to balance the daily care provided to the dependent relative, with all other obligations concerning the caregiver's own life^(4,11).

In this sense, the experience of conflicts related to the care process is perceived. Although, on many occasions, there are pleasant moments that can give a meaningful purpose to the activities performed, episodes of suffering during care are frequent, which are more associated with task overload problems performed by a single individual than specifically with the care provided. The absence of family support is a crucial point that directly affects the health status of these caregivers.

Research has revealed the negative influence of care performed on the caregiver's life, interfering with daily routine, individual and family income, work and/or studies, leisure and affective relationships^(1,5-6,12). The damage resulting from this prolonged care is not restricted to the individual sphere of the caregiver and may interfere with the quality of the actions performed and the patient's own physical integrity, since overload represents an important risk factor for violence and neglect⁽⁶⁾.

Given this, the use of coping strategies could be relevant tools for reducing burden and stress in these caregivers, such as the search for qualification, social support of family, colleagues, friends and health professionals, the strengthening of faith, the resolution of the problems faced and the skillful organization of time, so as to allocate moments for self-care and leisure⁽⁸⁾. Furthermore, it is necessary to promote self-care in these individuals, since many prioritize the care of dependent relatives over its own health care, causing diseases^(6,13).

Regarding suicidal ideation, it was observed that a small portion of the caregivers presented such thoughts once or twice a week, which is a warning sign, given that daily care to the dependent family member can enhance the experience of suffering and increase the frequency of thoughts related to death. Corroborating these findings, a study conducted in China found that care for family members surviving stroke caused

the development of negative feelings, which were progressively intensified as care time increased⁽¹⁴⁾.

Suicidal ideation is often linked to a constant presence of suffering and psychological changes, especially depression, making the individual more vulnerable to emotional distress, thoughts of frustration and worthlessness^(4,14-15). Depression is a very common problem between caregivers of people who require long-term care, such as stroke survivors, becoming a factor that may predispose the caregiver to self-inflicted violence and suicide^(7,16).

The sequelae resulting from stroke can also trigger suffering in the caregiver, leading to a higher risk of developing depression and thoughts of suicidal ideation. Another study conducted with 136 caregivers of people with stroke sequelae identified the impairment of the general quality of life and of all domains, being higher the mental suffering in caregivers of individuals with greater dependence on care, causing the psychological dimension the first to be affected⁽¹⁷⁾.

Before this situation, it is emphasized that the gender issue influences the process of choice of the family member who will be responsible for performing care and the extent to which this choice will affect the life's dimensions of such individual. The role of women in caring for the sick is historical and remains in the present day, directly reflecting on the choice of wife, daughter or granddaughter as the main caregiver, who also performs the housework and the care of the rest of the family, experiencing intense daily overload and accumulation of tasks, which often results in physical and mental diseases.

By correlating, it was possible to identify that thoughts of suicidal ideation increased as levels of depression, anxiety, and stress raised. This finding could be justified by the complexity involved in caring for a person with stroke sequelae, especially family members, since it is an unexpected event that generates temporary and/or permanent disabilities, causing changes in family organization, affection relationships and the financial structure of the family⁽⁴⁾.

In this context, many caregivers experience

moments of tension, anxiety, stress and depression, especially because they have to assume a new role for which they do not have knowledge or even training, which can trigger strong emotions, feelings of disability and anger and lack of perspectives, providing greater vulnerability to mental diseases and suicide^(7,18-19).

The caregiver's invisibility also represents a relevant issue in Brazil and internationally, which may contribute to the suffering of this individual, given that the lack of support from family and health professionals causes the neglect of their health status and their own individual needs. This favors the increase of depressive symptoms, which if not properly treated, may result in suicide attempt^(4,13,20).

In this sense, it is necessary that the health professional, when assisting patients with stroke sequelae, include the caregiver as an essential part of the care plan, seeking to clarify doubts, advise on care techniques, investigate as soon as possible the presence of overload and disease processes, providing necessary support and promoting the appreciation of the functions performed by this individual^(6,17).

Conclusion

Most caregivers showed normal levels of depression, anxiety and stress, with no thoughts of suicidal ideation. The correlation between the variables showed that high levels of depression, anxiety and stress favored the increased frequency of thoughts of suicidal ideation among caregivers, which indicates the need to early investigate the development of burnout processes that can result in serious impairment for health and quality of life of these individuals.

Collaborations

Costa TF, Bezerra TA, Pimenta CJL, Silva CRR, Ferreira GRS and Costa KNFM contributed to the conception, design or analysis and interpretation of data, article writing, relevant critical review of intellectual content and final approval of the version to be published.

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