

The Role of the Occupational Therapist In Hemophilia: Case Report

A Atuação do Terapeuta Ocupacional na Hemofilia: Relato de Caso

La Actuación del Terapeuta Ocupacional en la Hemofilia: Informe de Caso

RESUMO

Introdução: A hemofilia é um distúrbio hereditário grave de coagulação sanguínea que pode provocar deformidades e incapacidades permanentes ou transitórias, comprometendo o desempenho ocupacional em algumas áreas de desempenho do paciente acometido. **Procedimento metodológico:** este é um relato de caso que visa apresentar a atuação do Terapeuta Ocupacional junto a um lactente com hemofilia A grave durante o período de hospitalização no Instituto Estadual de Hematologia Arthur de Siqueira Cavalcanti – Hemorio. **Discussão:** a importância da Terapia Ocupacional no trabalho da equipe multidisciplinar humanizada, sendo essencial para a organização das funções físicas e mentais do paciente, através de práticas profissionais em conjunto. **Conclusão:** ressalta-se a necessidade da atuação terapêutica ocupacional nos casos de hemofilia desde a profilaxia a reabilitação. O profissional Terapeuta Ocupacional fazendo uso dos seus conhecimentos técnicos, avaliando e definindo o programa de tratamento, observando a relação entre a pessoa, seu envolvimento em ocupações importantes e o contexto/ambiente nos quais está inserida.

PALAVRAS-CHAVE: Hematologia; Hemofilia A; Hemofilia B; Terapia Ocupacional.

ABSTRACT

Introduction: Hemophilia is a severe hereditary blood coagulation disorder that can cause permanent or transient deformities and disabilities, compromising the occupational performance in some performance areas of the affected patient. **Methodological procedure:** this is a case report that aims to present the performance of the Occupational Therapist with an infant with severe hemophilia A, during the period of hospitalization at the Arthur de Siqueira Cavalcanti State Hematology Institute - Hemorio. **Discussion:** the importance of Occupational Therapy in the work of the humanized multidisciplinary team, being essential for the organization of the physical and mental functions of the patient, through professional practices together. **Conclusion:** the need for occupational therapeutic action in cases of hemophilia from prophylaxis to rehabilitation is emphasized. The professional Occupational Therapist making use of their technical knowledge, evaluating and defining the treatment program, observing the relationship between the person, his involvement in important occupations and the context/ environment in which he is inserted.

KEYWORDS: Hematology; Hemophilia A; Hemophilia B; Occupational Therapy.

RESUMEN

Introducción: La hemofilia es un trastorno hereditario grave de la coagulación sanguínea que puede provocar deformidades y discapacidades permanentes o transitorias, comprometiendo el desempeño ocupacional en algunas áreas del paciente afectado. **Procedimiento metodológico:** Este es un informe de caso que tiene como objetivo presentar la intervención del Terapeuta Ocupacional con un lactante con hemofilia A grave durante el período de hospitalización en el Instituto Estatal de Hematología Arthur de Siqueira Cavalcanti – Hemorio. **Discusión:** La importancia de la Terapia Ocupacional en el trabajo del equipo multidisciplinario humanizado, siendo esencial para la organización de las funciones físicas y mentales del paciente, a través de prácticas profesionales conjuntas.

Conclusión: Se destaca la necesidad de la intervención terapéutica ocupacional en los casos de hemofilia, desde la profilaxis hasta la rehabilitación. El profesional Terapeuta Ocupacional, haciendo uso de sus conocimientos técnicos, evaluando y definiendo el programa de tratamiento, observando la relación entre la persona, su participación en ocupaciones significativas y el contexto/ambiente en el que se encuentra.

PALABRAS CLAVE: Hematología; Hemofilia A; Hemofilia B; Terapia Ocupacional.

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INTRODUCTION

Hemophilia is a disease characterized by the deficiency of coagulation factors VIII or IX, classified as hemophilia A and hemophilia B respectively, with hemorrhage as the main symptom. The most common cause is hereditary (congenital), but it can also be acquired, where antibodies are produced in response to autoimmune diseases, cancer, pregnancy or idiopathic origin.¹

Hemophilia A accounts for 75% to 80% of cases, while hemophilia B accounts for 20% to 25%. It is normally transmitted by asymptomatic carrier mothers to male children. It may result from de novo mutation, that is, when it occurs in the absence of cases in other family members.¹

The classification of the disease is based on the plasma levels of the deficient factor, divided into mild, greater than 5%, moderate, between 1% and 5% and severe when the circulating factor is less than 1%.¹

The intensity of hemorrhagic manifestations in hemophilia varies according to the severity of the case. In the most severe forms of the disease, the first hemorrhages may occur before the age of two. The most characteristic forms are hematomas and hemarthroses. They may occur in the form of hematuria, epistaxis, melena/hematemesis and also as internal bleeding into the abdominal, thoracic and retroperitoneal cavities, in addition

to intracranial hemorrhage.¹

One of the main measures available to guarantee the physical, psychological and social integrity of patients was the implementation of the primary prophylaxis protocol in Brazil, according to the Ministry of Health in 2011, in addition to being the modality recommended by the World Health Organization – WHO.²

Thus, the importance of a multidisciplinary team is highlighted, aiming at humanizing treatment and rehabilitation, including professionals who bring important knowledge to this care.² Within this team, the action of the occupational therapist stands out, qualified to assess and care for the occupational performance of patients with hemophilia in different contexts.³

Based on this, the objective is to report the role of occupational therapy in assisting children diagnosed with severe hemophilia A.

METHODOLOGICAL PROCEDURES

This work is the case report of an infant diagnosed with severe hemophilia A presenting acute subdural hematoma in the right occipitotemporal region evolving to compartment syndrome and who underwent Occupational Therapy intervention during hospitalization at the Arthur Siqueira Cavalcanti Hematology Institute - HEMORIO, after approval by the Research Ethics Committee, as

well as the signing of the Free and Informed Consent Form (FICF) by the patient's legal guardian in compliance with CNS Resolution No. 466, of December 12nd, 2012.

Data collected from physical medical records, electronic systems, imaging tests and photos of the use of assistive technology (AT) devices were used.

CASE REPORT

An 11-month-old infant with typical development and no history of previous illnesses was taken to the university hospital in the city where he lives on July 11, 2021 due to a febrile seizure. Laboratory tests showed no abnormalities. He was medicated and remained under observation for 12 hours. Two days after discharge, the infant returned with his mother, pale, with edema at the puncture site used to collect the samples in the left upper limb (LUL), hematoma throughout the entire length, and pain upon movement. During hospitalization, the patient developed significant edema throughout the LUL.

After laboratory and imaging tests, changes likely to be the etiology of a coagulation disorder were found, which was confirmed by hematology, through a laboratory test that showed a decrease in the coagulation factor, diagnosing severe hemophilia A. The results of previous exams, tomography and laboratory tests showed an acute

right occipital-temporal subdural hematoma, extending to the falx cerebri and marked fluid infiltration in the left supraclavicular region in the hemithorax and upper portion of the left arm, axillary lymph node enlargement, anemia and Factor VIII with a value lower than the reference.

During the physical examination, motor deficits were observed in the upper limbs with bruising in the upper limbs. With these results, the university hospital contacted the Hemorio triage outpatient clinic directly, requesting an evaluation of the case. On August 6th, 2021, the infant was received by the triage department and admitted to the hospitalization department, starting the treatment protocol for severe hemophilia A, with factor VIII replacement, undergoing laboratory and imaging tests, and receiving multidisciplinary care related to the symptoms presented. After the psychiatric evaluation, the opinion of Occupational Therapy was requested, in view of the dysfunction of the upper limb.

OCCUPATIONAL THERAPY EVALUATION

Infant accompanied by his mother during the therapeutic approach. Both were quite irritable, justified by the length of hospitalization, as well as the limitations related to the hospital setting and the care required to preserve the patient. The caregiver reported difficulty in preventing the patient from worsening the existing condition, due to psychomotor agitation and also due to the dysfunction of the LUL. After forming the bond, it was possible to manipulate the patient.

During the physical inspection of the right upper limb (RUL), hardened edema and hematomas were found in the antecubital region of the wrist and hand, making it difficult to feel the pulse. The extremities were pink and warm with preserved capillary perfu-

sion, as well as movement. In the LUL, it was possible to see the presence of hematomas, edema, paresis and adduction of the thumb. These changes led to dysfunction of the limb. Bruises were observed in the dorsal region of the feet.

THERAPEUTIC INTERVENTION

Immediately using assistive technology (AT), an abductor orthosis known as a figure-of-eight was handcrafted using adhesive tape, which was the raw material available at the hospital, with the aim of keeping the thumb abducted. At the same time, a resting orthosis was made from foam material, with the purpose of keeping the hand in a functional position during sleep.

The person in charge received training in how to place the figure-of-eight orthosis to be used during activities of daily living (ADL), instrumental activities of daily living (IADL) and in the main activity of children, which is playing, promoting and facilitating manual skills. Regarding the use of the resting orthosis, the guidance was to use it during sleep, ensuring the functional positioning of the hand, reducing edema and avoiding deformities.

During the consultation with the guardians, the indication for the use of a functional glove made of neoprene material was discussed and planned, which, in addition to positioning the segment, facilitates hand function. The father and paternal grandmother are craftsmen, which made it possible to manufacture the device based on the model and material provided by the therapist. All devices were tested during therapeutic consultations, presenting positive results with improvements in occupational performance. During training in ADL and feeding, the patient recovered manual ability by holding the bottle and the food offered, as well as in the activity of playing, handling toys bilaterally in a more active way.

DISCUSSION

This report describes the role of Occupational Therapy in the sequelae of acute right occipitotemporal subdural hematoma during the hospitalization of an infant with severe hemophilia A at Hemorio, presenting limitations in occupational performance during ADL and in play, compromising the quality of life of the infant and his family. It highlights the importance of Occupational Therapy in the work of the humanized multidisciplinary team, being essential for the organization of the patient's physical and mental functions, through joint professional practices.¹

During data collection, we analyzed articles, including: "Quality of Life of hemophiliac patients followed up at the Hematology Outpatient Clinic in a Specialized Service"⁴, who conclude that biopsychosocial factors impair the quality of life of hemophilia patients and that multidisciplinary work is necessary to define inclusion programs for this individual. In the article "Limitations in the occupational performance of individuals with hemophilia at the Regional Hemotherapy Center of Ribeirão Preto", Barata et al., conclude that the Occupational Therapy approach is important, as it contributes to the rehabilitation of patients with hemophilia, minimizing deformities and disabilities, restoring function and autonomy.⁵

Therefore, Occupational Therapy is defined as the therapeutic use of daily activities (occupations) in individuals or groups with the purpose of improving or enabling participation in roles, habits and routines in different environments. The Occupational Therapist uses his/her knowledge about the relationship between people, occupation and contexts to outline intervention plans.⁶

CONCLUSION

Considering the magnitude of hemorrhagic manifestations in hemophilia, which vary according to the severity of the case, and that patients with severe forms have their first hemorrhages before the second year of life¹, this report portrays the contribution of Occupational Therapy in the care of hemophilia patients from the beginning of treatment, with an integrated view of the human being and human occupation. In view of this, the importance of occupational therapy in cases of hemophilia, from prophylaxis to rehabilitation, is highlighted. The Occupational Therapist, using his/her technical knowledge, evaluates and defines the treatment program, observing the relationship between

the person, their involvement in important occupations and the context/environment in which they are inserted. Using basic activities of daily living (ADL), adaptations, techniques and methods.⁶ In view of this, the work of Occupational Therapy aims to minimize the aggravation of the disease, improving occupational performance in different contexts, promoting an improvement in quality of life.

However, future studies are needed to highlight the importance of Occupational Therapy in assisting patients with hemophilia, encouraging the implementation of the service in reference institutions.

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Author's Contribution

The author was responsible for the conception, writing and revision of the text, organization of sources and analyses and approval of the final version of the text.

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