Original Article

Anxiety and hope: a study about the caregiver overload in the care of patients with stroke

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ABSTRACT: Stroke involves injury to the central nervous system, presenting most frequently as cerebral infarction and intracerebral hemorrhage. It's an important cause of disability worldwide, being associated with high burden to the patients' caregivers, who are, frequently, family members. In that matter, it is reported that the main caregivers of stroke patients have the same, or even greater incidence of mental illnesses, such as depression and anxiety. Therefore, we present this study protocol aiming to observe the association between the patient's type of stroke along with the severity of their sequelae, and the levels of anxiety and hope of their caregivers, in a descriptive, cross-sectional study with a quali-quantitative approach. For that purpose, patients of both sexes, over 18 years of age, who have had a stroke and are being followed up at the Cerebrovascular Diseases Ambulatory will be randomly selected. Then, data will be collected from the caregiver through questionnaires: Zarit Burden Interview (ZBI), Beck Hopelessness Scale (BHS), Beck Anxiety Inventory (BAI) and a socioeconomic questionnaire. The ZBI analyzes psychological, financial, social and physical aspects of the caregiver's universe, while the BAI and BHS are used to quantify the caregiver's anxiety state, and bring information about the individual's hope and life expectations. Information about the patient will be obtained from medical records. Finally, we hope to find useful information for health services about the reality in which they are inserted, in order to promote the creation of disease prevention measures, which is essential to improve the quality of healthcare provided.

Keywords: Stroke; Hope; Anxiety; Caregiver; Burden.

INTRODUCTION

Pathophysiology

Cerebrovascular Accident (CVA), or stroke, is a noncommunicable disease whose pathogenesis is based on low blood perfusion to the brain tissue, being the second leading cause of death worldwide in 2019, grouped into two main etiologies: Ischemia and Hemorrhage. It is known that almost all elderly people develop blockages in small brain vessels, but 10% can develop an obstruction sufficient to cause serious disturbances in the brain.

The brain is a highly irrigated organ, receiving 15% of the cardiac output and 20% of the blood supply of oxygen, thus the intense perfusional dependence of the structure is evident. In addition, the low rate of cell renewal

of the brain tissue implies the global or focal blockage of blood supply to the brain, even if transient, can lead to serious detrimental effects to the organism.

The first type, ischemic stroke or white infarction, is the most common and is characterized by a low output due to obstruction of an arterial vessel, such as an atherosclerotic plaque. It's been more frequent with the advancing population age and is directly related to other noncommunicable chronic diseases of metabolic occurrence, such as obesity and diabetes mellitus. Thus, among the complications of this atheromatous plaque, its rupture and consequent exposure of a highly thrombogenic surface to circulating clotting factors and platelets may occur, favoring thrombotic events and obstruction. The consequence of this phenomenon will be an acute ischemic phenomenon.

The second type, hemorrhagic stroke or red infarction, is caused by blood extravasation due to ruptured aneurysms and systemic arterial hypertension (SAH), responsible for about 25% of cases. Therefore, in addition to the low perfusion of the irrigated tissue by the ruptured vessel, there will be an increase in intracranial pressure due to compression of the region by the blood collection at the site, potentiating the deleterious effects of stroke, being the stroke type that offers greater lethality. This infarction may also provide a petechial pattern in the injured tissue due to microemboli present in the vasculature. It is believed that the red color is due to reperfusion of the site, either by collaterals or by the vessel itself after dissolution of the embolus.

Epidemiology

This pathology offers great value to public health, since, according to the World Health Organization, stroke kills 6.2 million people worldwide every year. Furthermore, about 17.3 million people died from cardiovascular diseases in 2008, corresponding to 30% of all deaths worldwide. Among these deaths, it's estimated that 7.3 million were due to coronary heart disease and 6.2 million were due to stroke[1].

In Brazil, according to the National Health Survey (PNS), conducted in 2013 in a shared action between the Ministry of Health and the Brazilian Institute of Geography and Statistics (IBGE), stroke affects about 2.231.000 people, of which 568.000 are in a state of severe disability due to this disturb. The research also showed the prevalence of stroke in 1.6% of male individuals aged 18 years or older, and in this group 29.5% had an intense or very intense degree of limitations for usual activities due to the stroke. In female individuals aged 18 years or older, the prevalence of stroke was 1.4% and, among them, the level of disability was 21.5%[2].

The PNS presented a sociodemographic profile for individuals affected by stroke at a national level, given that the prevalence increased with age, with lower level of education and in urban area residents. Self-reported skin color did not contribute statistically. However, it was not possible to trace epidemiological indicators in the country for the most affected people regarding the severe disability generated by stroke[3].

Stroke survivors and the importance of the caregiver

Stroke survivors have varied alterations, as the signs and symptoms will be directly related to the topography and severity of the lesion. The irrigation of the middle cerebral artery is the most common involvement in ischemic brain vascular accidents. These patients may develop reversible or irreversible motor, sensory and cognitive changes, including gait disturbance (ataxia), aphasia, dysphagia, disturbance of spatial orientation, vision, memory cognitive deficits and hemiparesis.

These limitations have direct implications on the quality of life of patients, affecting social and family relationships, lost years of productive life, in addition to the high financial costs required. In that matter, family members are the main responsible for achieving patient's well-being and rehabilitation throughout their biopsychosocial process[4].

Based on that assumption, it is observed that the presence of the caregiver has a positive impact on quality of life, from rehabilitation and readaptation to differentiated living conditions, the family of the patient occupies a strategic position in care, suggesting the importance of investing in the indissoluble patient-caregiver binomial[5].

Consequently, it is imperative to state that these relationships should be guided by actions towards the patient's rehabilitation and reintegration in the community and their families. Among the main practices, we highlight the preparation of the room, arrangement of pillows, moving the patient's limbs correctly, adequate diet, home safety to prevent falls, intimate hygiene, adequate clothing, as well as a healthy environment that favors the mental health of the patient and, of course, the provider of this care. These and other attitudes derive from the caregiver's search for information in various ways, including courses, books, internet and other vehicles of knowledge[6].

So, although there are international references regarding the impact of care, one must take into account how much the cultural and socioeconomic aspects in Brazil, a continental country, are relevant factors that tend to make it difficult for caregivers to provide support. Time, dedication, economic and structural resources are required to adapt to the new routine, which is often challenging considering the profile of Brazilian families.

The impact of daily living with an individual with limitations may worsen a mental disorder with the appearance of depressive symptoms in this caregiver. Andrade and Rodrigues, when they carried out a study

on family caregivers of elderly people with stroke, found profound impacts on the caregiver's social, physical and economic life[7]. Likewise, Bocchi found fatigue and sleep disturbances to be patent issues in these individuals, reaffirming the intense demands of care combined with the caregiver's unpreparedness[8].

Furthermore, Oliveira et al suggests that there is a gap in the process of guidance for health professionals regarding home care, in addition to the importance of discussing the need of the elaboration and implementation of a guidance plan to the caregiver in order to diminish their burden[9].

Moreover, one other relevant demand is the caregiver's mental health. Among the factors of low quality of life among caregivers, the domains "pain", "social aspects" and "mental health" configure the lowest scores among those patients with a higher degree of disability[8]. An ambivalence of feelings in the caregiver can be observed, which is experienced due to the lack of preparation to perform the function, along with the feeling of abdicating self-care[7].

Scores to assess the caregiver

Many scales are proposed to assess caregivers and the impact on their mental state. Oliveira et al. lists the Caregiver Strain Index, the Caregiver Reaction Assessment, the Sense of Competence Questionnaire, the Relatives Stress Scale and the Zarit Burden Interview, among others[10].

Since the high degree of burden can functionally disable an individual, and predispose them to depression and other mental disorders, the Zarit Burden Interview (attachment 1) is interesting for being used in our study [11]. This questionnaire is adapted to Portuguese for use in Brazil and employs a five-point Likert scale, ranging from always to never, for all 22 topics of the interview, which analyzes psychological, financial, social and physical aspects of the caregiver universe. Thus, it seeks to assess the relationship that the process of care subjectively impacts the caregiver's life, allowing the analysis of leading factors of their exhaustion. This scale offers, therefore, the overload indicators: mild (score from 0 to 14 points), moderate (score from 15 to 21 points) and severe (score above 22 points).

In addition, the Beck Anxiety Inventory (BAI) and the Beck Hopelessness Scale (BHS) will be applied, which were translated to Portuguese by Cunha[12]. The first questionnaire quantifies the caregiver's state of anxiety in the cross-sectional stage of interrogation, while the second one brings information about the individual's expectations regarding their life.

The Beck Hopelessness Scale (attachment 2) consists of 20 topics, which must be affirmed or denied by the interviewee. For each affirmative, they receive 1 point and, for each denial, they don't score. Then, the level of hopelessness, that is, the intensity of the caregiver's depressive symptoms, can be assessed: minimum (scores from 0 to 3 points), mild (scores from 4 to 8 points), moderate (scores from 9 to 14 points), severe (scores from 14 to 20 points).

The Beck Anxiety Inventory (attachment 3) consists of 21 topics that involve typical symptoms of anxiety and, in each one, the interviewee must quantify the presence and severity of the symptom from 0 to 3, with 0 meaning absence of symptom and 3 the maximum level. Thus, the level of anxiety will be defined: minimum (scores from 0 to 10 points), mild (scores from 11 to 19 points), moderate (scores from 20 to 30 points), severe (scores from 31 to 63 points).

OBJECTIVES

To assess the level of care burden, the level of anxiety and hopelessness of caregivers, and compare them with the types of sequelae resulting from the stroke.

To identify socioeconomic characteristics and family configuration of the patient's caregiver.

METHODS

Type of study
Descriptive, cross-sectional study with a quali-quantitative approach.

Place of Study
The study takes place at the Cerebrovascular Diseases Ambulatory of the Sao Paulo State University Medical School (FMB/UNESP), Botucatu campus.

Population
Patients of both sexes, over eighteen years of age, who have had a stroke for more than 3 days and who are being followed up at the Cerebrovascular Diseases Ambulatory will be randomly chosen. Their respective caregivers will participate in the research, being over eighteen years old and of both sexes.

Data collection
The collection of information will be made through interviews with caregivers and patients who are followed up at the Cerebrovascular Diseases Ambulatory, with the application of questionnaires by the researchers: Zarit Burden Interview (ZBI), Beck Hopelessness Scale (BHS), Beck Anxiety Inventory (BAI), and a socioeconomic questionnaire, which should all be filled out by the caregiver. Information will also be obtained by collecting data from the patients' medical records. Patients and respective caregivers will both only participate in the study after having signed a free and informed consent form. In order to ensure confidentiality, the patients involved in the research will be identified through the medical record number. This research project was submitted to and approved by the university research ethics committee, and has no conflicts of interest.

Variables

In this study, variables related to the demographic characteristics of patients who have had stroke will be evaluated, such as age, sex, date of occurrence, type of stroke, possible recurrences. Clinical data will also be analyzed: TOAST and Bamford classifications, admission NIHSS (National Institute of Health Stroke Scale), consultation NIHSS, Modified Rankin Scale (mRS), Barthel Index (BI), and whether or not thrombolysis was performed in the acute stage of stroke.

Variables related to the caregivers' demographic characteristics, such as age, sex, degree of relatedness to the patient and socioeconomic data will be analyzed, besides the level of hopelessness, depression and anxiety obtained from the questionnaires applied, cited above.

Research project linked to the Botucatu Neurosciences Academic League (LNB/UNESP)

Every week, a group of four to ten graduate and undergraduate students, who are academic league members, signs up to participate in the research, accompanied by academic league coordinators, who are older students, previously trained to execute the research methodology. Brief orientations are given to students by the coordinators concerning the pathologies that will be found in the ambulatory cases, and also about the questionnaires' application before the patient and their caregiver are called into the room. The students are given the opportunity to work on their own, talking to the patient and their caregiver and applying questionnaires, although coordinators are always present to assist them.

Data analysis.

The collected data will be tabulated and stored in Microsoft Excel sheets. Qualitative variables will be analyzed using Student's t-test. For the analysis of quantitative variables, it will be used mean, standard deviation and median. To verify the association between the variables of interest, Pearson's chi-squared test and Fisher's exact test will be used, considering $p<0.05$ as a significance level. The results will be presented in the form of graphs and tables.

RESULTS

This study will bring, as a result, the profile of stroke patients who are followed up at the UNESP Hospital's Cerebrovascular Diseases Ambulatory, and the impact of care on the lives of their caregivers. Expected results are impairments in the mental health of long-term caregivers, as well as more debilitating types of stroke. We hope to identify and map the caregivers at risk for mental illnesses, and insert them in our health system in a near future. An accurate overview of the patients' clinical characteristics and status in the acute and chronic stage will be possible through the analysis of neurological scales, such as TOAST classification, Bamford classification, admission NIHSS, consultation NIHSS, Modified Rankin Scale and Barthel Index. The analysis of the socioeconomic impact on the caregiver may show the implications of these social determinants on the health-disease process, whereas endorsing health promotion and raising awareness about relevant factors that worsen the caregiver burden in the care of stroke patients. Finally, we hope to find useful information for health services about the reality in which they are inserted, in order to promote the creation of disease prevention measures, which is essential to improve the quality of healthcare provided.

DISCUSSION

Considering the importance of the caregiver for the stroke patient survival, our project seeks to study if the caregiver overload, level of anxiety and hopelessness are associated with the severity of the patient's functional disabilities. The caregiver burden, associated with mental illnesses and impaired quality of life, represents an important issue in the Brazilian public health system. It's safe to say it is a universal challenge for health managers, given the necessity to offer social strategies capable of meeting the needs of the complicated process of rehabilitation, and alleviating the limiting impairments of these patients.

Furthermore, one differential of this work is that it was completely idealized, written and executed by undergraduate students, who are coordinators of the Neurosciences Academic League in Botucatu Medical School (FMB/UNESP), from fourth to sixth year of degree, orientated by a neurologist professor. There are other professors who help in the research execution and data analysis. This is an ongoing research project, in which undergraduate and graduate students participate, as mentioned above, and among the courses involved, there are: medicine, nursing, nutrition and biomedicine. Academic league members, from first and second years of degree, who attend basic cycle disciplines, and wouldn't have much contact with patients and doctors, are given the opportunity to be in medical scenarios, talk to people from multiple cities and with different stories and backgrounds, acquire new skills and learn about stroke in a practical way, whereas accompanying older students perform physical neurologic examination in patients. Constant positive feedback is received from students for having had opportunities to be engaged in such a large and relevant research study. The primary objective of this project is to stimulate the study of the neurosciences, clinical practice, and provide the students with opportunities to enter medical scenarios and interact with patients since the first year of degree, while promoting science and production of knowledge. In that perspective, an academic league can be defined as a group of study, tutored by a doctor, whose main objectives are the production of scientific knowledge through research, and the promotion of actions that seek to meet the population's needs with the university scientific knowledge and tools. That being said, on the first year this study was initially executed, an activity was conducted throughout the year, in which members of the academic

league would go to social city places in Botucatu, like shopping mall, schools, talk to people about stroke, how to recognize the disease and what to do in case of urgency. Considering stroke is one of the leading causes of death worldwide, it was staggering to see the amount of people who wouldn't be able to recognize a stroke. That is one facet of medical education, and an important role of ours, as prospective health professionals. Therefore, we highly endorse the relevance of academic league research and extension projects, since lives could be saved by actions like these.

Nevertheless, difficulties were found along the way. First off, when the study was about to start, there was the COVID-19 pandemic outbreak in China, which quickly spread around the world, forcing the coordination to postpone the beginning of activities. During the execution of the study, security health measures were taken to prevent infection with coronavirus, following strict regulations issued by the UNESP COVID committee. It was often difficult to interview patients and caregivers because of absences in the medical appointment, and also because of the lack of human resources to work in the study. One

reason pointed out as a possible cause was the patients and students' fear of contamination.

Besides, one other hurdle was the full and busy week schedule of all academic league coordinators, who are all attending last years of medical school. There were often no coordinators available to take students and work in the study. That is, perhaps, the main difficulty. However, alternatives have been discussed with the professors and work has been done to overcome this problem.

Finally, positive results of our research study are evident, since the coordinators and professors have been learning a lot in the process, working together. Plus, students who are given the chance to participate in the study often attend more than once, and are enthusiastic when describing new skills acquired and concepts learned. The caregivers, in general, appreciate the time spent with them, and the study itself. It often happens to have a caregiver cry in the room, because their burden is heavy and goes unseen, frequently. We hope to shed light on these people and their daily struggle in the care of stroke patients, for there is one patient, but two (or more) ill.

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