

Nursing care systematization for outpatient treatment care of patients with multiple sclerosis

SISTEMATIZAÇÃO DA ASSISTÊNCIA DE ENFERMAGEM PARA ACOMPANHAMENTO AMBULATORIAL DE PACIENTES COM ESCLEROSE MÚLTIPLA

SISTEMATIZACIÓN DE LA ATENCIÓN DE ENFERMERÍA PARA EL SEGUIMIENTO AMBULATORIO DE PACIENTES CON ESCLEROSIS MÚLTIPLE

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ABSTRACT

An experience report of nurses in the implementation of care systematization in ambulatory care in an interdisciplinary care center for patients with multiple sclerosis of a public hospital in Fortaleza, Ceará, Brazil. This implementation is based on the *NANDA International, Inc.*, Nursing Interventions Classification, and Nursing Outcomes Classifications. One of the results concerns systemized nursing care, which has enabled the identification and understanding of the responses of MS patients to potential and current health problems. Systematization entails expanding knowledge through a practice based on approach and encourage further research scientific evidence, in addition to promoting the role of the nurse in a comprehensive approach and encourage further research.

DESCRIPTORS

Multiple sclerosis
Nursing care
Nursing diagnosis
Nursing process
Health promotion

RESUMO

Relato da experiência de enfermeiros na implementação da sistematização da assistência de enfermagem para acompanhamento ambulatorial em um centro interdisciplinar de atendimento a pacientes com esclerose múltipla de um hospital público de Fortaleza, Ceará. Essa implementação é baseada nas classificações da *North American Nursing Diagnosis Association International*, Classificação das Intervenções de Enfermagem e Classificação dos Resultados de Enfermagem. Um dos resultados diz respeito à sistematização do cuidado de enfermagem, partindo da identificação e da compreensão das respostas dos pacientes com esclerose múltipla aos problemas de saúde reais e potenciais. A sistematização ensina ampliar os conhecimentos por meio de uma prática pautada em evidências científicas, além de favorecer a atuação do enfermeiro em uma abordagem integral e fomentar outras investigações.

DESCRIPTORES

Esclerose múltipla
Cuidados de enfermagem
Diagnóstico de enfermagem
Processos de enfermagem
Promoção da saúde

RESUMEN

Relato de experiencia de enfermeros en la implementación de la sistematización de la atención de enfermería para seguimiento ambulatorio en centro interdisciplinario de atención a pacientes con esclerosis múltiple de un hospital público de Fortaleza-Ceará. Dicha implementación estuvo basada en las clasificaciones de la *North American Nursing Diagnosis Association*, Clasificación de las Intervenciones de Enfermería y Clasificación de los Resultados de Enfermería. Uno de los resultados se expresa al respecto de la sistematización del cuidado de enfermería, partiendo de la identificación y de la comprensión de las respuestas de los pacientes con esclerosis múltiple a los problemas de salud reales y potenciales. La sistematización intenta ampliar los conocimientos mediante una práctica pautada en evidencias científicas, además de favorecer la actuación del enfermero en un abordaje integral y fomentar otras investigaciones.

DESCRIPTORES

Esclerosis múltiple
Atención de enfermería
Diagnóstico de enfermería
Procesos de enfermería
Promoción de la salud

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INTRODUCTION

Multiple sclerosis (MS) is a chronic inflammatory disease of the central nervous system, characterized by the destruction of myelin, which causes a defect in the conduction of nerve impulses and affects the appearance of symptoms. Its etiology is still not well known, but three factors may be involved: genetic predisposition, development of abnormal autoimmune response directed against components of the central nervous system, and environmental factors⁽¹⁾.

Multiple sclerosis is an important public health problem because it is a progressive and disabling disease, occurring in young adults, between 20 and 50 years old, greatly impacting work, family, social and economic issues, due to the loss of the labor force, and high cost of treatment⁽²⁾.

It affects about 2.5 million people worldwide, with the highest prevalence in countries located at latitudes more to the north and to the south, with an estimated prevalence of 50 to 200 cases per 100,000 population in these countries⁽¹⁾. In Brazil, although the distribution of cases of MS is not well known, studies on its manifestation in the cities of São Paulo and Santos revealed rates of 15 cases per 100,000 population⁽³⁻⁴⁾.

The recommended treatment is an individualized therapeutic program using immunomodulatory therapy, which reduces the rate of progression of the disease by lowering the development of new lesions in the central nervous system, number of relapses and physical and cognitive disabilities⁽⁵⁾.

In Brazil, immunomodulators are dispensed free of cost by the Unified Health System (SUS) to patients with MS and are integrated in the cast of medications of the specialized component of pharmaceutical care from the Ministry of Health. Ordinance No. 493, of 23 September 2010, established that treatment should follow a clinical protocol and treatment guidelines⁽⁵⁾. It recommends that the diagnosis and monitoring of the patient should be performed in reference centers, requiring complex exams and a multidisciplinary team that acts to promote health to control disease progression and improve the quality of life of the patient⁽²⁾.

The multidisciplinary team should care for the patient in a comprehensive manner, beyond the physical care, considering their psychosocial grievances and electing the quality of life as a constructor that includes the satisfaction of people in their daily life⁽⁶⁾, thus respecting one of the fundamental principles of the SUS health policy, namely, the comprehensiveness of health care. The comprehensive care for the user should give priority to preventive, special protection and health promotion actions, in addition to offering health care services at all levels of care⁽⁶⁾.

Nursing professionals can act in this team, from experience to identify and assess the needs of the individual, being entitled to intervene in the biopsychosocial and spiritual aspects of the person with MS, in order that he reaches balance and well-being within the limits imposed by the disease⁽⁷⁾.

Law N. 7,498, of June 25, 1986, which provides for the regulation of the nursing consultation, private nursing activity as a means of providing direct client care⁽⁸⁾. Nursing care enables the practice of actions that contribute to promotion, recovery and rehabilitation of the individual with MS, contemplating the principle of comprehensiveness⁽⁷⁻⁹⁾.

Resolution N 358 of the Federal Council of Nursing (COFEN) of 2009, advocates Nursing Care Systematization (SAE), which should be performed in all health institutions in which professional nursing care occurs. It is organized into five steps: nursing assessment, nursing diagnosis, planning, implementation and evaluation of nursing care⁽⁸⁾. Therefore, the reference center for monitoring patients with MS is a space for the development of nursing activities, such as a systematized nursing consultation.

Nursing care enables the practice of actions that contribute to promotion, recovery and rehabilitation of the individual with MS, contemplating the principle of comprehensiveness.

This article had as its objective to describe the lived experience of nurses in the implementation of SAE in an interdisciplinary Center of care for individuals with MS.

METHOD

This is an experience report of nurses in the structuring and implementation of SAE for ambulatory monitoring of nursing for patients with MS, in the Center for Interdisciplinary Care for People with Multiple Sclerosis of a public hospital that integrates the SUS network of the Municipality of Fortaleza Ceará. The hospital is a reference in the care of patients with MS throughout the state. It features a multidisciplinary team of two physicians, two nurses, a pharmacist, a physiotherapist and nutritionist, that offers weekly attendance, aiming at comprehensive care for the patient with MS.

There are currently 100 patients with MS monitored in ambulatory care nursing of patients in the Interdisciplinary Care Center for People with Multiple Sclerosis. The implementation of SAE began in January 2009 and the process of systematization of nursing care has continued, faced with the need for comprehensive care of these patients, it was the first clinic of the institution to implement the SAE.

The Theory of Basic Human Needs of Wanda Horta⁽¹⁰⁾ was used as a reference and, to develop the nursing diagnoses, the NANDA International (NANDA-I) taxonomy, which is an international terminology for classification of nursing diagnoses. Nursing diagnosis is defined as a clinical judgment about human responses of the individual, family and community to current or potential health problems⁽¹¹⁾.

For the interventions of nursing care, the *Nursing Intervention Classification* (NIC) was used, which defines nursing intervention as any preventive or curative treatment performed by a nurse, based on judgment and clinical knowledge, to improve the outcomes of the patient⁽¹²⁾.

For the evaluation of quality of nursing care, the *Nursing Outcomes Classification* (NOC) was used, which includes nursing outcomes that describe the state, behaviors reactions and feelings of patients in response to nursing care provided. It is a common language of outcomes specific to nursing, that contributes in an objective manner to the measurement of outcomes, assisting in the choice of interventions⁽¹³⁾.

For implementation of ambulatory nursing monitoring of the patients with MS, forms were prepared based on the NANDA-I, NIC and NOC classifications. For the nursing assessment, two instruments were prepared, the first being more complex and used in the initial evaluation of patients with MS; and the second, more simplified and designed for follow-up visits to monitor the progress of patients and evaluation of proposals in the above consultation. A form for nursing diagnoses and their respective interventions was also prepared.

RESULTS

The steps adopted for implementation of the SAE with the MS patients in ambulatory nursing was the development of three instruments. The first instrument was formulated based on the nursing assessment and history directed to the categories of basic human needs. Data from the instrument included patient identification, socioeconomic and cultural aspects, health promotion, nutrition, elimination and exchange, activity and rest, cognition and self perception, sexuality, knowledge about MS, up to coping with reactions towards the diagnosis, stress tolerance, safety, comfort and physical examination. This instrument is used in the first visit of the patient to the ambulatory for nursing consultation. The second instrument was developed for monitoring for the patient in the subsequent consultations. It is a specific instrument that contributes to monitoring and evaluating the interventions proposed in previous consultations, which are contemplated in the physical examination and the evolution of nursing.

During the utilization of these two instruments realized the need to improve them, to adapt them to the specific needs of patients with MS, addressing current and potential problems associated with the disease and including neurological problems, secondary complications, and the impact the disease on the patient and family.

The third instrument contemplates the nursing diagnosis and interventions, having been prepared after the successive application of the first form for a month, enabling detection of the more frequent objective and subjective problems in patients. This form includes the 11 most

frequent nursing diagnoses in patients with MS, as well as their respective interventions. Furthermore, each intervention is associated with a specific outcome to be achieved. We emphasize that in the patients treated in this service, the 11 most frequent nursing diagnoses are: impaired physical mobility (00085); disturbed sleep pattern (00198), activity intolerance (00092), impaired urinary elimination (00016), ineffective coping (00069), constipation (00011), impaired memory (00131), sexual dysfunction (00059), ineffective family therapeutic regimen management (00080) and acute pain (00132).

After the nursing diagnoses are established, actions are planned to be performed using the NIC, which describes the standardized interventions that nurses perform, from the most basic treatments to the most complex and specialized⁽¹³⁾. In this instrument, specific interventions are suggested for each diagnosis, targeted in order to resolve, maintain control and / or mitigate the diagnoses. In the evaluation of nursing interventions, we used the classification of nursing outcomes that are registered in the instrument for the follow-up visit.

The nursing consultations were performed weekly, on Wednesdays, during the morning, by two nurses who were part of the interdisciplinary team of the center for MS. The patient begins his joint monitoring at the Reference Center with the medical consultation and then proceeds to the nursing consultation.

The first nursing consultation, being more complex, requires more time and varies between one and two hours. At first contact, the nurse conducts the interview and physical examination, recording the needs expressed by the patient, such as: questions related to the pathology, degree of anxiety in facing the diagnosis, the difficulties in the self-administration of injectable medication and conducting the treatment, difficulty in mobility, as well as any limitations imposed by the disease. Based on these records, nursing diagnoses are established and the interventions planned, in view of the goals to be achieved.

During the nursing consultation, the patient receives orientation about the health problem, such as: what is MS, how to identify an outbreak and how to proceed when this occurs, the benefits of medication treatment and its importance in helping the patient to delay the evolution of disease. He is also be informed about the adverse effects of medications and their management, the importance of medication and nonpharmacologic treatment adherence, and the importance of maintaining healthy habits that may prevent disease progression and improve quality of life. The nurse listens to the patient so that he can express his anxieties, talk and discuss his questions about the disease and its treatment.

In the physical examination, movements, gait, balance and posture are evaluated to assess the risk for falls or pressure ulcers. It also assesses the patient and the change in

muscle strength and sensitivity, spasticity, gastrointestinal discomfort, visual impairment, swallowing disorders, cognitive function, on-site inspection of parenteral administration of the medication, and bladder function.

For the patient who presented with impaired urinary elimination, interventions are established for the adequate management of symptoms, such as: bladder reeducation, training for intermittent catheterization, and other strategies to minimize the problem.

When the patient is initiating medication treatment, a return is scheduled uniquely for orientation about general care, with the procedure of preparation and administration of parenteral medication. These guidelines include the care with transportation, storage and maintenance of the adequate handling of the equipment needed for administration, preceded by hand hygiene care; the choice of the site of administration, as well as alternating, observing the relevant recommendations to prevent complications, and the technique of self-administration of parenteral immunomodulator, which is clearly explained step by step. It is noteworthy that when patients received the medication at the pharmacy, they were oriented by the pharmacist about the care with transport and storage of the immunomodulator.

Questions of the patient are answered during the explanation of the technique of parenteral administration of the medication, and, in sequence, the patient performs the parenteral self-administration of the immunomodulator in the ambulatory clinic. The facilities and difficulties are observed and discussed below. When he is presented with difficulties in parenteral administration or he reports insecurity, additional visits are scheduled to repeat the technique, supervised by the ambulatory nurse. If the patient exhibits physical or cognitive limitations that make him incapable of the self-administration, the presence of a family caregiver is required.

In subsequent consultations, an assessment of the nursing interventions proposed previously is performed, conducting a physical examination, as well as a reassessment of the diagnoses.

When necessary, the nurse makes the referral to other professionals within the multidisciplinary team. The scheduling of return is planned every three months, according to the protocol of the Center for MS or according to the health conditions and on treatment of each client. Access to the nurse in the ambulatory center by the patient with MS occurs whenever patients have any questions or feel this need, regardless of the schedule.

DISCUSSION

The effective application of the nursing process for ambulatory patients with MS allows the diagnosis of the patient's needs, planning and implementation of nursing interventions appropriate for each diagnosis, as well as

evaluating the outcomes, improving the quality of nursing care and favoring humanized and individualized care. It offers nurses the opportunity to assess and reassess their interventions and decide the best manner for performing them⁽⁷⁻¹⁴⁾. The systematized care, however, aims to improve the quality of care, reduce the factors that can accelerate the evolution of the disease and promote health⁽¹³⁾.

In this context, the systemized nursing consultation enables individual examination of the patient and provides comprehensive care based on actions that contribute to the promotion, prevention and rehabilitation of the person, with the guiding axis of the principle of comprehensiveness provided by the Unified Health System⁽⁹⁻¹⁵⁾. In view of this complex disease, whose evolution results in functional limitations that can lead to multiple disabilities, varying enormously from one person to another⁽²⁾, it is essential to offer a holistic and individualized care that contributes to the promotion of health and improved quality of life. According to Teixeira, the individual needs of the patient should be considered in nursing care⁽¹⁵⁾.

To humanize the comprehensiveness of care, nurses need to develop differentiated actions exceeding the technical and mechanistic model. It is necessary that patients have a space to talk and reflect about their questions, increasing knowledge about their disease⁽¹⁶⁾. Nurses must acquire the ability to understand the patient with MS before the complexity of their condition, knowing how to listen, and interventions would need to have a comprehensive and humane character, respecting the reality and the feelings of the patient.

During the nursing consultation, patients have the opportunity to reveal their anxieties and uncertainties, as well as their experience in relation to the health - disease process and treatment, which takes advantage of educational interventions directed to the acquisition of knowledge and healthy habits, respecting the understanding and lifestyle of the patient. Such health promotion conduct is based on reflection, based in the reality of the learner⁽¹⁷⁾.

Living with multiple sclerosis is to live in a state of constant uncertainty. The challenge of adjustment to MS is more than a biophysical adaptation to the process of an illness, it is a lived experience that requires multiple changes to adjust to the conditions imposed by the disease⁽⁷⁾. In these circumstances, it is necessary to propose a change of lifestyle from a compensatory and motivational approach. These interventions are performed systematically during the nursing consultations, with the intention of empowering patients to face their everyday difficulties and to follow treatment from a positive perspective.

Among patients with MS, 65% progress toward bladder dysfunction, which represents a big impact on the social, professional, sexual, familial, that is, the quality of life of these patients. Many times, patients do not seek help because of embarrassment or lack of knowledge⁽¹⁸⁾.

In this sense the role of the nurse in diagnosing the nursing diagnosis is important, by using these clinical responses for planning the training for bladder self-catheterization, and bladder reeducation⁽¹⁹⁾, as well as other interventions, to prevent complications, provide greater autonomy, to allow social and affective interaction, and to improve self-esteem.

The pharmacological treatment for MS is administered parenterally, particularly the immunomodulatory agents that favorably modify the progression of the disease. The patient can self-administer at home, when trained by a health professional⁽²⁾. Accordingly, the orientations of nurses of patients with MS, linked to an educational process pass along knowledge about the treatment and the procedure for preparation and administration of immunomodulators, so that it can be performed at home by the patient himself⁽²⁰⁾. By appropriating knowledge, the patient is involved in self-care and greater autonomy in the decision of adherence to their treatment⁽²¹⁾. Santos confirms this idea by emphasizing that, by acquiring knowledge produced in the educational actions, for the patient seeking self-care, this provides him with the conquest of continuous quality of life⁽²²⁾.

In the orientation for self-administration of the injectable medication, a protocol is followed based on the nursing procedures for orientations of the patient with MS, in the application of the immunomodulator, standardized by Fernandes, and is necessary to ensure the safety of an effective treatment⁽²⁰⁾.

In the ambulatory consultation with the MS patients, interventions are agreed upon with him, focusing on his responsibility for self-care. To achieve this, his limitations are discussed with him, such as difficulties in self-administration of the parenteral immunomodulator, difficulties for performing bladder self-catheterization, as well as other activities related to self-care, whether by physical limitations, or by memory deficits. At this stage of the consultation, where possible, the family is included, which is done to enable its daily contact to support the treatment. Nursing interventions are an agreed upon strategy of developing patient autonomy, that could favor self-care⁽²³⁾. In this regard, the inclusion of the family in the care contributes to the promotion and rehabilitation of health of the patient⁽²⁴⁻²⁵⁾.

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Implementing the SAE encountered some difficulties due to lack of knowledge of nurses in relation to MS and the scarcity of literature addressing the role of the nurse in MS in the Brazilian reality. While institutions recognize the importance of SAE, including hospital accreditation, little invest in technology and human resources, including the physical space required for the nursing consultation, which in turn limits the nursing care to patients with MS. The complexity of the disease requires greater nursing time, along with adequate space for the nursing consultation.

CONCLUSION

The implementation of the nursing consultation provides the identification and understanding of the responses of patients with MS to actual and potential health problems, facilitating the choice of interventions. These interventions assist in pharmacological and non-pharmacological treatments, favoring adherence and aimed at improving the quality of life of patients with MS through strategies of health education.

The nursing consultation for the patient with MS enables a broader view of the health - disease process and facilitates the role of the nurse in that comprehensive approach. It is clear, however, that the proposal provides an opportunity to expand knowledge through a practice based on scientific evidence. Furthermore, the data generated by SAE may encourage further investigations for neurology ambulatory clinics.

This consultation brings benefits to patients and their families and the community, as it offers quality care and humane, that respects the individuality of the patient, to identify diagnoses and selection of interventions, allowing the evaluation of nursing outcomes, as a strategy for development of patient autonomy that could favor the self-care.

This experience of nursing consultation together with the patients with MS was important because of the possibility of disclosing a highly relevant intervention to constitute the knowledge and practice of nursing in ambulatory care for people with MS.

The principle of comprehensiveness provided in SUS is favored by nursing consultation and by the interdisciplinary actions for the patients with MS.

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