



NEUROLOGICAL SEQUELAE: PREPARATION OF A GUIDANCE MANUAL FOR HEALTH CARE

SEQUELAS NEUROLÓGICAS: ELABORAÇÃO DE UM MANUAL DE ORIENTAÇÃO PARA O CUIDADO EM SAÚDE

SECUELAS NEUROLÓGICAS: ELABORACIÓN DE UN MANUAL DE ORIENTACIÓN PARA EL CUIDADO EN LA SALUD

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ABSTRACT

Objective: describing the steps in the preparation of the manual titled Neurological Sequels: guidelines for patients and families. **Method:** a development study that presents the methodology used in the construction of the manual. The steps were: project design, selection of content of care for patients with stroke, the pilot manual drafting, reviewing and qualifying language, graphics, layout, review the suggestions and finalization of the manual. The researchers counted 20 participants to qualify the manual. The project was approved by the Research Ethics Committee, Protocol 06-428. **Results:** there were showed the concept of neurological / implications disease, skin care, health and comfort, mobilization, nutrition / hydration , preparing the home environment and communication. **Conclusion:** It is understood that an educational manual provides self-care and patient rehabilitation to subsidize the verbal guidance provided by health professionals. Furthermore, the development of the instructional material allows qualifying clinical practice in the guidance for the health care process. **Descriptors:** Health Education; Manuals; Nursing; Stroke.

RESUMO

Objetivo: descrever as etapas da elaboração do manual intitulado Sequelas Neurológicas: orientações para pacientes e familiares. **Método:** estudo de desenvolvimento que apresenta a metodologia utilizada na construção do manual. As etapas consistiram em: elaboração do projeto, seleção de conteúdos do cuidado aos pacientes com acidente vascular encefálico, elaboração do manual piloto, revisão e qualificação da linguagem, ilustrações, *layout*, avaliação das sugestões e finalização do manual. Os pesquisadores contaram com 20 participantes para qualificar o manual. O projeto foi aprovado pelo Comitê de Ética em Pesquisa, Protocolo n° 06-428. **Resultados:** foram apresentados o conceito de doença neurológica/implicações, cuidados com a pele, higiene e conforto, mobilizações, alimentação/hidratação, preparo do ambiente domiciliar e comunicação. **Conclusão:** entende-se que um manual educativo propicia o autocuidado e a reabilitação do paciente ao subsidiar a orientação verbal fornecida pelos profissionais da saúde. Além disso, o desenvolvimento de material instrucional permite qualificar a prática clínica no processo de orientação para o cuidado em saúde. **Descritores:** Educação em Saúde; Manuais; Enfermagem; Acidente Vascular Encefálico.

RESUMEN

Objetivo: describir las etapas del desarrollo del manual titulado Secuelas Neurológicas: guía para los pacientes y sus familias. **Método:** estudio de desarrollo que presenta la metodología utilizada en la construcción del manual. Los pasos fueron: el diseño del proyecto, la selección de los contenidos de la atención para los pacientes con accidente cerebrovascular, la elaboración del manual piloto, la revisión y el lenguaje de clasificación, gráficos, diseño, evaluación de las sugerencias y finalización del manual. Los investigadores contaron 20 participantes para calificar el manual. El proyecto fue aprobado por el Comité de Ética de la Investigación, Protocolo 06-428. **Resultados:** se presentaron el concepto de enfermedad neurológica / implicaciones, cuidado de la piel, higiene y comodidad, la movilización, la nutrición / hidratación, preparo del ambiente del hogar y de la comunicación. **Conclusión:** se entiende que un manual educativo proporciona el auto-cuidado y la rehabilitación del paciente para apoyar la orientación verbal proporcionada por los profesionales de la salud. Por otra parte, el desarrollo de material didáctico permite la práctica clínica de calificación en la guía para el proceso de atención de la salud. **Descriptores:** Educación para la Salud; Manuales; Enfermería; Accidente Cerebrovascular.

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INTRODUCTION

Neurological sequelae consists in the loss of voluntary control of muscle movements, sensory problems, incontinence, problems in communication and speech, which impair physical, emotional and social health of a person.¹

The most common sequelae are due to cerebrovascular accident (CVA) which is the third leading cause of death worldwide.² This is one of several dominant diseases in the age group over 50 years old, since 1960 considered as a major cause of hospitalizations, mortality and dysfunction, even surpassing heart disease and cancer.³⁻⁵ The incidence is higher in males and in individuals older than 65 years old.²

The CVA is defined as an acute neurologic dysfunction of vascular origin, and showing signs and symptoms corresponding to the involvement of focal areas of the brain.⁶ This disease causes great impact on patient health and their social and family relationships.³ Therefore, it is paramount importance the use of health education to obtain good results with respect to self-care and rehabilitation of individuals with neurological sequelae resulting from this type of health problem.

Health education is considered an inherent function to nursing practice and an essential responsibility of the profession.⁷ It is also an important component of self-care for the promotion, maintenance and restoration of health, as well as for individual adaptation to residual effects diseases because it helps them to cooperate with their therapy and learn to solve problems when they are faced with new situations.

Is understood as a set of self-care actions taken by the individual and the family to meet the needs of daily life, it is learned and perfected lifelong.² Have rehabilitation can be understood as one, continuous, progressive and dynamic process mainly education, aimed at functional restoration of individuals, their reintegration into family, community and society.³ Neurological rehabilitation nursing involves guidelines for the health care that help patients and / or people with disabilities to achieve a better recovery every sense: physical, mental, spiritual and social, enabling a better quality of life.²

There are different ways to guide the patient / family / caregiver, one being the use of written material as a way to reinforce the verbal directions. Educational textbooks assume an important role in the health education process as a facilitator of the mediation of learning content and function as a resource always available to the patient and

his family, who can consult in case of questions during the course of home care.⁷ In our reality, does not exist then a specific instructional material for the guidance of patients / families / caregivers, about how to perform self-care in the situation involving the care of neurological sequelae.

Justified this study based on the importance of an educational manual is for the patient and, in particular, for their families who, in most cases, end up becoming caregivers of the sick individual. For them, get this material can greatly facilitate the way in which care will be performed.

Being faced with a new situation, with someone who need permanent care can generate fear and anxiety, in addition, there is a significant transformation in the lives of caregivers and those receiving care, adaptations are necessary in the home and in settings familiar routine. So much besides informing the manual functions as a reassuring tool. It is hoped that this study will enable other professionals also prepare manuals for health care in order to best clinical practice with regard to the education of patients and families. Thus, this paper aims to:

- Describing the stages of development of the manual titled Neurological Sequels: guidelines for patients and families.

METHOD

The study raised from the development of a project carried out in a large university hospital in southern Brazil that aimed to establish a manual for health care directed to patients with neurological sequelae and their families. The study followed the methodological principles.⁸

The participants were health professionals who work in the hospital field study, students of the graduate school of Nursing attached to this institution, patients with CVA diagnosis and their families.

The sample was selected by convenience and consisted of 20 participants distributed as follows: two nurses, two physicians (a neurosurgeon and clinician), one practical nurse, psychologist, social worker, nutritionist, media professional and a member infection control. All of them with experience in the care of patients with neurological sequelae; also became part of the two students of undergraduate nursing, four patients with a diagnosis of CVA with preserved communication and four family / caregivers of these patients. Inclusion criteria: be professional knowledgeable in the field, student, patient or family, have cognitive ability to read and answer the questionnaire

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and agree to join the study. Some professionals were replaced for not having reported the manual on the agreed date.

The data collection took place in two stages. Initially, the authors sought to project development in the specialized literature and their experiences in information that could guide the construction process of a pilot manual. Subsequently, it was developed this pilot manual, which was submitted to the qualification by 20 study participants who were given the task of answering a questionnaire regarding the evaluation of the content and quantity of information, appropriateness of language, form and layout of the information and layout. Furthermore, it should make a critical reading of the text suggestions pointing corrections, additions and deletions of items.

The analysis of information occurred by reading the manual that was previously reviewed by the (pilot manual) participants, with attention to their suggestions, additions, deletions and corrections, in order to qualify the material and finalize the manual.

The project was approved by the Ethics and Research Committee and recorded in the Group for Research and Postgraduate Studies under n° 06 428. Respondents signed the consent form, which contained a clear and detailed manner the objectives and justification of the project as well as the benefits of it, consisting in facilitating the development of an educational manual.

The participants were informed about the guarantee of requesting response to any question or doubt; the freedom to stop participating at any time, without that bringing them prejudice in the institution; not be identified security and confidentiality of the information. In relation to patients and relatives was ensured guaranteed to receive hospital care regardless of their participation in the study.

RESULTS E DISCUSSION

The main result of this development project was the creation of the Manual *Neurological Sequelae: guidelines for patients and families*. In hospital, this field study, an educational manual is a booklet containing explanatory and illustrative information on specific care / health procedure and is used as educational resource for nurses and other health professionals to support the guidelines. Have at home, the same material can be an instrument of aid and consultation for both the patient and the caregiver.^{7,8} It is an enhancer element, since information written with specific guidelines that can support

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patients and family to participate more effectively and safely treatment, whether in hospitals, outpatient or at home. The increasing use of educational textbooks as resources for health education has assumed an important role in the teaching-learning process.⁹

In developing this manual titled *Neurological Sequels: guidelines for patients and families*; 10 steps were followed:

● 1st Stage: Construction of a development project

Initially, it was necessary to build a development project, which included the stages of introduction, purpose, method, schedule, budget, references, term of free and informed consent and tools for qualification of manual built.

This project was submitted to the Research Ethics Committee of the Institution, which contributed to its improvement and allowed obtaining funds from the Fund for Promotion of Research and Events (FIFE) needed to implement them.

It was interesting to note that in the initial process of drafting the manual professionals and students involved did not understand the importance of following a particular methodology. What do together brought the opportunity to discuss each stage of the process in depth and recognize its importance.

● 2nd Stage: Definition and selection of content

After the approval of the project, it began to search for information in the literature and the experiences of authors in scientific knowledge on the subject, in order to develop a pilot manual. For this it was necessary to define and select the concepts and the main care affecting patients with neurological sequelae and their families, emphasizing what is really important, indispensable as a manual cannot be too long; if it is, will not be read and / or used.

Currently, we note that the manuals are a trend in publishing, which reflects an appreciation of the proper implementation of technical procedures.¹⁰ The contents initially proposed to manual on caring for neurological sequelae directed to patients and families were: the concept of neurological disease and its implications; skin care; hygiene and comfort; mobilizations; nutrition and hydration; preparation of the home environment and guidelines regarding communication.

● 3rd Stage: Adaptation of language

This step was necessary to transform scientific knowledge of professionals in information easily understood by patients and relatives. We sought to develop consistent messages with vocabulary with the audience, inviting, easy to read so that the objectives of the manual could be achieved. Therefore, there was concern in using an accessible and short texts and language goals.

● 4th Stage: Inclusion of illustrations

The inclusion of graphics aimed to facilitate the understanding of information, since it is known that the image helps in fixing the content by the reader. Moreover, the figures facilitate visual communication and access by individuals with little familiarity with written language, as well as attract the reader, arouse interest in reading and assist in understanding the text.⁹ For the preparation of the illustrations was hired a designer, who sought, with the images produced, exemplify the care to be performed.

● 5th Stage: Pilot manual

Many reviews of the pilot manual were necessary, seeking to organize the content and interfaces, based on a model of logical reasoning and accurate patient care with neurological sequelae. Moreover, the contents were worked in order to make them clear and objective.

Clearly explain the reasons for certain steps to be performed, was also a concern and explored and highlighted in the manual point, since that helps the patient to engage in activities with a view to the proper performance of self-care. Patients and their families want and need to know the whys, which must be addressed in the written information.

It is believed that the difficulty of the person understanding, comprehending and fixing information is linked to emotional factors, and that education provides opportunities, which happens when learning that meets the interests of the individual target.^{11,12} This reinforces the importance of developing manual elucidating questions and contemplate specific concerns of the patient and his family, because in general they tend to forget the oral information due to the stress of the moment.

At this stage there was concern of authors in order to contemplate the answers to the questions that commonly occur in clinical practice in a clear and objective manner. And only when the authors realized that the manual was adequate began the qualification process.

● 6th Stage: Qualification of the manual

The qualification stage consisted in reading the pilot's manual for the 20 selected for the study (10 health professionals, two nursing students, four patients with neurological sequelae preserved communication with these patients and four family) participants.

Participants were assigned to make a critical evaluation of the pilot manual, through a close reading of the text content punctuating aspects that needed to be improved. It should also answer a questionnaire to evaluating the information content, the quality of language, the amount of information, the form and arrangement of information, the size of the font, the location of information in text, graphics adequacy of the clarity (if the guidelines were described in an understandable way) and relevance (if the topics expressed genuine relationship with the study proposal in question). After writing assessment, participants were heard in order to nurture the verbalization of its analysis regarding their suggestions for corrections, inclusion or exclusion of items.

Often, the literature is unclear, and discuss it with professional experts in the area is undoubtedly a unique experience that allows dialogue and provides exercise to learn why the need a lot of care; and it provided an opportunity to qualify. It was also possible to monitor the quandary of health professionals in questions of patients and relatives, and thus reflect on what is spoken and what is written and what is actually understood by patients and relatives.

The time used for read and response to the manual assessment questionnaire was approximately one hour, for further discussion of the meeting was 30 minutes. There were two meetings with each participant: the 1st for explanations and delivery of pilot manual, assessment questionnaire and signed an informed consent; 2nd to receive the corrected manual the completed questionnaire and to hear comments and suggestions regarding the content of the manual. These meetings were essential to a better understanding of the suggestions. Some professionals were replaced by others from the same category for not meeting the deadlines for the return of the manual.

The main contributions of the participants were related to the size and layout of the text, reported as too large and out of order; vocabulary, too far-fetched; and review of images sometimes assessed as inadequate. Even at this stage, suggestions for inserting information was received which authors had not thought of and that literature does not

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describe, and some contents were questioned about the veracity of the information, which led the authors to revise the contents on updated sources.

Is in the literature, the recommendation that the classification is performed by health professionals and education specialists for patients and groups of patients with the event approached.¹³⁻⁴

In our study the qualification process occurred with the multidisciplinary team in stages: first, gave up the manual for two specialist nurses; then, if implemented in the text suggested changes; and then it was delivered, as amended, for the other participants always with the realization of corrections every two returns for the text to be improved and updated. Completed step with professionals, we proceeded to the qualification with patients, family members and graduate students. It is understood that this order is important because initially it is necessary that the contents are well laid out and organized for later assessed by patients and their families.

Upon receiving the evaluations of participants including authors discussed each of the suggestions assessing their relevance with a view to improve the text. This phase was delayed because of the time required availability and researchers to discuss and implement the suggestions in the text, the most appropriate way.

The contribution of different professionals in the area over which the manual verses, as well as patients with sequelae resulting from stroke and their families, it was very important for the needs perceived by those who live the experience of this care were observed. The development of the manual also contributed to that behavior and techniques in relation to care could be widely discussed among the multidisciplinary team.

For the students, it was a moment for experiencing research in all its stages and an opportunity to modify, in practice, a perceived need for them - not knowing what and how to guide. Thus, the development of the manual also contributed to enriching the knowledge and therefore qualifying nursing care.

● 7th Stage: Manual layout

Held the qualification of the manual, there was concern about the layout of it, that is, with the font size of the letter, the distribution of text and pictures and linguistic revision. Besides viewing the objectives regarding the quality of information, an educational manual needs to be visually

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attractive to the reader. This step to better understanding and presentation of the text the authors received support from the Social Communication of the institution and underwent manual to a final linguistic revision.

● 8th Stage: Final printing of the manual

Performed the steps of preparing the manual, it was necessary to refer to the graphic of the institution, which has borne the financial burden of your final print in booklet form, as well as copies for distribution.

● 9th Stage: The Neurological Sequelae manual: guidelines for patients and families

In this step we have completed the manual, which includes the following items: concepts of neurological diseases and their consequences; skin care to prevent injuries; hygiene and comfort massage; mobilizations; nutrition and hydration; preparing the home environment; guidelines in relation to the communication disorder and family interaction and referrals. It also presents an area for suggestions from readers so that it is constantly improved.

Health education is a constant in the everyday practice of nurses and, therefore, it is necessary to encourage and adequate educational and creative practices. Among them is guiding.¹⁵ Manual Moreover, health education is the moment in which it applies the effective participation of individuals through dialog.¹⁶ In clinical practice of the hospital in which this project was developed the manuals have been a feature widely used in order to standardize and qualify the information to patients and families.

To fulfill its purpose, we cannot forget that the updated manual is very important, since scientific knowledge is constantly renewing itself. Alongside that, with a view to update, the last sheet of the manual is intended for review by the user. This review is on answering a questionnaire with nine questions simple choice and a free question for suggestions. The reader can hand it to the secretary of the unit where the patient is hospitalized, who will refer to the authors of the manual.

● 10th Stage: Distribution and access

The financial resources of the project provide copies for this manual may be freely distributed to health teams, and especially the patients and their families. Delivery occurs at the time of admissions and / or outpatient consultations in the institution.

Currently this manual is available both in print and available for all units of the

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institution, as the online version of the UFRGS (sabi.ufrgs.br) online library catalog.

At the end of the preparation of this book, it was gratifying to see the satisfaction of participants and stakeholders involved in their creation to distribute to patients and families a material that helped build.

CONCLUSION

It is understood that the stages described for the preparation of educational textbooks allows them to be designed with methodological rigor, which contributes to their quality. Develop research from necessities aroused from the healthcare practice provides, undoubtedly, important contributions to its improvement.

The *Neurological Sequelae Manual: Guidelines for patients and family members* corroborated this idea, because it was designed to meet the demands of people of a particular service, having aided in changes to improve the quality of information on neurological patients and their families. A manual can provide good results for self-care and rehabilitation of individuals with CVA, since it provides verbal guidance provided by health professionals, which allows qualified nursing care in the guidance for the health care process.

As implications for clinical practice, it is inferred that having technology to health education facilitates and standardizes the guidance of professional staff to patients and their families, aids in modifying health actions and the pursuit of physical, mental and social well-being. Thus, it is expected that the sharing of this knowledge can create opportunities that other professionals prepare manuals, helping to qualify the care with patients.

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