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Knowledge of patients with falciform disease about physiotherapeutic treatment

Conhecimento dos pacientes com doença falciforme acerca do tratamento fisioterapêutico

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RESUMO | INTRODUÇÃO: Doença Falciforme (DF) é uma doença genética recessiva que compromete o funcionamento de órgãos e sistemas, influenciando negativamente na qualidade de vida, funcionalidade e capacidade funcional. Portanto, é imprescindível que esses pacientes sejam devidamente informados sobre as opções terapêuticas existentes, visando minimizar complicações oriundas da doença de base e das comorbidades associadas. **OBJETIVOS:** Descrever o conhecimento dos pacientes com DF sobre tratamento fisioterapêutico. **MATERIAIS E MÉTODOS:** Estudo transversal e descritivo, no qual 50 indivíduos com doença falciforme, 26(52%) mulheres sendo 43(86%) do genótipo SS e 7(14%) SC. Todos responderam a um questionário semiestruturado elaborado pelos pesquisadores, o qual coletou informações sobre diagnóstico, tempo de tratamento, enfermidades associadas, internamento, orientação pela equipe de saúde, conhecimento da fisioterapia como tratamento, realização de tratamento fisioterapêutico, sentimento após tratamento fisioterapêutico, tempo de realização da fisioterapia e interesse em informações sobre tratamento fisioterapêutico. **RESULTADOS:** Quarenta e oito voluntários (96%) foram hospitalizados por complicações da doença e apenas 19(38%) dos indivíduos tiveram o diagnóstico da doença na triagem neonatal. Problemas musculoesqueléticos foram os mais frequentes 50(100%), seguido de pneumonia 28(56%). Apenas 4(8%) voluntários estavam em tratamento fisioterapêutico, sendo que 34(68%) nunca tinham passado pela fisioterapia, 4(8%) receberam indicação para o tratamento fisioterapêutico pelo médico que os acompanhava e 10(20%) receberam informações da equipe de saúde. Quando questionados se desejavam ter recebido informações sobre os benefícios que a fisioterapia poderia trazer, 49(98%) relataram ter o interesse nessas informações. **CONCLUSÃO:** Indivíduos com Doença Falciforme não possuem o conhecimento devido sobre a fisioterapia e não são devidamente orientados sobre a possibilidade do tratamento fisioterapêutico.

PALAVRAS-CHAVE: Anemia Falciforme. Informação. Fisioterapia. Educação em Saúde. Reabilitação.

ABSTRACT | INTRODUCTION: Sickle cell disease (DF) is a recessive genetic disease that compromises the functioning of systems and systems, negatively influencing quality of life, functionality and functional capacity. Therefore, those who are being informed about the existing therapeutic options are essential, in order to minimize the complications of the underlying disease and the associated comorbidities. **OBJECTIVES:** To describe the knowledge of patients with FD about the physiotherapeutic treatment. **MATERIALS AND METHODS:** A cross-sectional and descriptive study in which 50 individuals with sickle cell disease, 26 (52%) women, 43 (86%) of the SS genotype and 7 (14%) SC. All respondents to a semistructured questionnaire prepared by the researchers, which collected information on diagnosis, treatment time, associated diseases, hospitalization, orientation by the health team, knowledge of physical therapy as treatment, physical therapy, feeling after physiotherapeutic treatment, time of accomplishment of physiotherapy and interest in information on physical therapy treatment. **RESULTS:** Forty-eight volunteers (96%) were hospitalized for complications of the disease, and only 19 (38%) of the subjects were diagnosed with neonatal screening. Musculoskeletal problems were the most frequent 50 (100%), followed by pneumonia 28 (56%), 4 (8%) volunteers were in physiotherapeutic treatment, and 34 (68%) had never had physical therapy. Again, only 4 (8%) received an indication for physiotherapeutic treatment by the attending physician and 10 (20%) received information from the health team. When asked if they wished to receive information about the benefits that physiotherapy could bring, 49 (98%) reported having an interest in this information. **CONCLUSION:** Individuals with sickle cell disease have no knowledge about physiotherapy and are advised about the possibility of physical therapy.

KEYWORDS: Sickle cell anemia. Information. Physiotherapy. Health Education. Rehabilitation.

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Introduction

The Sickle Cell Disease (SCD) is a common genetic disease in Brazil and its incidence has variations depending on the region, with special emphasis on the state of Bahia, due to the number of african of scendentes[1]. According to the Ministry of Health, every 650 children born in the capital Salvador, one has SCD[2].

The most aggressive SCD genotypes are FA, which occurs due to the replacement of glutamic acid by valine in the 6th position of the hemoglobin beta chain, which results in HbS (Hemoglobin S). Hemoglobin is a protein composed of four globins that contain four binding sites for oxygen. It is responsible for air Carry oxygen in the blood to the body tissues, and AF HbS, during deoxygenation, undergoes the sickling process where the amino acids are polymerized to RBC giving a more rigid aspect sickle shape. In this format, the erythrocyte loses the ability to diapedesis and can't pass through the microcirculation, causing accumulation of these erythrocytes in certain regions. These vase-occlusive events cause endothelial injury, tissue hypoxia and infarction of several tissues[3].

The clinical manifestations are varied, and because it is a chronic disease, they tend to aggravate over time, thus compromising the functioning of various organs and systems. Painful crises, respiratory distress, fever, inflammation and infectious among others consists the symptoms of patients with SCD especially the genotype SS and SC[4-5]. Co morbidities such as acute chestsyndrome, aplastic crisis, splenic sequestration, gallstones, stroke, priapism, ulcers in the lower limbs and infections are common in AF, which aggravates the clinical picture and decreases the quality of life, functionality and functional capacity[6].

The diagnosis of SCD can be performed in two ways: in the neonatal screening for HbS ("foot test"), or at a later time being detected by a laboratory examination called electrophoresis of hemoglobin. This test detects the hemoglobin type of present in the blood. Hemoglobin A is considered normal, and if other types such as S, C, D or E are detected, then hemoglobinopathy is diagnosed[1,7,8].

The treatment of SCD should be performed as soon as it is known to avoid the associated complications. Medical treatment encompasses the use of medications and administration of special vaccines that enhance the organic defenses and prevent some complications. It is important that these patients be accompanied by a multidisciplinary team aiming at a better therapeutic result. Physical therapy is one of the areas of health that have several resources that can contribute to the increase of well - being, and consequently better quality of life, functionality and functional capacity for this population[6,9].

The chronicity of the disease, the treatment is done along of life and, to be successful, both individuals with SCD as family members should be aware of the treatment options[10,11]. Although the importance and broad benefits of physiotherapeutic intervention for this population have already been discussed in the literature[12], what is observed in practice is that few individuals with SCD are enrolled in physiotherapeutic rehabilitation programs. The cause of this is unknown. Therefore, the main objective d our work is to describe the knowledge of patients with SCD (SS and SC) on physical therapy. As secondary objective to describe the referral by health professionals to physiotherapy in this population.

Methods

This is a cross-sectional and descriptive study carried out in an ambulatory of hematological diseases in the city of Salvador, Bahia. This research was submitted to the analysis of the ethics committee of HEMOBA and also by the SESAB Ethics Committee with the Certificate of Presentation for Ethical Appreciation (CAAE) of number 07656212.7.0000.0052, being approved in both institutions. Participants were guided about the purpose of the research, risks and benefits, and when they agreed to participate, they signed the informed consent form.

Individuals with a diagnosis of sickle cell disease with SS and SC genotypes of both sexes and of any age were included. Patients who didn't present cognitive acuity to answer the questionnaire or who did not

agree to participate in the study were excluded from the study.

50 subjects participated, divided into 26 (52%) women and 24 (48%) men, with the mean age of the sample being 17 ± 12 years. Regarding the genotype, 43 (86%) people with HBSS were found, and 7 (14%) presented HBSC. According to the domicile of the interviewees, 30 (60%) reside in the capital, and the others in the interior of the state. Regarding the diagnosis, 19 (38%) people were aware of the disease in the neonatal screening and 31 (62%) people only obtained the diagnosis at a later time.

A semi structured questionnaire developed by the researchers was applied in the period from May to June 2015. Information was obtained on diagnosis, treatment time, associated diseases, hospitalization, orientation by the health team, knowledge of physical therapy as treatment, physical therapy, feeling after physiotherapeutic treatment, physiotherapy time and interest in information about physical therapy treatment. The information was tabulated in absolute and relative frequency. The search used the checklist Consolidated Criteria for Reporting Qualitative Research (COREQ) to describe the project.

Results

The most frequent associated comorbid were osteoarticular and/or muscular 50(100%), pneumonia 28 (56%), and stroke 13 (26%) and cardiovascular disease 13 (26%).

Table 1. Frequency and percentage of nurses observed in the sample

Variable	Frequency (n)	Percentage (%)
Osteoarticular or muscular pains	50	100
Were Hospitalized	48	96
Pneumonia	28	56
Stroke	13	26
Cardiovascular Dysfunctions	13	26
Lower Limb Ulcer	4	11
Others	17	34

In population studied, only 4 (8%) people were sent for physical therapy, being that these people only received this referral after appearance of the complications of the stroke, which resulted in limitations in activities of daily living (ADL).

Of the 50 people interviewed, 34 (68%) never underwent physiotherapeutic treatment, and 12 (24%) performed only during hospital stay as a routine hospital protocol. Regarding guidance by the health team, only 10 (20%) received information about physical therapy as a treatment. Of interviewees, 49 (98%) showed interest in obtaining information regarding the physiotherapeutic treatment.

Table 2. Aspects on physical therapy referral and treatment

Variable	Frequency (n)	Percentage (%)
In physiotherapeutic treatment	04	08
They underwent physiotherapeutic treatment	12	24
No physical therapy treatment	34	68
Medical Indication to Physiotherapy	04	08
Health team Guidance*	10	20
Would like guidance *	49	98

*about Physical Therapy

Discussion

Responding to the motive question of this study, we observed that patients with SCD haven't knowledge about the physiotherapeutic treatment, which consequently generates a small insertion of this population in physiotherapeutic rehabilitation programs. In addition, responding to our secondary objective, we note that the referral of these patients by the health professionals who accompany them is still insufficient. Faced with these results, the question that arises is the motives that feed this reality?

One hypothesis that may be put forward to explain the results obtained is that there is no time in the protocol of care for this population to explain how physiotherapeutic rehabilitation can contribute to the improvement of quality of life and functionality. We observed that most of the patients (98%) were interested in receiving guidance on physiotherapeutic treatment, but few had access to this guidance (20%). Most of the sample population (80%) haven't knowledge of physical therapy as a treatment, because they have never been informed by the health team, and still claim they have never seen anything about media written or spoken.

Research published in the national journal, highlights the importance of health education and the need for patient empowerment with SCD on clinical and therapeutic aspects d his sickness[13]. Health servers have as primary function dealing with clinical and functional consequences of SCD, however, should not neglect their role as educators, informing their patients various possibilities of existing treatments.

Another survey conducted in Brazil points Nurses and doctors are the yields were below 75% when evaluated on the knowledge of s clinical and functional aspects that SCD entails[14]. Researchers also like to say that, indirectly, the level of knowledge presented reflects the quality of care that is provided to sickle cell patients[14]. In our research, it was not possible to evaluate the level of knowledge of the professionals involved. This would allow to be aware of how and les know about the physiotherapy performance in the SCD. However, it is the responsibility of physiotherapists, especially those working with this population to disseminate among health professionals and also to the scientific and lay community, what physiotherapy can bring to the benefit of this population.

In a study conducted by our research group, we observed that cardiologists say they do not indicate cardiac rehabilitation because they are unaware of sites or professionals working with these patients. The conclusion of this study points out that the lack of medical referral is also the responsibility of physiotherapists who rarely divulge their work[15]. The actuation of physical therapist in the multidisciplinary team in the care of sickle cell patients is essential. Being subject to the medical indication to begin the physiotherapeutic treatment. The physiotherapist should have an active role, show their knowledge and the capacity that physiotherapy has to contribute to the control of the harmful effects of this disease, providing a higher quality of survival for these patients.

Another possibility to explain the findings is that many of these patients are residents of other locations, since in their cities there are no referral centers for SCD treatment. These people depend on transportation from the city hall of their municipalities, going to the capital usually 1 to 2 times a month. Perhaps because of this, the health professionals involved in the care of this population do not offer guidance regarding physical therapy treatment, believing that there is no possibility of access to physiotherapy in their cities of origin. This could be solved with health policies that aimed quality care more broadly, that is, it was not restricted to big cities. However, we believe that even in the face of the geographical obstacle of care, these patients have the right to know about all the treatments that may bring benefits to their health.

Analyzing the educational profile of the population, we identified 49 participants (98%) self-declared literate, which exempts any justification linked to the possible difficulty of these patients to receive information about the underlying disease and available treatments.

In addition, the main complaint among the patients, in an absolute way, was the presence of osteoarticular or muscular pain, one of the main factors of disability among sickle cell patients, due to its intense and repetitive characteristics. Other studies have demonstrated s result similar, being the main clinical manifestation found and the most common cause of hospitalization[16,17]. A plausible explanation for the beginning of the painful crises would be the ischemic process generated by characteristic format of the sickle cells, however, the triggering mechanism of pain is certainly complex and heterogeneous.

SCD presents many complications, which causes the emergence of associated diseases. Among those diseases, pneumonia and stroke were the most frequent among the subjects. Research conducted in the US showed that 35% of people with SCD have been hospitalized due to recurrent pneumonia frame.18 In another study, the authors did not find the stroke between the main clinical complications and reason for hospitalization, but they emphasized the importance of this affection, since the recidivism after the first episode is high[19].

In this study, all patients who underwent physiotherapy at some time, both in the hospital and post-complications, reported being benefited with the physiotherapeutic treatment. The evolutions mentioned were: attenuation of pain, improvement in ventilation, return to ambulation and ADLs. These findings enables the social reinsertion and better quality of life for patients with reduced d hospitalization time, lower risk of hospital infection and deleterious effects of immobility. In addition to reducing costs for public coffers[5].

Conclusion

According to the results of this study, individuals with SCD don't have adequate knowledge about physical therapy and aren't properly referred for physiotherapeutic treatment by the health team.

Author contributions

Petto J and Santos ACN participated in the study design conception, data collection, search and statistical analysis of research data, interpretation of results and writing of the scientific article. Sacramento MS, Mata CS and Silva VC participated in the writing. Cordeiro ALL participated in the interpretation of the data and in the writing of the scientific article.

Competing interests

No financial, legal or political competing interests with third parties (government, commercial, private foundation, etc.) were disclosed for any aspect of the submitted work (including but not limited to grants, data monitoring board, study design, manuscript preparation, statistical analysis, etc.).

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