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REHABILITATION OF CHILDREN AND ADOLESCENTS WITH MYELOMENINGOCELE: NURSING PRACTICE REPORT [1]

Giselle Lima de Freitas*
Roseni Rosângela de Sena**
Josana Cristina Faleiros e Silva***
Deyse Cardoso de Oliveira Braga****
Fabiana Faleiros *****

ABSTRACT
This article was developed by nurses with more than five years of practice, at a network of rehabilitation hospitals in Brazil, reference in Latin America. The objective of the present study is to report the activity of nurses in the rehabilitation of children and adolescents with myelomeningocele. The authors held face-to-facemeetings and videoconferences, discussions and exchange of experiences until a consensus was reached and the content was validated. The report was organized and divided into three topics: training for activities of daily living; training for vesicointestinal rehabilitation; training for activities of practical life: autonomy and participation. Families of individuals with myelomeningocele face difficulties related to the chronic condition and lack of structure and humanized services that guarantee and qualify home care. The challenge consists of providing subsidizes that guide professionals in the maintenance of home care, improving communication and training family members of children and adolescents with myelomeningocele.

Keywords: Rehabilitation. Myelomeningocele. Nursing.

INTRODUCTION

Open Spina Bifida (SB) or Myelomeningocele (MMC) is a congenital malformation that occurs due to the closure of the embryonic neural tube, resulting in the exposure of the spinal cord and meninges on the dorsal surface of a newborn at birth, characterized by a cystic protrusion of exposed nervous tissue[1].

MMC is the most common central nervous system (CNS)congenital disease(1), compatible with life, with a global incidence ranging from 0.1 to 10 cases per 1000 live births(2). According to the latest data published by the World Health Organization (WHO), Brazil is the fourth country with the highest MMC incidence rate (1.139 per 1000 live births)[3].

The scientific and technological advent caused an increase in survival and, currently, we now have the first adult generations with MMC, generating a new demand for rehabilitation nursing care, that is, the nurse plays a fundamental role so that people with MMC achieve their maximum functional potential, considering the limits resulting from their injury[4]. The increase in survival is a result of innovations in treatment, such as MMC closure surgery, the bypass valve for hydrocephalus (HC) treatment and the performance of intermittent bladder catheterization (IC) to prevent deterioration of the renal tract[5].

However, despite advances in the treatment of complications, the management of activities of daily living and participation, associated with cognitive deficit, have been a challenge for these people, their families and health professionals[6].

Rehabilitation nurses act in the training of these people with MMC for self-management of activities of daily living, seeking to maximize autonomy and participation. In this process, the concept of rehabilitation considers, with scientific foundations, the development and/or

* Nurse. Doctoral student at the Federal University of Minas Gerais' Nursing School. Belo Horizonte, Minas Gerais, Brazil. E-mail: gisellelf@yahoo.com.br
**Nurse. PhD in Nursing. Professor Emeritus from the Department of Maternal-Infant Nursing and Public Health of the Federal University of Minas Gerais' Nursing School. Belo Horizonte, Minas Gerais, Brazil. In memoriam.
***Nurse. Master's student at RibeirãoPreto College of Nursing, University of São Paulo.Ribeirão Preto, São Paulo, Brazil. E-mail: jofsilva@usp.br
****Nurse. Doctoral student in Nursing at the Federal University of Ceará – Postgraduate Program in Nursing. Fortaleza, Ceará, Brazil. E-mail: deysecard@yahoo.com.br
*****Nurse. Professor at the Department of General and Specialized Nursing at RibeirãoPreto College of Nursing,University of São Paulo.Ribeirão Preto, São Paulo, Brazil. E-mail: fabifaleiros@eerp.usp.br.

recovery of the individual's functionality, having their participation as the ultimate goal[7].

Despite the relevance of this theme, Brazil still lacks literature especially focused on this content and its specificities, about rehabilitation nursing and specialized health services. In this sense, this article has as its main objective to describe the practice of nurses in the rehabilitation of people with MMC, based on the experience of nurses from a Brazilian network of rehabilitation hospitals.

PROFILE OF PROFESSIONALS AND METHODOLOGY

The report was elaborated from the professional experience of the 5 authors, between 30 and 65 years of age, being 4 nurses and 1 pharmacist, all female, who have been working for more than 5 years in the rehabilitation of children and adolescents with MMC, in the Northeast and Southeast regions of the country.

The interest in concretizing this experience report arose from the common practical experience among the authors and, mainly, aiming to meet the demand for scientific production in rehabilitation nursing in Brazil, still incipient in the country. Initially, a work plan was elaborated, consisting of scheduled face-to-face meetings and videoconferences for discussions and exchange of experiences, since the authors were in different cities, in addition to seven rounds of reviews of the report itself until the authors reached a consensus and validated the content, in the course ofapproximately 12 months.

The report was divided into three topics that represent the main focuses of nursing practice in rehabilitation: a) training for activities of daily living; b) training for vesicointestinal rehabilitation; c) training for activities of practical life: autonomy and participation.

REPORT OF NURSES'S PRACTICE ON REHABILITATION

Contextualizing MMC rehabilitation

The rehabilitation of individuals with MMC aims at functionality, autonomy and social participation. Rehabilitation nurses are essentially involved in this process, encouraging and enabling the individual and his/her family to perform activities of daily and practical living[7].

The orthopedic, renal and neuropsychological sequelae inherent to MMC characterize it as a chronic condition[8]. Chronic conditions include health problems of varied nature that persist over time, require some permanent professional care and are highly demanding for patients, families and the healthcare system. The chronic condition deriving from this congenital malformation affects the daily life of families, with implications to the continuity of care in the home environment, which imposes a need for adaptations, causing a great impact on daily activities, requiring a new organization for care[9].

It is emphasized that the entire process of MMC rehabilitation is permeated by difficulties resulting from the disease, especially the cognitive deficit. Attention, memory and visuoconstructive deficits are associated with type II Arnold Chiari malformation and hydrocephalus. Visuoconstructive deficits refer to activities that require orientation, quickness and coordination, spatial configuration, relations between figures, completing shapes; some tasks are visual, others are graphic and motor, some require cognitive flexibility and others require memory[10]. Another factor that interferes with rehabilitation is the family context, especially the degree of parental investment and family socialization goals.

Rehabilitation care requires nursing to be able to modify its action, sharing the management of and responsibility for care with patients and their families. In this sense, compliance with pre-established protocols does not guarantee the continuity of home care planning, demanding an intersubjective relationship between the nurse and the individual, seeking individuality for the success of the continuity of the rehabilitation plan[11].

Training for activities of daily living

Activities of daily living refer to the set of actions developed by the individual and his or her family to meet human needs, being learned and improved throughout life. They include: mobilization and locomotion, hygiene, dressing

and undressing, and physiological eliminations[4].

Initially, the nurse should assess the potential and the physical and cognitive difficulties of the individual, as well as his or her family context, through participative observation during the performance of activities of daily living, identifying obstacles and suggesting adaptations and strategies that facilitate their performance [12]. Then, individuals and families are trained to continue with and practice them at home. Strategies for overcoming obstacles are elaborated in the sense of encouraging the performance of activities of daily living in an independent manner, according to the potential of those involved.

Deficit or lack of cutaneous sensitivity increases the risk of skin lesions due to inability to perceive pain and differences in temperature. Pressure ulcers, burns, trauma and other skin lesions associated with the use of lower limb orthoses are common in this population. Body perception and intensive skin care should be stimulated. Rehabilitation nurses train people for the prevention of injuries, emphasize the daily self-examination of the skin, with priority inspection of areas with bony prominences and protection of the lower limbs, especially feet, with the use of suitable shoes and orthoses. In the identification of cutaneous area with fixed hyperemia (stage I pressure ulcer), orientations included pressure interruption, rest, skin hydration and heliotherapy, until cutaneous integrity is restored. Wheelchair users should be subjected to total or partial restriction of wheelchair use in the case of pressure ulcers in the ischial and sacral regions.

Body and oral hygiene represent a basic human care that promotes the protection of the skin and the oral cavity against pathogenic microorganisms, and the feeling of wellbeing. For people with MMC, this care can be difficult to perform, mainly due to the difficulty of locomotion, the attention deficit and the absence of an adapted bathroom. Advised strategies include the use of a printed, laminated script placed on a wall in the bathroom, with all showerand dental brushing steps, associated with the daily repetition of the activity until its memorization. The adaptations include comfortable and safe plastic or shower chairs, as well as bath sponges with elongated sticks, which allow the brushing of the most distant areas of the body. Oral hygiene encompasses the establishment of schedules, the correct way of brushing and the use of dental floss and appropriate brushes.

Toilet activities refer to training for the use of the toilet independently, for intestinal and urinary elimination. Toilet activities also involve changing diapers, whose training involves the identification of individual characteristics, seeking the best positions (sitting, lying, orthostatic) and places (bed, wheelchair) for their execution.

When it comes to clothing activities, the ability to undress and dress the upper and lower limbs is assessed.The objective is toguide and facilitate their execution, through recognition of clothes (reverse and obverse), and body positioning and movements that make clothing more dynamic. For the use of buttons, ties, zippers, snaps and shoelaces, cloth cubes containing an accessory on each face are used. Patients are recommended to wear comfortable, more relaxed clothes without accessories that can cause skin lesions and are easier to put on and off.

The rehabilitation program includes mobility, since MMC causes motor deficit and demand locomotion aid, such as walking sticks, crutches, walkers, wheelchairs, in addition to lower limb orthoses. Accessibility and transfers, especially for wheelchair users, are handled in the hospital environment, at home and in the community[11]. The team, made up of nurses, physical education teachers, occupational therapists and physiotherapists, can work with one individual or groups of individuals, always with similar characteristics. People are instructed to raise the wheelchair because of obstacles, do transfers from the wheelchair to the car-bed-floor-showerchair, and vice versa, using transfer boards, as well as locomotion around bumpy environments, with or without slope. With professional supervision, individuals are encouraged to move around the streets and sidewalks of the city and to use the public transport service, working concurrently on their participation as active members of society[13].

Groups of activities of daily living are important tools to encourage the performance of these practices. The initiative brings together

individuals from the same age group and with similar difficulties and stimulates them for activities of daily living, which contributes to the motivation, cooperation and concentration of participants and their families[14].

Training for vesicointestinal rehabilitation

Rehabilitation, re-education or vesicointestinal handling refers to the set of actions aimed at the treatment of the neurogenic intestine and bladder, in an attempt to obtain a new pattern of vesicointestinal functioning[14]. This approach is part of the rehabilitation program for children and adolescents with MMC, and nurses are the main responsible actors[15].

The impairment of the renal tract caused by the neurogenic bladder is characterized by urinary incontinence, repetitive urinary infections, vesicoureteral reflux and hydronephrosis, which can lead to renal deterioration and changes in sexual activity. The objective of neurogenic bladder treatment is to protect the renal function and urinary continence. For this reason, intermittent bladder catheterization (IC) is preferably used worldwide to promote vesical emptying at regular intervals, four to six times a day, by insertion of a urethral catheter[16].

Catheterization is indicated after urological propaedeutics, with the performance of laboratory tests, ultrasonography and urodynamic study. Once the indication for catheterization has been confirmed, training is started, preferably of the individual with MMC, through self-catheterization; or of the caregiver, with assisted catheterization guidance. The IC clean technique is demonstrated by a rehabilitation nurse and then the caregiver or individual is monitored throughout the procedure until he or she shows ability and security to perform it without professional supervision, becoming fit for the continuity of care at home.

Children with preserved cognitive ability begin to be stimulated for self-catheterization from the age of six, as it increases the chances of acquiring urinary continence, as well as greater body control and self-care accountability, boosting autonomy and social insertion[14]. The nurse should be alert to assess their potential for self-catheterization. This assessment consists of verifying the individual's motor ability, such as trunk balance, abduction and movement of the lower and upper limbs, including the need for adaptations,aiming at carrying out the steps of the intermittent bladder self-catheterization technique, such as sitting, undressing, personal hygiene, visualizing the urethral meatus, inserting the catheter through the urethra, dressing.

The neurogenic intestine causes intestinal incontinence, sometimes severe constipation. Recommendations for intestinal re-education include a diet rich in laxative foods such as fruits, vegetables and vegetable oils, as well as adequate water intake and restriction of constipating foods. Bowel emptying maneuvers in synergism with the laxative diet are an essential part of rehabilitation[17].

Bowel emptying maneuvers comprehend daily toilet training, associated with abdominal massage, Valsalva maneuver with abdominal press, digital rectal stimulation, and manual extraction of feces when necessary. Abdominal massage should be performed at regular times, 30 to 45 minutes after meals, for about 10 minutes, clockwise, following the intestinal path. The use of emollients such as oils and creams is indicated to facilitate the sliding of the hands during the massage. The association of these maneuvers favors daily bowel habits and promotes effective evacuation, preventing fecal losses throughout the day, as well as intestinal constipation[17].

Training for activities of daily living: autonomy and participation

The autonomy process implies that the person takes on the protagonism in his or her own care, as the latter is shared between caregiver/nurse and patient/person with MMC. Progressively, knowledge is built by the participation of both, balancing needs and information, potentialities and ties[18].

Participation is closely related to autonomy. It encompasses tasks that promote the management of one's own life and participation in society, be they developed in a home environment or in the community, also called activities of practical life. In rehabilitation, training should be promoted for the organization of the home environment, the acquisition and correct use of medication, the performance of

domestic tasks, the administration of financial resources, the use of public transportation, shopping and referral to professionalization and insertion into the labor market[19].

The goal is to promote the management of daily needs, including all the logistics necessary for self-care and, thus, favor the insertion of the person into the family and the community. With this proposal, groups are developed with members selected according to age, cognitive ability and motor difficulty.

In the first moment, individuals are oriented as to the performance of routinely domestic tasks, through adaptations created in the hospital. These activities include organizing the house, the clothes and the bed, the use of utensils for house cleaning and the manipulation of foodsfor the preparation of one's own meals.

In the second moment, practical activities are carried out in the community. Adolescents take to the streets, with the supervision of professionals, to perform previously scheduled tasks, such as using public transportation and shopping in the supermarket, bakery and pharmacy. The use of money and the development of notions of time and space are stimulated. Relatives and caregivers participate in this process and are clarified about the importance of the activities performed by the adolescents, favoring their reasoning and stimulating their autonomy and social participation. For continuity, the use of places close to their residences is suggested.

Activities of practical life also include guidance on the professionalization and rights of people with chronic physical disabilities, with a view to empowerment and effective participation.

FINAL CONSIDERATIONS

The families of children and adolescents with MMC face difficulties related not only to the chronic condition, but also to the lack of structured and humanized services that guarantee and enable the acquisition of self-care, autonomy and participation.

The Brazilian Unified Health System [Sistema Único de Saúde] (SUS), based on the doctrinal principle of comprehensiveness, aims to guarantee its users' access to health services available at the different levels of attention, from the simplest to the most complex ones, to promotion, prevention and treatment actions for rehabilitation. However, it is considered that there are problems in the coordination of the various healthcare, assistance and social services, represented by the poor network articulation and little rationalization of the system as a whole. This fact compromises the specific care of the needs of people with MMC and their families, which ranges from primary attention during prenatal care to rehabilitation services for the integration of these individuals into society.

The challenge is to structure a network of health services that takes care of pregnant women from prenatal care to puerperium, maintaining home care, improving communication and promoting the training of family members of children with MMC. Thus allowing the rehabilitation of these people with the goals of autonomy in self-care and social participation soon from the first years of life.

This study suggests the introduction of rehabilitation and spinal, congenital and traumatic lesions theme in the education and qualification programs of nurses, with emphasis on personal and family training. It is necessary to develop and research new technologies with the purpose of empowering, adapting and facilitating the daily life of these people who, as a result of the changes inherent to the MMC, are subjected to a healthcare practice that lead them to very different living conditions from their age peers, hindering the performance of their role in society.

REABILITAÇÃO DE CRIANÇAS E ADOLESCENTES COM MIELOMENINGOCELE: RELATO DE EXPERIÊNCIA DE ATUAÇÃO DA ENFERMAGEM

RESUMO

O artigo foi desenvolvido por enfermeiras com mais de cinco anos de atuação, em uma rede de hospitais de reabilitação no Brasil, referência em toda a América Latina. O objetivo do presente estudo é de relatar a atuação de enfermeiras na reabilitação de crianças e adolescentes com mielomeningocele. As autoras realizaram reuniões presenciais e por videoconferência, discussões e troca de experiências até o consenso e validação do conteúdo. O relato foi organizado e dividido em três tópicos: capacitação para as atividades de vida diária; capacitação para a reabilitação vesicointestinal; capacitação para as atividades de vida prática: autonomia e participação. As famílias de indivíduos com mielomeningocele

enfrentam dificuldades relacionadas à condição crônica e à escassez de serviço estruturado e humanizado que garanta e capacite quanto ao cuidado domiciliar. O desafio é fornecer subsídios que orientem profissionais na manutenção do cuidado domiciliar, melhorando a comunicação e promovendo a capacitação dos familiares das crianças e adoelscentescom mielomeningocele.

Palavras-chave: Reabilitação. Meningomielocele. Enfermagem..

REHABILITACIÓN DE NIÑOS Y ADOLESCENTES CON MIELOMENINGOCELE: RELATO DE EXPERIENCIA DE LA PRÁCTICA DE ENFERMERÍA

RESUMEN

El artículo fue desarrollado por enfermeras con más de cinco años de experiencia, en una red de hospitales de rehabilitación en Brasil, una referencia en América Latina. El objetivo de este estudio es dar a conocer la actuación de enfermeras en la rehabilitación de niños y adolescentes con mielomeningocele. Las autoras llevaron a cabo reuniones en persona y por videoconferencias, debates e intercambio de experiencias hasta el consenso y la validación del contenido. El relato fue organizado y dividido en tres temas: capacitación para las actividades de la vida diaria; capacitación para la rehabilitación vesicointestinal; capacitación para las actividades de la vida cotidiana: autonomía y participación. Las familias de las personas con mielomeningocele enfrentan dificultades relacionadas con la condición crónica y la falta de servicio estructurado y humanizado que garantice y capacite en cuanto al cuidado en el hogar. El reto es proporcionar subsidios que guíen a los profesionales en el mantenimiento de la atención domiciliaria, mejorando la comunicación y promoviendo la capacitación de los familiares de los niños y adolescentes con mielomeningocele.

Palabras clave: Rehabilitación. Meningomielocele. Enfermería.

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Corresponding author: Giselle Lima de Freitas. Avenida Alfredo Balena, 190, Belo Horizonte, CEP: 30130 100, Minas Gerais, Brasil. Telefone (31) 988233674. E-mail: gisellelf@yahoo.com.br.

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