

Guidelines on the process of care of post-stroke individuals in the hospital context from the perspective of caregivers and healthcare professionals

Diretrizes da prática do cuidado de indivíduos pós-AVE em contexto hospitalar na perspectiva de profissionais de saúde e cuidadores

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ABSTRACT: The aim of this research was to suggest guidelines for creating a manual for care of post-stroke patients from the perspective of caregivers and healthcare professionals. This is a qualitative study through 40 individual interviews. analyzed using the content analysis method, which pointed the need for: support for the execution of daily life activities and psychological support for the caregiver; development of practical and affective aspects of healthcare; and professional training for improving the caregiver's knowledge about the disease and daily life activities. It is, thus, recommended that manuals for the management of post-stroke patients are created and used.

KEYWORDS: Stroke; Caregivers; Health education.

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RESUMO: Esta pesquisa foi fruto de uma dissertação e buscou sugerir diretrizes para a elaboração de um manual de cuidados direcionados a pacientes pós-AVE, em contexto hospitalar, com base na perspectiva dos profissionais de saúde e cuidadores. Trata-se de um estudo qualitativo com quarenta entrevistas individuais. A transcrição das entrevistas foi realizada através da Técnica de Análise de Conteúdo e apontou: necessidade de suporte para a execução das AVD e suporte psicológico para o cuidador; habilidades relacionadas aos aspectos práticos e afetivos do cuidado; conhecimento sobre o AVE e AVD para a capacitação. Recomenda-se a criação e utilização de manuais de orientação para cuidadores de pacientes pós-AVE.

DESCRITORES: Acidente vascular cerebral; Cuidadores; Educação em saúde.

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INTRODUCTION

Life expectancy is increasing progressively in Brazil and worldwide, and given the population ageing, the clinical worsenings and chronic non-communicable diseases (NCD) gain ground in the statistics as the main death causes.

Stroke¹ is among these diseases and can be described as a sudden nontraumatic neurological deficit resulting from the blockage or rupture of a cerebral blood vessel of different etiologies: cerebral artery malformation, arterial hypertension, cardiopathies, thromboembolism^{2,3}. Such changes negatively influence the quality of life of the affected individuals, who struggle to perform their daily activities in an autonomous way, requiring, thus, a caregiver⁴.

Around the world³, the estimated prevalence is from 5 to 10 cases of stroke per each thousand inhabitants. According to the Ministry of Health, the annual stroke incidence is 108 cases per 100,000 inhabitants, being the leading cause of death and disability in Brazil².

The post-stroke rehabilitation should be started early, because the sequel period may influence the performance of functional activities, since the neural regeneration occurs more intensely in the first six months after lesion⁵. Therefore, the presence of the rehabilitation team and a well-oriented caregiver, since the hospital admission, positively influence the patient's functional prognosis^{5,6}.

Training the professional since graduation is required, with the acquisition of technical, communicative, social, and behavioral skills targeting the patient's rehabilitation^{7,8}, so that a better orientation can be provided.

A study examining the perception of caregivers for elderly with stroke about a hospital discharge guidance program in a public hospital of Rio Grande do Sul, Brazil, suggests the need for implementing programs in health services for this specific public⁹. Another study, by Ramos et al.⁹, evaluated a multi-professional training program for informal caregivers in the quality of life of the elderly, emphasizing the importance of the formation of groups with this public by health professionals. The authors highlighted the importance of the formation of these groups for exchanging experiences and knowledge about strategies to improve the healthcare⁹.

A prospective, multicenter, longitudinal cohort study evaluated the satisfaction of post-stroke patients and their caregivers about the information received and the access to the rehabilitation team, pointing out positive

aspects in relation to the rehabilitation treatment¹⁰. The study emphasizes that training should be carried out according to the demands of each caregiver¹⁰.

A qualitative study assessed the experience of individuals who have suffered stroke and of their 12 caregivers while receiving educational interventions by the health team. The study points out the need for increasing the inclusion of caregivers in education and strengthening the communication, by providing guidance and proposing an approach with more theoretical elements for creating a curriculum and, consequently, an improvement in the results¹¹.

Considering the lack of educational materials for neurological patients' caregivers, our study aims to suggest guidelines for creating a care manual for neurological patients in the hospital context, from the perspective of health professionals and caregivers. The objective is to address all the characteristics of stroke: its influence on the quality of life (both of the one who takes care and of the one who is affected by the disease); the relevance of the caretaker to the rehabilitation of neurological patients; the overload of the caregiver in the hospital context or not; and the need for social support to this professional.

METHODOLOGY

This study was conducted in a hospital-school of Recife, from August to October 2016, by an occupational therapist with a wide professional experience in treating people with neurological deficits, with specialization in the subject in question, and in search of a master's degree.

For developing the study, caregivers of patients dependent in their daily life activities (DLA), who were hospitalized for a period greater than or equal to seven days, were selected, as well as graduate health professionals who provide direct assistance to patients and caregivers. Twenty caregivers and twenty health professionals attended the research, in a total of 43 who work at the research site.

Data on the demographic profile of caregivers were collected and subsequently tabulated and analyzed in simple frequency. The interviews approached the main caregivers' difficulties, the abilities to work with neurological patients in hospitals and the contents to be addressed in a practical training. The full speeches were transcribed and analyzed through the content analysis method, proposed by Bardin¹². This method establishes categories for interpretation of contents¹². Thus, after reading the interviews, the researcher: (1) highlighted

the main points of the interviews; (2) identified the units of analysis; and (3) structured the analysis with the identification of categories.

These interviews were identified by numbers, preserving the participant's identity.

This research was approved by the Research Ethics Committee of the Faculdade Pernambucana de Saúde – FPS (CAAE: 54342116.6.0000.5569) and developed in accordance with the provisions of resolution No. 466/12 of the National Health Council. The participants were informed about the research and invited, as volunteers, to sign an informed consent form. The interviews were identified by numbers, preserving the identity of the participants. The information obtained will be used only for scientific purposes.

RESULTS AND DISCUSSION

In relation to the demographic profile of the caregivers, 16 (80%) were female and 12 (60%) were aged between 40 and 59 years. About 65% of them had elementary education and 80% were from Recife and the metropolitan region. Also, among the participants 10 (50%) were catholic and 17 (85%) had household income equal to or greater than the minimum wage. Among the caregivers 10 out of 20 interviewed (50%) were children of the patients.

The main weaknesses in the process of caring pointed in the interviews were: (1) performance of DLA; (2) psychological support for the caregiver; (3) professional aspects of the act of caring.

According to health professionals' opinion, the most important skills of a caregiver in the hospital context refer to (1) practical aspects (the performance of DLA) and (2) affective aspects of care (attention, interest, involvement with the patient).

In the data analysis on theoretical and practical contents required for the caregiver in the hospital context, professionals highlighted the following categories: (1) knowledge about the disease (stroke): definition, functional prognosis and care required in hospitals and at home; (2) knowledge about the practical aspects of care: performance of DLA.

Data presentation and discussion

The findings related to the gender of the caregivers are similar to those from a quantitative study, conducted in the city of Ijuí, Rio Grande do Sul, Brazil, on the identification and description of

the activities of family members who care for people disabled by stroke¹³. The sample comprised 35 family caregivers, predominantly wives and daughters¹³. This predominance is due to the role historically attributed to women, related to the care of people with difficulties, whether in professional – in careers in the nursing field, for instance – or familiar context^{14,15}.

The caregivers of the study in question, 65% have completed only primary school. Highlighting this data is important, because caregivers, who are essential to the rehabilitation of the patients, receive guidelines from the health team and perform complex tasks (administration of medicines, for example)^{14,15}, which reinforces the need for educational proposals that prioritize the acquisition of technical skills along with the communication, behavioral and social skills^{16,17}.

Still concerning the characterization of the caretakers, 50% of them were children of patients. These data are similar to those from the study by Morais et al.¹⁸, which deals with the overload and the changes in the lives of stroke patients' caregivers in Fortaleza, Ceará, Brazil. The authors point out the importance of knowing the difficulties faced by caregivers to increase the support to this public.

The family caregiver of an individual with compromised health status experiences negative changes in his/her routine, which causes dissatisfaction and isolation¹⁸. Due to the closeness in the everyday life, most of the care is carried out by family members, in situations of short, medium or long term¹³.

In this study, the main weaknesses experienced by caregivers in the process of care were identified: (1) performance of DLA; (2) psychological support for the caregiver; (3) professional aspects of the act of caring.

Regarding the first category, most of the functional recovery of individuals affected by stroke occurs at home, and the support for the new functional needs during the DLA is often required^{13,19}. Thus, the more prepared the caregiver is after the hospital context, the better the patient's functional recovery is.

The need for guidelines to perform personal hygiene activities, such as bathing and dressing the familiar member, was identified as a demand of the caregivers. The fact that the disease in question causes disability creates this need, as exemplified in the following excerpts:

I think that, well, I mean... How to give a bath? (C16).

I wanted to learn many things... To change the sheets, ... how do I do it? To dress, to bathe (C20).

A study by Araújo et al.²⁰ on the effects of a training provided to informal caregivers of post-stroke patients concludes that the guidelines were effective to make the caregivers feel more confident in the everyday life.

A review about studies of interventions for caregivers of patients with cerebrovascular diseases in developed countries notes not only positive results in the management of the DLA of the one being cared for, but also a reduction in depression cases in caregivers and increased knowledge related to the disease²¹.

A study on the importance and the main difficulties when taking care of elderly highlights that care involves complex, delicate and triggering of suffering tasks¹⁵ that can overload the care, requiring emotional support.

In this study, the viewpoints of caregivers about their needs can be illustrated in the fragments below:

“It is all very difficult, the worst thing is seeing a person on the bed and not being able to understand what she is going through. So I think a counseling would become things much better, because physically I already know how it is done, the psychological part is the most difficult” (C4).

How do I deal with it? How do I reach it? How do I calm her down at the time of a medication? ..., my mother (...) had her sixth stroke, so every time we come here is difficult. Because I can't do it alone...” (C19).

These views differ from data from a study on the perception of family caregivers about their contribution to the rehabilitation of the patient with stroke⁶; in it, the caregivers did not regard the actions of psychological support as care, so that the authors preferred to emphasize actions that enhance and mobilize the family in the rehabilitation process⁶.

Still concerning the problems faced by caregivers, professional aspects of the act of caring were cited, involving areas of functional mobility and language stimulation exercises:

“Do exercise. When the person is like this (...) a physical therapy of stroke” (C14).

“More physical therapy and care of the voice were necessary” (C15).

This need may be caused by the high demand of the rehabilitation team in the infirmaries, which hinders from providing daily assistance to all patients. Even

without the scientific knowledge of the disease, the companions recognize the importance of professional interventions from the rehabilitation field as a possibility of patient's improvement. In this context, an handbook with guidelines about each professional assignments can help caregivers to identify the level of need for interventions.

Twenty graduate health professionals also were interviewed for identification of important skills of a caregiver in the hospital context and the theoretical contents that should be approached with the public concerned. Practical (the performance of DLAs) and affective (involvement with the patient, attention, interest) aspects were identified:

It requires attention... Being attentive, interested, careful, having a relationship, (...) an emotional attachment (P1).

You have to know how to deal with people, have to appreciate, want to help (P2).

First, you have to understand the disease... You have to understand that the patient is sick and he/she will need specific care (P4).

His/her availability is important (P14).

Bathing, for example, bed hygiene, change of diapers and sheets are very important for a bedridden person (P18).

The opinions are similar to those from a study aiming to identify and analyze the social representations of the care provided by caregivers of patients with post-stroke functional sequelae²². In the aforementioned study, the author states that technical and emotional training is required to provide care²², stressing that, in a few moments, the care provided by the participants assumes a compulsory character, which does not befit the concept of care (to meet the needs of an individual, with the mastery of the practice and pleased to care)²².

Data on the theoretical and practical contents required in a training for caregivers in the hospital context were also collected, from the perspective of professionals providing the service. The following categories were identified: (1) knowledge about the disease (stroke): definition, functional prognosis and care required in hospitals and at home; (2) knowledge about the practical aspects of care: performance of DLAs. The professionals interviewed highlighted the importance of the understanding of stroke by patients.

The informal caregivers usually do not have knowledge about stroke and, consequently, they are not prepared to deal with the problems caused by the disease²⁰. Thus, trainings addressing this condition increases the possibility of providing safe and effective interventions, that is, in favor of the patients' functional prognosis.

Regarding the practical aspects of care, the interviewed participants also stressed the importance of trainings that inform caregivers about the performance of DLAs:

*I think that knowledge about the **way to position the patient in bed**, on how to transfer him/her, even to sit hi/her down to avoid bedsores. It really helps us to deal with the question of wounds and to **increase the patient's functionality** (P2).*

*They need to have the knowledge of **self-care**. The knowledge of different ways to take care, about how to **change diapers**, how to **stand the patient up**, how to **bathe**, how to **clean the mouth**, how to **feed the patient** (P6).*

Andrade et al.²³ claim that the multi-professional teams working in hospitals need to be aware that the hospitalization of patients with stroke is temporary, and that professionals should ensure the qualification of caregivers for the rehabilitation period at home.

A study on a manual about positioning and performance of DLA for patients with stroke also reinforces the importance of information about rehabilitation at home²⁴. Purposing a handbook with guidelines for caregivers is essential to ensure the patient's rehabilitation²⁴.

Regarding the DLAs, it is known that they are performed by any individual in his/her everyday life and that the caregiver is fundamental for rehabilitation, for meeting the daily needs and for encouraging the patient's autonomy and independency⁶. The interdisciplinary team professionals recognize this importance:

*I think the caregiver must **encourage the patient in the basic activities of life**, stimulate small things, such as talking, eating, doing basic daily activities (P1).*

I would think about the question of stimulation. Sometimes patients have difficulty in remembering something, sometimes they forget some relatives, then I ask some family photos to show to them slowly (...), without much pressure (P14).

Also in relation to practical aspects of care, information about the nasogastric tube (NET) and its handling are seen by the participants as fundamental, especially due to the risk for aspiration. Some excerpts illustrate this theme:

***Feeding tube!** Many patients go back home with feeding tube. Patients went back home with the tube and returned; experienced bronchoaspiration and died (P6).*

*I think they need to know about the **feeding tube** and its contention... They need to know why they have to put water subsequently, for example (P18).*

Dysphagia and decreased body mobility are associated with prescriptions of nasogastric tubes for individuals affected by stroke, since the clinical interventions for this group are based on the prevention of complications and reduction in the length of hospitalization, in the mortality and in hospital costs²⁵.

The educational material and an institutional and emotional structure enable better conditions for caregivers to exercise their function properly^{19,20}. Training post-stroke patients' caregivers when they are still in the hospital context is important, considering the disability nature of this disease and the need for continuous care for a better quality of life for all the people involved.

FINAL CONSIDERATIONS

The difficulties related to care in the hospital context reported by the participants encompass issues regarding the performance of DLA, the need for psychological support and the professional aspects of care.

In the perspective of health professionals, skills and contents concerning caregivers' training involve practical and affective aspects, such as knowledge about the disease and DLA, and information about nasogastric tube and its handling.

Thus, creating a *Manual for caregivers of post-stroke individuals*, which is currently in the process of validation, was possible. Thus, it is recommended the creation and use of handbooks with guidelines for caregivers of patients with neurological disorders from the perception of those involved in the care process: their own caregivers and health care professionals who work in this area. These support materials can facilitate the work of the multidisciplinary teams, improve the patients' functional prognosis and reduce the work overload of caregivers.

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