



Caregivers of people with stroke - needs, feelings and guidelines provided*

Cuidador de pessoa com acidente vascular encefálico – necessidades, sentimentos e orientações recebidas

Cuidador de persona con accidente cerebro vascular – necesidades, sentimientos y orientaciones recibidas

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ABSTRACT

Objectives: Understand the needs and feelings of the caregiver of individuals who have experienced a stroke, and identify the information provided to these caregivers by health professionals. **Methods:** This exploratory, descriptive qualitative approach used semistructured interviews to understand the experience of six caregivers, during the period from May to August, 2008. The data from these interviews were analyzed using discourse analysis. **Results:** Three categories were identified: the initial needs of the caregiver, the caregiver and his/her feelings, and the guidance received by the caregiver from health professionals. Needs of the caregivers were varied, but primarily concerned adaptive difficulties. Diverse feelings were identified, including ambivalence, and a range of intensity of those feelings was noted. Guidelines provided by health professionals ranged from a total absence of information, to guidance that was felt by caregivers to meet all of their needs. **Conclusions:** There is need for discussion regarding provision of standardized guidelines for caregivers, and a strategy to support caregivers and patients.

Keywords: Stroke; Caregivers; Home nursing

RESUMO

Objetivos: Compreender as necessidades e sentimentos do cuidador e identificar as orientações prestadas por profissionais de saúde. **Métodos:** Pesquisa exploratória e descritiva com abordagem qualitativa, utilizando entrevista semiestruturada. Junto a seis cuidadoras nos meses de maio a agosto de 2008. Os relatos foram submetidos à análise de discurso. **Resultados:** Configuraram-se três categorias analíticas: as necessidades iniciais do cuidador; o cuidador e seus sentimentos e as orientações recebidas pelo cuidador. As necessidades envolvem diversos aspectos, representando dificuldades adaptativas. A diversidade de sentimentos vivenciados denotou ambivalência e diferentes graus de intensidade. Houve desde a ausência total de orientações, orientações incompletas e o fato de não sentirem falta de nenhuma orientação. **Conclusões:** Há necessidade da discussão a respeito de um plano de orientações, sendo uma estratégia de apoio para cuidador e paciente. **Descritores:** Acidente vascular encefálico; Cuidadores; Assistência domiciliar

RESUMEN

Objetivos: Comprender las necesidades y sentimientos del cuidador e identificar las orientaciones dadas por profesionales de la salud. **Métodos:** Investigación exploratoria y descriptiva con abordaje cualitativo, realizado mediante la aplicación de una entrevista semiestructurada a seis cuidadoras, en los meses de mayo a agosto del 2008. Los relatos fueron sometidos al análisis de discurso. **Resultados:** Se configuraron tres categorías analíticas: las necesidades iniciales del cuidador; el cuidador y sus sentimientos y las orientaciones recibidas por el cuidador. Las necesidades involucran diversos aspectos, representando dificultades adaptativas. La diversidad de sentimientos vivenciados denotó ambivalencia y diferentes grados de intensidad. Hubo desde la ausencia total de orientaciones, orientaciones incompletas y el hecho de no sentir falta de ninguna orientación. **Conclusiones:** Hay necesidad de discusión respecto a un plan de orientaciones, siendo una estrategia de apoyo para el cuidador y el paciente.

Descriptores: Accidente cerebrovascular; Cuidadores; Atención domiciliar de salud

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INTRODUCTION

Encephalic vascular accident (EVA) can be defined as a syndrome, characterized by the sudden onset of a neurological deficit persisting for more than 24 hours. Reflecting a focal, sometimes global, involvement of the central nervous system, resulting from a disorder of brain circulation due to an anatomopathological process in the blood vessels⁽¹⁾.

Encephalic vascular accident is a global public health problem, accounting for a large proportion of neurological diseases⁽²⁻⁴⁾. It is an important cause of morbidity and mortality, constituting the third leading cause of death worldwide, behind only cardiopathy in general and cancer⁽⁵⁻⁷⁾. It contributes to about five million deaths and more than 15 million non-fatal events per year, with 50 million survivors, many of whom (one in every six patients) will have a new EVA or Transient Ischemic Attack within five years⁽⁴⁾. The problems and the impact generated from the manifestation of an EVA in a person vary according to each particular case⁽⁸⁻¹⁰⁾. However, the repercussions always involve transformations in the quotidian life, of the person as well as the family and the society.

Some studies⁽¹¹⁻¹²⁾ indicate that after the experience of an illness such as EVA, the person is likely to return to their domicile with physical and emotional alterations which cause a disruption in the family organization and life. Being a frequent and disabling disease, it also requires the involvement of caregivers for success in the rehabilitation of the patient⁽¹³⁾. The alterations in people after EVA reflect in their functional capacity by often preventing or hindering the performance of simple tasks, such as activities of daily living, that were once easily performed, making them dependent and thus removing their autonomy⁽¹⁰⁾. On return to the domicile, the family finds itself weakened and the family caregivers that provide care, often do it intuitively. This means that there may be gaps in care, arising from both absence and gaps in the guidance received at the hospital, as well as from the short time for the appropriation of the guidance.

Faced with this theme, it was asked: What is the meaning of becoming a caregiver to a person with disabilities resulting from EVA? What are their main needs and feelings at the time of the return to the domicile? What guidance does the future caregiver received at the time of hospital discharge? All these questions lead us to seek to comprehend the phenomenon "to become a caregiver to a person with disabilities after EVA." Therefore, this study aimed to comprehend the needs and feelings of the caregiver and to identify the guidance provided by health professionals. It is intended that the data may support a practice of

guidance for the future caregiver, which begins during the hospitalization of the patient and at the time of hospital discharge.

METHODS

This is an exploratory, descriptive, qualitative study, being the procedure for collecting information from semistructured interviews. The choice of sampling in qualitative research is guided by the participation of people linked to the problem investigated, and the representativeness guided by the possibility of covering the totality of the object of study in its multiple dimensions⁽¹⁴⁾. The study participants were six caregivers of patients hospitalized in the University Hospital of Londrina State University (HU/UEL) with the diagnosis of EVA, residing in the city of Londrina, who were at different moments after returning to their domiciles and continued with some impairment that generated dependency. The interviews were conducted from May to August 2008, and the discourses are identified according to the order of the interviews, namely: D1 to D6. The caregivers were informed about the purposes of the study and, after agreeing to participate in the study, signed the terms of free prior informed consent, contained in a research project that was approved by the Research Ethics Committee of the University Hospital/UEL under protocol n^o. 269/06.

The semistructured interviews were conducted using a script with questions to generate of dialogue addressing the difficulties and feelings experienced by caregivers during the first week after hospital discharge, how the caregiver performed this care and aspects of the guidance received by the caregivers during the period of hospitalization and discharge of the family member. The interviews were recorded on an mp3 device, transcribed and deleted from the device, after being analyzed. For the analysis, the technique of discourse analysis⁽¹⁵⁾ was used, divided into two parts. In the first part the individual or ideographic analysis of the discourses was performed, in which a thorough reading was carried out without seeking interpretations, followed by the identification of the units of meaning related to the phenomenon in question. In the second part, the nomothetic analysis was performed from the rereading of the individual psychological structures, taking the units of meaning as if referring to all cases. Next, there was the approximation of the discourses seeking evidence among the individual propositions, establishing the convergences and divergences. This form of analysis allowed the search for evidence among the units of meaning, allowing the preparation of three analytical categories that configured the structure of the phenomenon studied.

RESULTS

The study participants were six female caregivers, between 25 and 67 years of age. Three of them worked outside the home environment, five of them were wives with incomplete elementary education and the other one was a daughter. The disabilities found in each patient ranged from dysphagia, aphasia, hemiparesis and hemiplegia to light cognitive deficits. The time elapsed after EVA varied from ten days to six years after hospital discharge.

After analysis and interpretation of the six discourses, the three analytical categories were configured: needs of the caregiver; the caregiver and their feelings; the guidance received by the caregiver. The first analytical category covers the initial needs of the caregivers related to the moment of the return to the domicile of the patient until the mastery of quotidian activities.

In becoming a caregiver, some interviewees compared the act of caring for the person who presents a disability resulting from EVA, with the act of caring for a child. Thus, it constitutes care that requires time and dedication, especially as this care is different because they are adults.

"I thought that it was like caring for a child, but you have to be more careful even than a child. He became worse than a child to care for."

They reported perceptions about the person who suffered the EVA and the changes in the life of that person after this episode, bringing repercussions to the family routine and their interpersonal relationships. In this sense, the loss of the person's autonomy leads to the need for adaptation.

"He would not eat ... when he would eat we had to put the food in his mouth." (D2)

They highlighted the lack of economic resources for the purchase of materials for the development of the new routine, such as a liquidizer and bath chair and also for architectural adaptations in the physical structure of the domicile. The verbalizations denoted the presence of barriers in the domicile environment, which was not structured to receive a person with limitations or disabilities, and therefore hampered patient care. Thus there is a need for structural and economic resources.

"(...) The wheels of the bath chair caught in the doorframes and also did not fit inside the shower, this made it very difficult for us." (D2)

In some cases, the family opted for the purchase of

a hospital use instrument to facilitate the care.

The caregivers also reported how they performed the transfers of the patient in the early days and all the difficulties that this procedure involved. They described the need for assistance from other people:

"I started caring but, as I worked outside the home, I depended on his mother to help me (...) Sometimes, a neighbor of mine (...)." (D6)

This need for help was provided, either by other relatives, friends or neighbors as well as by health professionals, privately employed or not.

"In the early days, I did not know how I would do it. So I hired a nurse who cared for him in the hospital for ten days." (D2)

"The girl of the clinic comes here and separates the drugs that he mixes." (D3)

Some study participants demonstrated difficulty in performing care when it came to the use of physical force. There is, therefore, the need for physical force to provide care, especially when moving or transferring patients from one place to another.

"You have to use a lot of force of the arms to lift the patient from the bed." (D2)

One of the factors hampering the process of adaptation for the caregivers was the lack of perception of the patient regarding the limitations imposed upon him and the feelings experienced due to this. This reality reveals the need for comprehension of the person after EVA.

"He does not perceive the paralysis that he has (...). We do not want to point out the difficulties that a person has and cannot see, but there are moments that require this. You need to open the eyes of the sick person. (...) My husband, who was a strong man, a man full of vigor, became like this, became ill, disabled, developed sequelae ... this changed his self-esteem a lot and sometimes he becomes aggressive, and it is very difficult for those who live with him." (D2)

The caregivers expressed the need to develop patience, based on the account of the difficulties faced in the quotidian life.

"I seek patience daily (...) the family members that live together, from day to day become exhausted, start to lose the strength, to lose patience." (D2)

From the observation of the condition of

impairment of the patient, the caregivers indicated the need to be an active participant in the process of rehabilitation of the patient, stimulating their autonomy.

"When I saw that he was not going to have many sequelae in the head (...) what I could teach him, I began teaching (...). Eat with your left hand, brush your teeth with your left hand." (D6)

The interviewees also demonstrated the need to become stronger through spirituality to overcome the difficulties encountered.

"We hope for the reward in God. The important thing is the reward that God gives to us." (D1)

This category explores the diverse needs of the caregivers. It was perceived that the needs revealed were related to each other, so that all are connected to the care provided by the family members.

The second category considered the feelings experienced by the caregivers from the moment they met with the occurrence of an EVA in a family member to the return to the domicile and the adaptation to the new situation. During hospitalization, some feelings begin to manifest themselves. As this is an unexpected and unknown moment, it creates an impact that culminates in an explosion of very intense feelings experienced by the caregiver. Among them, feelings cited were of despair, fear and insecurity, related to thoughts of possible death of the family member and to not knowing the future from that moment.

After returning to the domicile, the caregiver experiences a feeling of ambivalence demonstrated by happiness and hope due to the patient being alive and expectations of recovery. These are contrasted with feelings of stress, anxiety and profound sadness, which were expressed through continuous crying, demonstrating feelings close to the loss of control that accompanied the abdication of self-care in order to care for others.

"I left my job to care for him." (D4)

"I could not sleep, I just cried (...). I was un able to care for myself." (D2)

During the adaptation period in the domicile, the caregivers encountered difficulties, but after facing them experienced a feeling of transcendence. Some were surprised by the positive manner in which they dealt with the situation.

"We cannot weaken facing the problems that happen, right? And I could care for him." (D6)

"I won" (D1)

The third and final category consisted of discourses that ranged from total absence of guidance, partial or incomplete guidance to the fact that they felt no lack of guidance. They reveal ambiguities and even contradictions in their statements.

"They did not tell me anything, I learned by myself." (D5)

"They did not guide me at all. I went to visit, but they did not tell me anything." (D1)

"They did not teach me anything, they told me to take him to the clinic (...). They discharged him, they did not call us, a friend of his went and brought him home." (D3)

The content of the guidance varied from partial information about the disease, including the risk of death and the severity of the case, to information, also partial, on nutrition, hygiene, transportation and care in preventing accidents.

"Concerning the food, they said that it had to be lighter food ... and they said I had to take care when giving him a shower, so he would not fall." (D5)

The interviewees also referred to the welcome from the health team, not sensing any lack of guidance:

"I did not think anything was missing. I think they were very efficient." (D2)

Conversely, they also positioned themselves saying that information was lacking, and some evidenced the total absence of guidance. From the reports of the caregivers, it was observed that learning in relation to some care was not mentioned as guidance received, but was acquired from observation of the practice of the professionals:

"I remembered how they did it, so I could try to do the same." (D6)

In summary, the results demonstrated the lack of systematic guidance to both the patient and their caregivers.

DISCUSSION

At the moment the patient and the caregiver returned to the domicile, they faced new necessities and difficulties. Activities related to nutrition, hygiene, dressing and movement, previously performed with ease in quotidian life, have become tasks that require specific support and care. The caregivers revealed that the degree of difficulty in performing these new activities was directly related to the level of dependency imposed by the disabilities

of each patient.

The time and the dedication to care for the post-EVA person are prominent among the needs outlined by the caregivers. Concerning the care needs, they compared the family member with a child, emphasizing the complexity in the care of an adult who is like a child regarding their limitations and needs, without, however, ceasing to be an adult who is faced with a new way of living and a new position in the world. The caregivers experienced the need to adjust to the new routine that arises unexpectedly and intensely, accompanied by other problems such as economic and structural difficulties and the need for support.

Through the discourse analysis, it was perceived that caring requires various skills, such as patience and physical strength. The activities that require physical effort are highlighted in another study as those that pose the greatest difficulty for the caregiver⁽¹²⁾. Thus, the help originating from other people, including health professionals privately employed or from the primary healthcare system of the municipality, was an assistance factor in the process. Without help, to assume the integral care of a person with disabilities becomes more stressful and can generate frustration and social losses⁽¹⁶⁾. The help from other people brought benefits for the subjects involved in the care and to share the care represents a stress reducer, in both physical and emotional aspects⁽¹⁷⁾.

The caregivers also expressed needs related to emotional support to cope with this new reality. They denoted the strengthening through support in the spiritual environment to overcome the difficulties encountered. Generally, spirituality emerges at the moment of instability, to sustain the individual, becoming a cornerstone for support in the difficulties faced by the patient⁽⁸⁾. Often, family caregivers can act more emotionally than rationally. When this happens they end up not contributing to the rehabilitation process, which has a practical and functional character⁽¹⁷⁾. Nevertheless, the caregivers in this study revealed that even experiencing intense affective situations could also positively influence the recovery of their family member, encouraging the development of their autonomy.

The role of the health team is, through perception, presence, commitment, solidarity and above all the establishment of bonds in interpersonal relationships, to help people reorganize their existence to get through the experience of a disease⁽¹⁸⁾. It is comprehended that this assistance and support should also be extended to caregivers, through information about the EVA and its prognosis, as well as guidance regarding daily routines. Generally, care is the responsibility of a family member who, in the majority of cases, do not have a technical background to perform this function, without this interfering in the care they must take of themselves⁽⁸⁾.

The feeling of abdication of self-care was also found in another study⁽¹⁰⁾. It was also possible to perceive that, based on the difficulties, adaptation mechanisms emerged, and after some time, feelings of conquest.

With regard to the guidance received by caregivers, a similarity was noticed with another study⁽¹²⁾ which, supported in the results, deduced that the guidance provided to caregivers was not sufficient to make them secure in their provision of care and perhaps may even have contributed to increasing their fears related to care. Reports that there was no lack guidance, may be related to the fact that, before entering into contact with the direct care of the patient in the domicile, caregivers do not realize the future difficulties that they will have to face and thus do not know what is needed to perform the care. It then becomes necessary to use systems of reference and counter reference among the health service professionals of different complexities, thus providing continuity of patient care, particularly when such difficulties arise in the domicile⁽¹¹⁾. Thus, the importance of the relationship between health professionals and the family caregiver can be observed, especially the nurse, due to being the professional who stays with the patient for more time during hospitalization. One study⁽¹⁷⁾ conducted with family caregivers for some time in the domicile, noted that the relationship between the professional, with their scientific knowledge, and the family, with the knowledge acquired in their daily dealing with the disease, should be one of cooperation and exchange. However, such cooperation should be present in all moments of contact with family members, aiming to improve the quality of care provided by the family caregiver.

Considering that health education constitutes an activity essential to generate changes in behavior and to lessen the signs and symptoms of disease, the role of the nurse becomes relevant⁽¹⁹⁾. The application of knowledge and skill to teach can contribute to the change in lifestyle and improvement of the health of the caregiver and patient. The importance is emphasized of preparation of this professional for the development of educational practice. Importantly, this study revealed that the accompanying person observed the care offered by the health professionals during hospitalization. Thus, professionals aware of this possibility can use this moment to make a space for teaching and learning with the family members, the future caregivers. This type of visual communication enables the implementation of a systematic and participatory educational practice during the hospitalization period of the patient. However, it should be considered that the observation of the practice in the hospital occurs differently for each accompanying person, thus, it should not replace a more systematic verbal guidance.

The preparation of the future caregiver before hospital discharge can increase the satisfaction of their needs during and after the discharge, and can often contribute to the development of their perception in relation to the balance between the new activities that are involved in their routine and the old ones. Consequently, an increase occurs in the quality of life of the caregiver and the quality of patient care⁽²⁰⁾. The implementation of programs developed by health professionals for caregivers should include reflections that help them to comprehend the act of caring not only as a synonym of resignation, of absence of social life and of lack of freedom to take care of themselves⁽¹⁶⁾. The site of support of these caregivers could be the health unit of their area, through a social-political program, putting into practice the rights they have as people who care, but who also need care.

This study creates space for other studies on the elaboration of subsidized guidance plans based on the needs and feelings experienced by caregivers of people with disabilities generated by an EVA. The complexity of this situation requires the involvement of the multidisciplinary healthcare team in this process in an integrated and participatory way during the period of patient hospitalization.

FINAL CONSIDERATIONS

The results of this study highlighted the initial needs experienced by caregivers of post-EVA people who required time and dedication, the need to adapt to the new routine, to economic and structural resources, to help from others, to physical strength, to patience,

among others, in order to provide care. The need to comprehend the post-EVA person as an active participant in the process of rehabilitation and the strengthening of spirituality were also revealed. Upon returning to the domicile, faced with the new routine, the caregivers experience feelings of ambivalence and, being individuals with no technical skills to perform the care, often express the feeling of abdication of care for themselves. After some time, they adapt to the situation and have the feeling of conquest. The guidance provided by health professionals was insufficient to meet the needs of the caregiver in the initial period, which suggests a gap in the guidance process of the health professionals regarding domicile care.

There is an evident need for discussion on the elaboration and implementation of a guidance plan for caregivers in order to construct a support strategy for them and for the patients, which can minimize the impact on the family of which they are a part. More important than this, is the fact that health professionals need to incorporate the caregiver as the focus of the production of care, establishing an insoluble binomial between the person with disabilities and their caregiver. Thus, the production of health care should be focused on this binomial, considering the care needs of both. Thus, the health professionals involved in the context of care for post-EVA patients and their families, especially physicians, physical therapists and nurses, must give attention to the need for assistance and support to caregivers and family members. The relationship of these professionals, aimed at better meeting the needs experienced by families, developing an integrated and multidisciplinary practice is considered vitally import.

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