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Researcher developed an educational manual for family caregivers

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Stroke is among the main global causes of death and disability in the last $15\,$ years according to the World Health Organization (WHO). People who used to be independent suddenly find themselves in need of help in daily activities. This assistance is usually provided by a close person, usually a family member who has no training in the area.

In her master's dissertation, researcher Ana Cláudia Fuhrmann decided to identify the barriers faced by family caregivers and, from there, build an educational manual to assist them. The work was supervised by professor Lisiane Paskulin of the Nursing School at UFRGS, in partnership with researchers from the University of Minho, Portugal. The idea is that the manual serves as a support material for caregivers to clarify doubts about the treatment of patients at home. However, the material does not detract from the importance of medical aid. It is common, at the time of discharge from the patient who suffered a stroke, that professionals do not have enough time to explain all the necessary care, and the large amount of information received by the family member in this moment of tension tends to be partly forgotten.



in their homes - Photo: Bournemouth Borough Council / CC BY NC 2.0.

The disease occurs when a certain region of the brain stops receiving blood, causing total or partial paralysis of that brain area. It happens all of a sudden, without giving any clues, but its symptoms are immediate. Depending on the location affected in the brain, the person may have paralysis on one side of the body, a crooked mouth, loss of strength in the arm and / or leg, speech difficulties, double vision, imbalance fainting, behavioral changes and memory loss. The researcher highlights the importance of noting the time when the symptoms started and calling the medical service.

The chances of having a stroke are increased in the elderly and men. People who have at least one of the risk factors are also more likely to suffer from this disease. Among them, the following stand out: history of heart and vascular diseases, smoking, physical inactivity, overweight, diabetes, high blood pressure (hypertension) and excessive use of alcohol and drugs. In the case of people with advanced age, the sequelae left by a stroke can contribute to the worsening of age-related weaknesses.

There are two types of strokes: ischemic and hemorrhagic. The first is caused by the obstruction of an artery or vein by a blood clot, causing a reduction or loss of blood flow to an area of the brain. This clot can be formed in different parts of the body: the brain itself, the heart or the neck. Ischemic stroke is the most common, accounting for about 85% of cases.

Hemorrhagic stroke is more severe and occurs when a blood vessel ruptures, due to the high pressure that acts on it, and spreads blood over region of the brain in which it is found, causing hemorrhage

The prevention of a new occurrence of the disease is carried out through laboratory imaging tests and continuous cardiovascular monitoring. In cases of ischemic stroke, medications are also used to dissolve the clot and restore blood flow. In hemorrhagic patients, blood pressure is regularly controlled.

Construction of the manual

The study was developed in four stages: focus group, preparation of the manual, content validation and graphic design validation. In the first one, the focus group was held with family caregivers of patients being monitored in the Stroke Care Line - services provided by the hospital for the recovery and rehabilitation of the patient – of the Hospital Conceição Group (GHC). This method uses group sessions to discuss a certain subject, allowing the exchange of experience between members. In the survey, it was chosen as a form to identify the family's most recurring doubts and difficulties.

The following stage was the construction of the educational manual according to the questions brought up in the group's meetings and the protocol created in a previous study by Naiana Santos, one of the members of the Center for Studies in Education and Health in the Family and ommunity at UFRGS, to instruct nurses about care after illness. In addition, the researcher had the collaboration of six nurses with experience in the area of "home care for stroke survivors", who worked on listing the topics and images that should be included in the manual and adapting the language, in order to make it accessible to layman caregivers. At this stage, a photo session was also held with a patient and a family member at home to illustrate how care should be taken.

After completion, the manual went through two validations. In the content section, GHC nurses assessed whether the material contained all the information necessary for patient care and whether it was being addressed in a clear and appropriate manner. In the graphic design assessment, family caregivers of elderly people who suffered a stroke were invited to answer a questionnaire about the accessibility of the $manual. \ After \ completing \ all \ the \ steps, \ the \ research \ participants \ received \ a \ printed \ copy \ of \ the \ material.$

The manual is now in an institutionalization process at the GHC so that it will soon be available in its digital repository and in physical versions at the hospital. The idea is that health professionals can use it as a reference in preparation to hospital discharge and in Primary Health Care, performed in health community centers. According to Ana Cláudia, by improving the quality of care and caregiver training, the risks of the elderly person going through a new hospitalization are decreased.

The dissertation resulted in two interconnected articles: one on the focus group and its results; and another on the construction and validation of the manual. Both will be published in scientific journals, the first in Rev ra de Enfermagem, and the second in Revista Latir ana de Enfermagem. In addition, the manual is available for download on the SUS Knowledge Portal, supported by the Ministry of Health, and on the Brazil AVC Network website.

Dissertation thesis

Title: Construction and validation of an educational manual for family caregivers of elderly people after stroke

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