



Revista da Escola de Enfermagem da USP

ISSN: 0080-6234

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Universidade de São Paulo

Brasil

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Revista da Escola de Enfermagem da USP, vol. 43, núm. 1, marzo, 2009, pp. 37-43

Universidade de São Paulo

São Paulo, Brasil

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The problematic aspects of the family caregiver of people who suffered strokes

A PROBLEMÁTICA DO CUIDADOR FAMILIAR DO PORTADOR DE ACIDENTE VASCULAR CEREBRAL

LA PROBLEMÁTICA DEL CUIDADOR FAMILIAR CON EL PORTADOR DE ACCIDENTE CEREBRAL VASCULAR

Luciene Miranda de Andrade¹, Maria de Fátima Maia Costa², Joselany Áfio Caetano³, Enedina Soares⁴, Eveline Pinheiro Beserra⁵

ABSTRACT

The purpose of this study was to identify the problematic aspects of the families of people who were hospitalized because of strokes, and discuss the difficulties of the family caregiver toward household care. The sample consisted of 154 families of patients admitted in a public hospital in Fortaleza, Ceará state, Brazil. The results showed that most caregivers are women, 104 (67.5%); 122 cases (79.2%) showed family commitment and changes in the daily life of 115 accompanying partners (74.7%); 150 (97.4%) were not instructed about the care, but 143 (92.9%) felt safe to provide care. The predominant feeling was sadness, in 125 (81.2%) of the subjects, and the main doubts were: eating habits, 64 (41.6%); administering medication, 49 (29.9%); and possible clinical complications after discharge, 49 (29.9%). These results are worth noting for the nurse's role as an educator, not only regarding the prevention of chronic-degenerative diseases, but also concerning delivering instructions to family caregivers about providing care after hospital discharge.

KEY WORDS

Home nursing.
Caregivers.
Stroke.
Nursing.

RESUMO

Objetivou-se identificar a problemática da família de pessoas acometidas de acidente vascular cerebral hospitalizadas e discutir as dificuldades do cuidador familiar para o cuidado no âmbito domiciliar. A amostra constou de 154 famílias de pacientes internados em um hospital da rede pública de saúde, Fortaleza-CE. Conforme os resultados denotam, a maioria dos cuidadores são mulheres, 104 (67,5%); 122 casos (79,2%) apresentam comprometimento familiar e alterações na vida diária em 115 dos acompanhantes (74,7%); 150 (97,4%) não receberam orientações acerca dos cuidados, mas 143 (92,9%) sentem-se seguros para acompanhá-los. O sentimento predominante foi a tristeza, 125 (81,2%), e as dúvidas principais foram: alimentação, 64 (41,6%), administração de medicamentos, 49 (29,9%), e possíveis complicações clínicas após a alta, 49 (29,9%). Estes resultados alertam para o papel do enfermeiro como educador, não somente na prevenção das doenças crônico-degenerativas, mas, também, na orientação aos cuidadores familiares sobre os cuidados dispensados após a alta hospitalar.

DESCRIPTORES

Assistência domiciliar.
Cuidadores.
Acidente cerebral vascular.
Enfermagem.

RESUMEN

El objetivo fue identificar la problemática de la familia de personas acometidas de accidente vascular cerebral hospitalizadas y discutir las dificultades del cuidador familiar en el ámbito domiciliar. La muestra fue constituida por 154 familias de pacientes internados en un hospital de la red pública de salud, en Fortaleza, CE. Conforme los resultados denotan, la mayoría de los cuidadores son mujeres, 104 (67,5%), 122 casos (79,2%) presentan comprometimiento familiar y alteraciones en la vida diaria en 115 de los acompañantes (74,7%); 150 (97,4%) no recibieron orientaciones acerca de los cuidados; sin embargo 143 (92,9%) se sienten seguros para acompañarlos. El sentimiento predominante fue la tristeza, 125 (81,2%), y las dudas principales fueron: alimentación, 64 (41,6%), administración de medicamentos, 49 (29,9%), y posibles complicaciones clínicas después del alta hospitalaria, 49 (29,9%). Estos resultados alertan sobre el papel del enfermero como educador, en la prevención de las enfermedades crónico degenerativas, y también la orientación dada a los cuidadores familiares sobre los cuidados a ser realizados después del alta hospitalaria.

DESCRIPTORES

Atención domiciliar de salud.
Cuidadores.
Accidente cerebrovascular.
Enfermería.

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INTRODUCTION

Cerebrovascular accident (CVA) or stroke is a sudden loss of brain function resulting from the rupture of the blood supply to a part of the brain. As shown in studies, this event is the main cause of death and permanent injuries (sequels, disability) in Brazilian adults. The stroke is classified in two broad categories: ischemic stroke, when an artery irrigating a given part of the brain is blocked, depriving this region of nutrients and oxygen, and hemorrhagic stroke, when an encephalic blood vessel ruptures⁽¹⁻²⁾.

Although preventive measures have caused a significant decline in its incidence in the past years, stroke is still the third top cause of death worldwide, with a mortality rate of 12 to 37% for the first episode and above 62% for the subsequent episodes. As shown in statistics, nearly two million people who survive strokes remain with some disability: of these, 40% need assistance in daily activities⁽¹⁾.

As observed, a series of neurological deficits may be present after a stroke episode. With that, the deterioration of the patients' quality of life becomes evident, since at least two thirds of the survivors retain some sort of disability and become dependent, especially to speak, walk, see or feel, and they are sometimes incapable of performing their daily activities. In this context, a very important person arises: the family member who provides care⁽¹⁾. By caregiver, we understand a person whose duty is to perform the tasks which the patient impaired by the morbid episode cannot do any longer⁽³⁾. These tasks may vary from personal hygiene to financial participation in the family.

Therefore, in the authors' opinion, this theme was considered relevant for discussion, since there are no specific strategies focused on care for people with chronic and degenerative diseases at home, when the family caregiver is called to action, supporting care. As seen, transferring the function of caring to the family requires clarity regarding the family structure, the type of care that will be provided, the time demanded, the characteristics of the disease and the importance of monitoring by healthcare professionals. It is understood that the family should be responsible for the health of its members and, as such, needs to be heard, valued and encouraged to participate in the whole care / cure process⁽⁴⁾.

The family, either the nuclear type, formed by parents and children, or the extended type, including people considered as members of the same family, regardless of blood or parental ties, is the primary source of care and help for its members, from birth to death⁽⁵⁾.

According to findings of studies about this theme, in order to subsidize Public Healthcare Policies, it is necessary to take appropriate measures for the orientation of care-

givers, so as to perform care on the dependent clientele, because the physical alterations caused by the disease generate a series of weaknesses and, consequently, deficits in self-care and dependence for a caregiver. Therefore, the impact of the disease in the family is very strong, and can involve changes in affective, financial, power relationships and other variables, depending on the process of family organization.

This reality, in view of situations like those caused by strokes and their sequels, shows that the implementation of nursing actions focused on improving family coping is necessary, by teaching the family members about health-care and strengthening their collaboration in planning care. In this situation, the family members are expected to show positive attitudes and have adequate coping mechanisms to participate actively in the rehabilitation process, thus encouraging the patient to seek recovery and collaborate with the treatment.

Studies in the nursing field show that the family caregiver responsible for a stroke victim lacks qualification and support. Therefore, the need to perform studies on this theme is fundamental, because it is important to know and investigate the difficulties experienced in home care and to develop, implement and evaluate educational programs for the family caregiver.

Therefore, it is worth questioning: what are the problems of families of hospitalized stroke victims and the difficulties to maintain care at home?

The objective of the present study was to identify the problems of the families of hospitalized stroke victims and to discuss the impact caused on the family caregiver related to the difficulties for care, in order to maintain care at home after the patient is discharged from hospital.

METHOD

This is a descriptive, exploratory study with a quantitative approach, developed in the emergency and inpatient units of a public hospital, a reference in the area of Neurology in the city of Fortaleza, CE. These units were selected since they had high demands of stroke-specific care for patients from Ceará and its neighboring states.

The target population consisted of the accompanying partners of patients with a stroke diagnosis, which yielded a sample of 154 accompanying partners. The following inclusion criteria were adopted: being an accompanying partner or family caregiver during the hospital stay and after hospital discharge, and volunteering to take part in this research.

Structured interviews were used for data collection, using a previously elaborated list with objective and sub-

By caregiver, we understand a person whose duty is to perform the tasks which the patient impaired by the morbid episode cannot do any longer.

jective questions about gender, age, degree of relativity; changes in daily activities during hospitalization; orientation and safety in the provision of care; feelings manifested after the stroke and difficulties in the care process.

As determined by resolution #196/96 of the Ministry of Health⁽⁵⁾, this study was submitted to the Ethics Committee of the study institution and approved according to file #9000/05 in December 14, 2005. Next, after the term of consent had been signed, the participation of the family caregiver in the study was started.

Data collection was performed in the first semester of 2006, with one of the authors performing the interviews during his work shift, in a reserved place, away from the client and at a time convenient for the respondents.

The results were presented in descriptive percentages and in tables, which allowed for the visualization of the findings according to the proposed objectives. Regarding the quantitative answers, the values are different from the total subjects in the study, since some of them mentioned more than one justification in their answers.

RESULTS AND DISCUSSION

Data related to the accompanying partners of hospitalized stroke patients regarding gender, age and type of relation showed that the main caregivers are women, with a total of 104 (67.5%). The age ranges were as follows: from 31 to 44 years old, 59 caregivers (38.3%); from 17 to 30 years old, 44 caregivers (28.6%), followed by 45 to 58 years old, with 42 caregivers (27.3%). Regarding female caregivers, daughters are worth of note, with 74 (48%) accompanying partners.

Due to their higher sensitivity and attention towards the human being, women have always been seen as the ones responsible for providing care to sick people. This result can be the reflection of cultural standards. Frequently, the role of women in the family, as the main or primary caregiver, as seen in foreign literature⁽⁶⁾, has been described in terms of characteristics of the caregiving person, in view of the circumstances of care and the person receiving care. In addition, over the years, the practice of life-supporting care is fundamentally linked to the activities of women. They give birth and have the responsibility of overseeing everything that maintains life in its most minute details⁽⁷⁾. As seen, young people are sometimes made responsible for other family members, for monitoring and providing the care they demand. This may be a consequence of the necessity of better physical conditions to withstand the hospital environment – by itself uncomfortable, at times, and the stroke victim's dependency of care.

In this natural order of human evolution, it is common, at first, for the parents to care for their offspring during

childhood and throughout the whole development process, including the moments when they are infirm. Later, when the parents reach an advanced age, they require care and, since they cannot perform this self-care, their children usually assume this responsibility.

In this study, changes in the daily routine during the hospital stay occurred in 115 (74.7%) of the accompanying partners. This put the family structure at risk in 122 (79.2%) cases. It was also observed that low family income (lower than two times the minimum wage) was often cited. Therefore, there were no resources to hire someone to provide care for the patient. Consequently, one of the members of the family had to take this responsibility.

As observed, even with unfavorable conditions for the accommodation of the accompanying partners, they are present during the hospital stay. Regarding receiving orientation within the hospital environment about the care to be provided to their relatives, as observed, most of them, 159 (97.4%) had not received orientation related to direct care, especially the care to be provided at home after discharge.

Regarding their confidence in accompanying their patient, 143 (92.9%) said they felt safe due to the trust they had in the healthcare team that provided care, and because they were in a well-regarded hospital, itself a reference in Neurological care. Most caregivers took turns in their accompanying routines, 122 (79.9%).

Providing care to a patient uninterruptedly for twenty-four hours after a stroke is not an easy task, demanding more than one caregiver to take turns, sharing the work and the accompanying times. Taking turns is a form of relaxing from the hospital dynamics, although the accompanying partner is often incapable of detaching himself/herself from the patient⁽⁸⁾.

These accompanying partners, often seen as caregivers, are constantly worried – for example, about never leaving the patient alone for long, and they fear neglecting care. As it is known, lack of technical preparation due to lack of information may be the cause of personal overload, causing changes in the life dynamics of the caregiver, as well as inefficient care for themselves and the patients. Therefore, when advised and oriented, the family members will be better prepared to adequately intervene in the situations of care, without damage for their lifestyle or their physical and emotional health⁽⁹⁾.

Table 1 shows the main alterations related to the routine of the family caregiver. Such alterations are: missing workdays, 63 (40.9%); concerns for their younger children, 36 (23.4%); altered household routine, 23 (14.9%); stress, 12 (7.8%). Others, such as concerns for the household, missing classes at school and health problems were less frequent, although understood as having the same importance.

Table 1 - Distribution of the alterations in daily activities of caregivers responsible for stroke patients - Fortaleza - 2006

Variables	F	%
Being away from work	63	40.9
Concerns about younger children	36	23.4
Altered household routine	23	14.9
Stress	12	7.8
Concerns about the household	8	5.2
Missing school days	6	3.9
Health problems	6	3.9

From these concerns, being away from work is worth of note, especially since it causes financial damages for the family, even for the purchase of medicine, food, hygiene products, among others. This is directly reflected in not being paid. According to the evidence, in some cases, the absence meant dismissal from the job. When this occurs, the situation is aggravated, because the risk of losing one of the financial providers leads to fear and increased necessities of maintenance, associated to non-complementation by the other family members.

Another factor seen as grieving is the concern for younger children who are home alone, being taken care of by neighbors or, in some cases, children being taken care of by other children.

Issues related to these changes concern the family caregivers because, as they see it, their loved ones cannot live by themselves at home, since they cannot manage their domestic environment. Therefore, the family caregiver assumes this managerial responsibility, which will be even greater when added to managing their own life⁽¹⁰⁾.

Changes in the family's daily life can unbalance its structure, because of the vulnerability of its members who are still not stabilized after changing roles. This makes the environment ripe for the occurrence of severe family crises, because the pace of these relatives' lives is intensified by the disease, which can consequently bring ruptures.

As seen, in spite of the stress caused by hospitalization associated to the fear of the death of a family member, the caregivers feel safe because they trust the care that was being provided by the healthcare team and the institution.

In all circumstances, safety is a decisive factor, and the reasons that cause insecurity turn care into an activity that is even more stressful and wearisome. As observed, one of the most significant difficulties faced by the caregiver is certainly due to obtaining resources to maintain treatment. These factors can cause a vicious circle around the disease – lack of treatment – aggravation of the disease, making the caring activity harder and harder for the caregiver⁽²⁾. Nowadays, the healthcare system aims at dehospitalization but, for so, it is necessary to create adequate strategies to see to the needs of the person receiving care and his/her caregiver.

However, in spite of all the difficulties related to care in the hospital environment, such as the need to transfer the patient to third-party services for neurological evaluation, the cost of treatment, insufficient beds for hospitalization, increased incidence of infections, poor accommodation conditions and low availability of prophylactic physical therapy treatment, in addition to treatment performed in specialized units, it is important to keep in mind that diagnosing and treating strokes does not mean simply diagnosing and treating the resulting disabilities. It is also necessary to enable the individuals to reacquire the ability to interact with their environment and to aid their social inclusion.

Regarding the feelings manifested by the caregivers after the stroke, sadness is most often mentioned, with 125 (81.2%), followed by concerns, depression, pain, faith and hope and loss. Uselessness and nervousness are mentioned less often.

Providing care to a relative who has suffered a stroke triggers several antagonistic feelings in a short time span: love and hatred, patience and intolerance, affection, sadness, irritation, frustration, pity, anger, insecurity, negativity, loneliness. All these feelings raise several questions about care, the fear of becoming ill, fear that the patient is suffering, fear that the patient may die⁽¹¹⁾.

Culturally, stroke is associated with death, disability and dependence. Therefore, coping with this disease within the family environment brings more intimate implications and, sometimes, people become more fragile by the imminence of the loss of a loved one. This sadness may also be associated to having to face the situation of dependence, especially because it is a person whose life was happy and independent, to develop activities that were not characteristic before.

The caregivers are exposed to several events that cause fear, anguish and insecurity. They suffer because they do not know what may happen to the stroke victim, uncertainties regarding the disease and treatment, and by fearing the possibility of disability. The caregivers suffer by watching the suffering along with the relatives who had a stroke, and by seeing them suffer; also, they experience the pain of feeling important, of being incapable of freeing their relatives from the suffering.

Religion emerges as one of the ways of coping with suffering. This factor was evidenced due to the feelings of faith and hope in view of the perspectives of improvement, either favorable or unfavorable. Representations of loss and uselessness also emerged from the interviews. All these feelings are awakened when life and living are seen as not being the same any longer, since the loss of the physical independence of the stroke victims renders them incapable of performing activities experienced before. Another feeling mentioned was nervousness, which emerges because the caregivers feel tired and overwhelmed.

Regarding the doubts of the caregivers about providing care in the household after hospital discharge, in Table 2,

the main aspects mentioned were: diet and nutrition, 64 (41.6%), as they ask *which food can be offered? How should this food be given? What should be done when they cannot chew or have trouble swallowing?* Next are items like how to administer the prescribed medication and how to deal with or prevent clinical complications like breathing difficulty and seizures, both with 49 (29.9%).

Table 2 - Distribution of the doubts presented regarding the procedures to be performed in order to maintain care to the stroke victim in the household after hospital discharge - Fortaleza - 2006

Variables	F	%
Diet and nutrition	64	41.6
Administering medication	49	29.9
Clinical complications (difficulty breathing, seizures)	49	29.9
Fear of not knowing how to care	34	22.0
Replacing the caregivers when they are absent	17	11.0
Body and oral hygiene	16	10.9
Dealing with death	11	7.1
Eliminations	5	3.2
Risk of accidents	3	1.9

Other questions reported by the family caregivers were: the fear of not knowing how to provide care, 34 (22%), since these caregivers are required to provide special care to their patient; body and oral hygiene, 16 (10.9%), due to dependency for daily life activities; replacing the caregivers in case they are absent, 17 (11%), due to concerns about maintaining care, as well as the turns that are necessary to manage their own lives; and finally, difficulties in dealing with death, 11 (7.1%), since stroke victims are susceptible to complications.

However, as mentioned, such difficulties, faced when one has to perform the activities attributed to the family caregiver adequately, require basic orientation and guidance. These orientations should always be addressed in several aspects, within a basic informative plan. For example, questions about human, social and psychological relationships, notions about the most frequent diseases that can afflict the patients with stroke sequels, attention to hygiene, diet, small bandages, aid in walking, among others. Therefore, when these orientations are seen to, household care may be efficient as a form of rehabilitation or improvement in the clinical situation⁽²⁾.

Although a part of the caregivers have several doubts and reasons for distress, these are justified and stem from the fact that the stroke is usually a disease followed by the patient's dependency regarding self-care. Moreover, since most caregivers are lay people, they are afraid of not knowing how to care adequately and cause further complications to the patients under their care. Therefore, the healthcare

team, especially the nurse, should prepare the patient for discharge as early as the hospitalization period by carefully instructing the caregivers about care, from simple hygiene to preventive measures against infection and pressure ulcers.

As known, the caregiver's lack of preparation may cause serious damage to the patient and result in further hospitalizations. In addition, it can cause anxiety, greater physical exhaustion and cause situations of risk for both the care receiver and the caregiver. As such, it is necessary that the caregiver can develop skills to care for the patient, as well as strategies to cope with stress⁽¹²⁻¹³⁾.

In order to maintain the care provided by the family caregiver at home, a process of healthcare orientation should be started while the patient is still hospitalized. This means effectively preparing the patient for hospital discharge, and the nurse should be truly committed to this purpose and clarify the possible dependencies of the patient and the initial care to be provided by the family, forging a relationship of mutual cooperation⁽¹⁴⁾.

As we see it, care provided to stroke patients should also be directed towards the family, because resolution requires a certain amount of preparation and, sometimes, it triggers doubts and conflicting feelings. In view of such demands, in the role of healthcare educators, the nurses need to be aware that hospitalization represents a temporary situation in the lives of the patients, while the family is a permanent institution that will provide for them. As such, orientation is essential, considering the qualification of families to provide care, especially in the case of dependent diseases with a long period of rehabilitation, such as stroke.

Therefore, the philosophy of caring for the victim of this type of disease requires a lot of thought, due to the undeniable importance of physical and emotional support to the caregiver and, especially, the positive result of this care to those afflicted by strokes.

FINAL CONSIDERATIONS

As verified in this study, most caregivers are females in the age range from 31 to 44 years old, usually the daughter of the patient, with alterations in their daily routines and family commitment. Such caregivers do not usually receive orientations about the care to be provided in order to maintain family treatment, although they usually feel secure to provide care and take turns with other family members or with other people whom they have affinity with.

Regarding the consequences of the hospitalization process and changes in everyday life, the main problem mentioned was being away from work, with consequent economic damages for family upkeep. However, the caregivers mention that they feel secure regarding the care provided to the hospitalized patients, since they are closer to medical and nursing care, in addition to being in an institution that, according to them, is trustworthy.

As mentioned, the feeling most usually manifested by the caregiver was sadness, and the most distressing doubts regarding care provided to the patient at home were related to the diet, administering medication and possible clinical complications after discharge, such as breathing difficulty and seizures. For these reasons, as we see it, the caregiver should receive basic orientation and guidance to perform the activities done at home, since they revealed a lack of knowledge in their discourses. It is up to the nursing professionals to transform these caregivers' anxiety and lack of preparation into productive forces oriented towards care, being their right and duty to play this role.

As the patient's recovery is directly linked to the early start of a rehabilitation program and care focused on preventing deformities, the nursing team should be prepared to provide this type of care and encourage the patients and their relatives to perform them correctly. The household is a space where the nurse can also collaborate. In this case, it becomes homecare, which represents a work method that needs to be better developed and explored by the healthcare professionals, in consonance with the caregivers.

We believe that publicizing this knowledge may become a reference to the healthcare team during the elaboration of interventions focused on families of stroke victims, as a strategy to cope with difficulties and, consequently, to improve these families' quality of life.

However, it is observed that neither healthcare professionals nor public and private hospital institutions are sufficiently prepared or motivated to deal with this reality and guarantee the continuity of household care. However, it is necessary, particularly when there is a desire to provide better quality of life for the population and lower rates of re-hospitalization.

Other factors are added to these distressing factors, such as the absence of support programs for family caregivers and the lack of financial resources and community organizations, because chronic-degenerative diseases impose new demands on the families. In this perspective, real and feasible spaces are needed to develop orientation programs for the caregivers. As such, they can act adequately and competently.

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