



Hemophilia: Health Promotion through an Interdisciplinary Dialogue between Health and Education

Hemofilia: Promoção da Saúde através de um Diálogo Interdisciplinar entre Saúde e Educação

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ABSTRACT

To identify the perceptions of professionals working in educational institutions regarding hemophilia and to formulate strategies for health education on this topic. This is quantitative-qualitative research, analyzed descriptively through the SOFTWARE MAXQDA version 18.1.1, under the content analysis strategy. A total of 40 investigated in the research, it is perceived that only 11 were able to define hemophilia, half did not know about the forms of bleeding, 27 did not know the characteristics of a bleeding and only 10 reported knowing how to act in the face of such an event, revealing lack of knowledge of the professionals of educational institutions about this health condition, who claim to have never been trained to understand the disease. This work promotes an interdisciplinary dialogue between health and education on hemophilia, in which the lack of knowledge on the theme of professionals from educational institutions and proposed health education strategies was recognized.

Keywords: Teacher Training. Health education. Child Education. Elementary and High School. Educational Inclusion.

RESUMO

Identificar a percepção dos profissionais de instituições de ensino sobre a hemofilia, e diante disso formular estratégias de educação em saúde sobre o assunto. Trata-se de pesquisa quanti-qualitativa, analisados de forma descritiva através do software MAXQDA versão 18.1.1, sob a estratégia de análise de conteúdo. Do total de 40 investigados na pesquisa, percebe-se que somente 11 conseguiram definir hemofilia, metade não sabiam sobre as formas de sangramento, 27 não sabiam as características de um sangramento e somente 10 referiam saber como agir frente a tal acontecimento, revelando desconhecimento dos profissionais de instituições de ensino sobre esta condição de saúde, que afirmam nunca terem sido capacitados para entendimento sobre a doença. Este trabalho promove um diálogo interdisciplinar entre saúde e educação sobre a hemofilia, no qual foi reconhecido a falta de conhecimento sobre o tema por profissionais de instituições de ensino e proposto estratégias de educação em saúde.

Palavras-chave: Capacitação de professores. Educação em saúde. Educação Infantil. Ensino fundamental e médio. Inclusão Educacional.

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INTRODUCTION

Hemophilia is a hereditary bleeding condition linked to sex, which can cause spontaneous bleeding or as a result of traumatic events. Clinical manifestations usually begin after the first year of life and may lead to irreversible, disabling injuries and, in some cases, death.¹

Historically, hemophilia has often been referred to as a “royal disease”, since in the 19th century, the condition affected members of the British royal family and spread to several members of European royalty due to marriages within the nobility, which spurred research in the area.²

According to the World Federation of Hemophilia, there has been a significant increase in the number of individuals with hereditary hemorrhagic coagulopathies, from 300,000 to more than 429,000 between 2000 and 2021. Among these cases, 60% correspond to Hemophilia A or B. In addition, among the almost 120 countries studied, Brazil has the fourth largest population of hemophiliacs, with more than 13,000 registered individuals, behind only India, China, and the United States of America.³ Hemophilia must be discussed at different levels of complexity with health professionals, public authorities, and civil society, with the aim of developing actions and public policies aimed at preventing serious bleeding, which can lead to irreversible injuries and death.

Hemophilia is a rare genetic condition related to the deficiency of factors VIII (Hemophilia A) and IX (Hemophilia B), which can predispose individuals to bleeding. Severe deficiency of these proteins (< 1%) can lead to spontaneous bleeding or in response to minimal trauma, with more frequent bleeding in joints, retroperitoneum, intramuscular and musculoskeletal. Such clinical manifestations generate acute hemarthrosis and chronic synovitis, affecting the quality of life and possibly leading to death.^{4,5}

Hemophilia treatment is multidisciplinary and requires constant interaction with a trained

staff to meet the demands of this population. Pharmacologically, the main treatment is replacement therapy, in which the deficient clotting factor is administered on demand and/or as prophylaxis, with the aim of stopping bleeding or preventing severe bleeding.³ However, recently, new therapies, such as the use of long-lasting factors, monoclonal antibodies, and gene therapy, have revolutionized treatment, bringing new perspectives and significant improvements in quality of life, especially in conditions of greater risk and severity, as in the case of inhibitors and even potentially curative therapies.^{3,4,7,8}

Even in the face of daily challenges considering the severity of this condition, people with hemophilia must have a life filled with opportunities in all environments, whether at home, in their community, in leisure activities, at school, or work, and therefore, knowledge and information about this condition is necessary, so that care can be provided as soon as necessary in a democratic and unrestricted way. Therefore, evidence must be given to the educational context, since children and adolescents spend a good part of their day in educational institutions. The school emerges as a differentiated space of culture and social relations that aims to contribute to the integral formation of the subject, considering them in their cognitive, affective, motor, and social aspects.⁹

Individuals with hemophilia have a distinct health condition, full of intricacies, therefore, they must benefit from the appropriate educational environment, receive them, and respect their limitations, without restricting the right to life, in its socio-cultural concept.¹⁰ For this to happen, teaching institutions and education professionals should have a good understanding of the health condition, its weaknesses, and its strengths, culminating in a relationship of mutual trust between teachers and students.¹⁰ In already diagnosed cases, the school management must be aware of the legal procedures that must be taken when this individual needs school leave due to

complications and hospitalizations that can be prolonged.^{11,12}

This study was motivated by the need to instruct and train professionals from educational institutions who, many times, are not prepared and have difficulties in relating with people who have special health conditions, in particular, individuals with hemophilia. For this, it is necessary, in the first place, to evaluate and understand the investigated reality to subsequently propose propositional interventions.

In this context, the present study was carried out and developed from the question: What do professionals from educational institutions understand about hemophilia and what is the decision-making process in the face of a hemorrhagic event (traumatic or spontaneous) in a student with hemophilia? In this way, this research aimed to identify the perception of professionals from educational institutions about hemophilia, and given that, to formulate health education strategies on this theme.

METHODOLOGY

This was a quantitative, qualitative, descriptive, exploratory study, developed between February and June 2018. The researched geographic space corresponds to a region of the Vale do São Francisco, in the state of Pernambuco, in which these students reside, encompassing the municipalities of Lagoa Grande, Cabrobó, Petrolina, Santa Maria da Boa Vista, Afrânio and Trindade, which are part of the jurisdiction of the Regional Management of Education of the Sertão do Médio São Francisco.¹³

The practical phase of the research only took place after approval by the Research Ethics Committee of the Federal University of Vale do São Francisco (UNIVASF), under opinion 2.453.622, on December 21, 2017, and fully complied with the Resolutions of the National Health Council 466/2012 and 510/2016.

Sampling was non-probabilistic, for convenience, since the quantification of subjects depended on the estimate of hemophiliacs treated at a Treating Center for Hereditary Coagulopathies (CTCH) of the University Hospital of Univasf (HU-UNIVASF) who were in kindergarten and elementary school.

Inclusion criteria were: men and/or women aged 18 years or over, who work in the public education network in the state of Pernambuco and who live in the school environment with hemophiliac children and adolescents treated at the CTCH, in Petrolina. Professionals who were away from work due to leave and/or illness were excluded.

Initially, screening on the medical records of patients followed up at this center identified how many were of school age in kindergarten and elementary school. This school stage was chosen because of the higher probability of the occurrence of bleeding events. After this identification, contacts were established with those responsible to verify which patients were attending the school. Then, visits were made to educational institutions to assess the situation of students about health conditions and identify possible learning difficulties.

Research participants were informed about the purpose of the project and were invited to participate in the study. After accepting and signing the Informed Consent, they were interviewed using a semi-structured script consisting of 9 questions, of which 4 (items 2, 4, 6, and 8) were quantitative guiding variables, with answers of YES or NO, objectively, and other 4 questions were conditioned to the previous ones (items 3, 5, 7, and 9), respectively. If the respondent said YES, items 3, 5, 7, and 9 were answered and coded as categories.

For content analysis, interview items were categorized into: concept of hemophilia (item 1), perception of forms of bleeding in a hemophiliac (item 3), perception of bleeding characteristics in hemophilia (item 5), intervention in cases

of bleeding (item 7) and training on health conditions in educational institutions (item 9).

Data obtained by the interview using the semi-structured script were qualitatively and descriptively analyzed, in which the objective questions were translated and expressed in numbers and percentages, and the subjective questions were qualitatively analyzed, in the MAXQDA 18.1.1 software and interpreted by the content analysis method.

RESULTS

Up to the time of sample selection, the CTCH follow-up on 34 patients with hemophilia showed that all were male, aged between 02 and 82 years, of which 20 were of school age for basic education.

The contact with those responsible identified 11 patients served by this center that were active in the school phase of kindergarten and elementary school, while 6 were in high school. Also, identified that 2 children were not enrolled in schools because those responsible were afraid that the professionals would not know how to deal with the health condition of their children. Furthermore, one child was enrolled in a private educational institution. The present investigation focused on the school-age population of kindergarten and elementary school, considering the greater vulnerability of these individuals to the occurrence of bleeding events.

The number of 11 students was the initial basis for selecting 10 institutions to be visited, as 02 children studied at the same school. Visits were made to educational institutions for interviews with professionals, 05 of which were located in Petrolina, 02 in Lagoa Grande, and 01 in each of the following cities: Cabrobó, Santa Maria da Boa Vista, and Trindade.

A total of 40 individuals agreed to participate in the research, composing a sample

made up of different professionals, which included the institution's manager, coordinator, teacher, cook, general service assistant, and doormen. The decision to include different professionals from educational institutions brings a broader view of this group regarding the same topic (principle of homogeneity), ensuring a more representative narrative.^{14,15} The sample was intentionally diverse, allowing for a global and greater representativeness, since part of these is also inserted in the sociocultural context of families affected by hemophilia, bringing an epistemic perspective.^{14,15}

The results of the interview showed that in the category "concept of hemophilia" (item 1), 17 out of the 40 interviewees did not know how to define and had no idea what hemophilia is; 12 had some notion, as family members tried to explain it at the time of enrollment (n=5) or deduced by the prefix 'hemo' (n=7) that it would have something to do with blood. The remaining 11 were those who were able to define hemophilia: "... Hereditary, it affects only men, it is a blood issue and blood does not clot... (Teacher - School 01)". "Blood does not clot... (Pedagogical Coordinator – School 07)". "...Children who cut themselves have bleeding, need medication to stop bleeding... (Manager - School 07)".

When asked if they knew how a child with hemophilia could bleed, half of the population did not know (50%) in item 2. Thus, the category referring to the perception of forms of bleeding (item 3) showed that the 50% who answered affirmatively in item 2, described: "...it can be due to external or internal cuts and bumps...(Manager - School 02)". "...Tooth extraction, bumps... (Teacher – School 09)". "...at the top, it could be due to an injury or bump, it could cause internal bleeding...(Teacher - School 02)". Correlating these results with item 1, of the professionals who somehow knew how to define the disease, only twenty described how the bleeding occurred, highlighting the need for greater interaction on the subject.

The item that corresponds to variable 4, about perception regarding the characteristics of bleeding, revealed that 67.5% (n=27) respondents did not know, and those who described something in item 5 associated bleeding only when there is external visibility: "...with blood exposure... (Teacher – School 10)", "...where the blood comes from... (Manager - School 05)", "...when you see bleeding... (Physical Education Teacher – School 01)".

When asked about what to do in cases of bleeding in item 6, only 10 reported knowing how to act in such a situation, and even so none of the answers were fully complete in item 7: "...Using ice... (Professor of Physical Education – School 01)", "...Call the mother to make arrangements, in an eventuality, I washed it with cold saline solution and applied cotton... (Manager - School 02)", "...Call the parents to take them to the hospital... (Pedagogical Coordinator)", "... Take immediately to the hospital and the parents have the medicine... (Teacher - School 10)".

Regarding the last category (items 8 and 9), which concerns training on the health condition, the negative answer was unanimous. Given this answer, when asked what should be done to better spread the issue, everyone emphasized the importance of health education, training, and lectures on the subject.

DISCUSSION

Of the total of 40 investigated, only 11 were able to define hemophilia, half did not know about the forms of bleeding, 27 did not know the characteristics of bleeding and 10 reported knowing how to act in the face of such an event, revealing the lack of knowledge of professionals in education institutions about this health condition, who say they have never been trained to understand hemophilia.

The Ministry of Health recognizes that education about hemophilia should not only be

for patients with hemophilia, but also everyone involved in their life cycle, such as family members, caregivers, and educational institutions, and it is essential to provide adequate knowledge about the disease to quickly identify the signs and symptoms of bleeding so that in this way, they can proceed with the appropriate treatment as soon as possible.¹¹

Trained and qualified professionals are necessary to deal with individuals with hemophilia in the educational context, since adequate assistance, which consists of early recognition of hemorrhages and correct referral to the necessary emergency care, can prevent a series of injuries and complications, in addition to providing hemophiliac students with a safe school environment where they can develop.¹⁶

Bleeding in hemophilia varies according to the severity and occurs as follows: when hemophilia is mild (> 5% circulating clotting factor), bleeding correlates with greater hemostatic challenges (such as polytrauma, blunt cut injuries) or surgeries; in moderate hemophilia (<5% and >1% clotting factor), bleeds are associated with less severe trauma or a surgical procedure; on the other hand, when hemophilia is severe, bleeding of various types (intra-articular, intramuscular, retroperitoneal, central nervous system and others) may occur spontaneously, as the latter is associated with less than 1% activity of the clotting factor.^{8,17,18}

As mentioned, hemorrhagic manifestations in patients with hemophilia are very heterogeneous, but predominate in the osteoarticular regions, mainly in the knee, elbow, and ankle joints, which in general cause a lot of discomforts, arthralgias and, consequently, school absenteeism. In addition, bleeding can occur in anatomical regions that are more difficult for a non-specialized professional to identify, leading to risks to the health of this child. Considering all the peculiarities of educational institutions in the country, with their capacity, educational demands, and heterogeneous public, it becomes

challenging for educators and professionals of these institutions to identify these problems, intervene early and even prevent them.^{9,11,16,19}

When bleeding is identified, some steps must be followed: if there is edema, pain, and/or discomfort, apply and keep an ice pack on the affected area; if there is visible bleeding, keep the place pressed with a clean compress; never administer medication containing acetylsalicylic acid or other antiplatelet agents or non-hormonal anti-inflammatories, unless recommended and monitored by a specialist; wait for the parents, as they usually have the dose of the factor at home and can apply it to stop the bleeding.¹⁰

Early identification of bleeding in this population is essential to minimize damage and reduce the risk of sequelae and injuries. Therefore, in a school environment, a careful look to identify it early and appropriately treat it can prevent bleeding from lasting and causing organic and psychological-social damage.¹⁸⁻²⁰

The suppressive behavior of society towards these families is notorious, but it is not known whether the origin of this problem lies in misinformation, poor training of teachers, educators, civil society, or even the neglect of government offices and public power. In any case, this 'behavioral rhetoric' generates the invisibility of this portion of citizens, in an exclusionary narrative, of distrust and fear.

In this educational context, the literature is scarce and characterizes critical levels of misinformation by types of professionals. However, reports and content analysis have pointed to a greater difficulty among Physical Education professionals, who often, when they do not respect the peculiarities of these individuals, "overprotect" them, not contributing to their insertion in society.²¹ Therefore, when it comes to hemophilia, professionals from educational institutions should be trained and guided about the health condition, with emphasis on identifying bleeding, which is potentially serious, and how the initial approach should be.

The inclusive educational environment goes beyond opening vacancies for people with specific needs, it is necessary to think beyond the disciplinary program and provide professionals from educational institutions with conditions so that they can understand the disease and conduct their educational practices without prejudice to the student, stimulating their maximum potential and allowing participation in activities.¹⁶

The National Education Plan provides that systems and schools must provide conditions for the ordinary classroom teacher to explore and stimulate the potential of all students and that they must observe some guidelines, among them, the training of teachers for educational specialized assistance and the development of inclusive educational practices.²⁰

In addition to the need for teacher training, schools need to be inclusive to serve everyone. According to the Salamanca Declaration in 1994, the fundamental principle of inclusive schools is that all students must learn together, whenever possible, regardless of the difficulties and differences they present, where these inclusive schools must recognize and meet the diverse needs of their students to guarantee a good level of education for all.²²

As detailed before, the student with hemophilia is like any other student who goes to school to feel part of it, interacting and participating in all pedagogical activities. However, hemophiliacs require special attention when it comes to health and preventive care within the school environment. For this, the school, as a partner of the family, takes on the role of making everyone aware of the disease, in an informative, preventive, and demystifying way, avoiding doubts, risks, and, above all, prejudices.²¹

In this sense, teachers have to be aware of pedagogical activities that do not compromise the health of students with hemophilia. There must be a relationship of trust between teacher and student, ensuring assistance in the preventive sense and guaranteeing educational development.

Getting to know the student with hemophilia is to signal to everyone who is part of the school environment that the student can and should participate in all curricular and extracurricular activities.

Thus, under the aegis of inclusive education and society, investments in information, knowledge, and open discussions with the actors involved in these social relations are necessary, to identify risk factors within the school environment. In addition, the teacher's careful look at the student must be preventive, avoiding strong impacts on the body, as can occur during recreational activities, without, however, isolating the student from this socialization process.

The school can also propose in the school planning, pedagogical activities written with themes about hemophilia, and presentations and groups. These actions contribute to demystifying the disease and strengthen ties between students, teachers, parents, and employees, providing an education based on the heterogeneity of being, inclusive and accessible to all.

This study has limitations, as it is restricted to a limited number of schools and uses a written semi-structured questionnaire as a data collection instrument, which limits the narratives and, in a way, compromises the more subjective analysis of the content, according to the principle of exhaustiveness. Nevertheless, as a scientific method, it brings an unprecedented structured diagnosis of deficiencies and gaps in education for the inclusion of this population.

Such a diagnosis should serve as a basis for proposing public policies for insertion and integralization, using continuing education tools, such as lectures, workshops, instructional material, and conversation circles. Several fundamental topics must be addressed, such as the recognition of a hemorrhage, the measures to be taken when there is bleeding, which professionals are able and involved to better serve them and where to find them, the insertion of the child in their environment social life, in addition

to the fears and challenges faced by parents and family members.

CONCLUSION

This work promotes an interdisciplinary dialogue between health and education about hemophilia. The lack of knowledge on the subject by professionals from educational institutions was recognized, and health education strategies were proposed, including incentives for training and interventions in the school environment. This will positively influence the safety, health, and well-being of hemophiliacs, promoting the educational inclusion of children and adolescents

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