ORIGINAL ARTICLE

Educators' knowledge about sickle cell disease in the public schools of Montes Claros – MG

Conhecimento de educadores sobre doença falciforme nas escolas públicas de Montes Claros – MG

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ABSTRACT

This cross-sectional, quantitative and descriptive study assessed the level of information about sickle cell disease among educators in the public schools of Montes in which there are students with the SS homozygous subtype (sickle cell anemia). There were 136 educators in the research, 94.9% of them teachers, 2.9% principals and 1.5% supervisors We found that 67.6% had no knowledge there were enrolled students with sickle cell disease, 83.1% had heard of sickle cell disease, 47.8% classified it as an hereditary disease, 39% related it to nutrient defficiency, 64.7% could not differentiate between sickle cell disease and sickle cell traits, 65.4% had no information on symptoms, and 95.6% had no knowledge of the Teacher's Manual on sickle cell disease distributed by the Brazilian Health Surveillance Agency (ANVISA). Educators were unaware of the presence of students with sickle cell disease in the school, thus demonstrating the need for health education actions to promote better care for these students.

Key words: Anemia, Sickle Cell; Health Education; Students.

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RESUMO

Este estudo transversal, quantitativo e descritivo, avaliou o grau de informação de educadores da rede pública de Montes Claros sobre a doença falciforme, em escolas que possuíam aluno(s) com o subtipo homozigótico SS (anemia falciforme). Participaram da pesquisa 136 educadores, sendo 94,9% professores, 2,9% diretores e 1,5% supervisores. Verificou-se que 67,6% desconheciam alunos matriculados com anemia falciforme, 83,1% já tinham ouvido falar sobre anemia falciforme, 47,8% a classificaram como doença hereditária, 39% como devido à falta de nutrientes, 64,7% não sabiam a diferença entre anemia e traço falciforme, 65,4% desconheciam sua sintomatologia e 95,6% desconheciam a existência do Manual do Professor, da ANVISA, sobre doença falciforme. Constatou-se desconhecimento dos educadores sobre a existência de alunos com doença falciforme na escola, o que demonstra a necessidade de promover educação em saúde para melhor assistência a esses alunos.

Palavras-chave: Anemia Falciforme; Educação em Saúde; Estudantes..

INTRODUCTION

Sickle-cell anemia is one of the most frequent hemoglobinopathies in the world. It is the result of an autosomal recessive genetic disorder stemming from to a defect in hemoglobin (Hb) structure, associated or not with a synthesis alteration. The mutation determines the substitution of the glutamic amino acid for valine at posi-

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tion six of the hemoglobin's beta chain, resulting in the formation of an abnormal hemoglobin S (HbS) instead of the normal A (HbA).[1]

Sickle-cell disease is known as the group of all the symptomatic forms of the HbS gene, either in homozygosity or in combination. The HbS gene can be combined with other inherited hemoglobin disorders, such as hemoglobin C (HbC), hemoglobin D (HbD), beta-thalassemia, among others, generating symptomatic combinations, denominated, respectively, hemoglobinopathies SC, SD, S/beta-thalassemia.[2]

Sickle-cell anemia is characterized by a modification in the structure of the red blood cells, which take the shape of a sickle under conditions of low oxygen tension. The sickling of the red blood cells is responsible for obstructing blood vessels, leading to pain crisis, heart attack and necrosis of important organs.[2]

Some genetic characteristics greatly affect the clinical gravity of the disease because they modulate the intracellular concentration of HbS. However, environmental factors are as important as the genetic variations and are also responsible for clinical variability and prognostic. Socioeconomic and educational levels are major factors for they directly influence the disease's evolution and prognostic, be it because of access to medical care, early diagnosis, quality nourishment and nutrition, access to sanitation, less exposure to infections, better conditions of life and work, and prompt treatment of complications.[3]

Some factors may cause high stress levels among carriers of sickle-cell anemia, for instance, work, intense exercise, anorexia, pregnancy, increase of osmotic concentration, low pH levels, conditions of low oxygen tension, infection, emotional stress, decrease in body or room temperature, and anesthesia.[4]

Sickle-cell anemia influences the growth and development of children and teenagers as school performance is affected by frequent hospital admissions, absence at school, subclinical brain lesions caused by repeated episodes of vascular occlusion, besides its more frequent association with a precarious social economic situation.[4]

The Associação Baiana das Pessoas com Doença Falciforme (ABDFAL), an association for persons with sickle cell disease in Northeastern Brazil, cites the crucial role of schools in being aware of the particularities concerning the growth and development of children with sickle-cell disease, the importance of their always ingesting liquids and, for this reason, that their requests to leave the classroom to go to the toilet be understood as natural.[5]

Physical Education teachers must be informed that students with sickle-cell disease should avoid overexerting physical activity in respect of their limits and of their need to keep hydrated during the practice of any exercise.[6]

Children with sickle-cell anemia must be enrolled in schools as any other children unless there are specific reasons for not doing so. It is important that parents notify the teachers and principals of their children's clinical condition and encourage them to study and stay in school when occasional incidents occur.

The Hemocentro Regional de Montes Claros/ Fundação Hemominas plays a pivotal role in the north of the state f Minas Gerais in delivering ambulatory care service to carriers of hemoglobinopathies and coagulopathies, with 2,250 registered carriers of sickle-cell diseases. Moreover, it also cares for patients that need blood transfusions and blood-letting.

This study aimed to evaluate the awareness about sickle-cell disease subtype SS (sickle-cell anemia) among education professionals: principals, supervisors, and teachers at public schools in Montes Claros, Minas Gerais, where students with this hemoglobinopathy were enrolled.

METHODOLOGY

This is a cross-sectional, quantitative, and descriptive study carried out with educators in public schools in the municipality of Montes Claros, MG, where students with sickle-cell disease were enrolled.

Children and teenagers with sickle-cell disease, with their respective subtypes SS, SC, S/beta-thalassemia, registered in the outpatient clinic at the Homocentro Regional de Montes Claros, had their diagnosis made by the Minas Gerais State Triage Program (PETN-MG), implemented in 1998. The test used to characterize them according to hemoglobinopathy subtype was electrophoresis of red blood cells. For this research, only students with SS homozygous sickle-cell disease (sickle-cell anemia), the most symptomatic form of the sickle-cell disease, were analyzed. Research was done later with the educators in schools where these students were enrolled, to a total of 6,714 currently enrolled and active students, aged between 8 to 18 years old.

The schools were selected based on the results of the research entitled "Perfil Educacional dos pacientes com anemia falciforme atendidos no ambulatório

do Hemocentro Regional de Montes Claros – Fundação Hemominas", on the educational profile of patients with sickle-cell anemia carried out in 2010.[1]

All public schools that had students with SS homozygous sickle-cell disease (sickle-cell anemia), in school age, enrolled and attending class during the year of 2010 were surveyed, totaling nine institutions. Data collection was done with educators: principals, supervisors, and teachers, in the period of August to December 2011.

Data were collected in nine public schools, and 136 educators agreed to participate in the survey, including principals, supervisors, and teachers. The profiles of these educators included the following variables: professional field, gender, age, and how long they had been working in the schools (Table 1). The educators' general knowledge about sickle-cell anemia (Table 2) was analyzed based on a questionnaire with the following variables: whether they had ever heard of sickle-cell anemia, knew the difference between sickle-cell anemia and sickle-cell trait, and knew what the symptoms of anemia were.

The professionals that agreed to participate in the research signed the Free and Informed Consent Form and answered the questionnaire to evaluate their knowledge about sickle-cell anemia and about the sickle-cell disease teacher's manual edited by the National Sanitation Agency, ANVISA.

Table 1 - Profile of the participants of the research

Professional	Number	Percentage %
Principal	4	2.9
Supervisor	2	1.5
Teacher	129	94.9
Did not answer	1	0.7
Gender		
Female	121	89.0
Male	14	10.3
Did not answer	1	0.7
Age		
18 to 30 years	11	8.1
31 to 40 years	44	32.4
41 to 50 years	42	30.9
Above 51 years	36	26.5
Did not answer	3	2.2
Period they have been working at the school		
Less than a year	11	8.1
1 year	6	4.4
2 to 5 years	30	22.1
More than 5 years	88	64.7
Did not answer	1	0.7
Total	**136**	**100.0**

Table 2 - The educators' general knowledge about sickle-cell disease

Had already heard about sickle-cell disease	Educators (n)	%
Yes	113	83.1
No	22	16.2
Did not answer	1	0.7
How the educator classified sickle-cell disease	**Educators (n)**	**%**
Infecto-contagious	2	1.5
Hereditary	65	47.8
Due to lack of nutrients (vitamins deficiency)	53	39.0
Did not answer	16	11.8
Is there a difference between sickle-cell disease and trait	**Educators (n)**	**%**
Yes	41	30.1
No	88	64.7
Did not answer	7	5.1
Knowledge about the sickle-cell disease symptomatology	**Educators (n)**	**%**
Yes	35	25.7
No	89	65.4
Did not answer	12	8.8
Total	**136**	**100.0**

A bivariate analysis was conducted to assess the educators' knowledge about sickle-cell anemia and the presence of currently enrolled students with sickle-cell anemia between 2010 and 2011 attending the schools where these educators worked (Table 3).

The collected data were tabulated and presented as a group, with the descriptive statistical analysis with simple and relative frequency made using the software Statistical Package for Social Sciences (SPSS), version 18.0. The information was presented as a group thus preserving the participants' anonymity.

This study was approved by the Ethical Committee of the Universidade Estadual de Montes Claros (UNIMONTES) under the number 3.087/11.

RESULTS

We observed that 83.1% of the educators had already heard about sickle-cell anemia, 47.8% considered it hereditary, 39% associated it to lack of nutrients, 64.7% did not know the difference between sickle-cell anemia and sickle-cell trait, and 65.4% were unaware of its symptoms. We verified that 67.6% did not know that there were students with sickle-cell disease subtype SS (sickle-cell anemia) enrolled in the schools at which they worked.

More than half the answers conveyed lack of knowledge about clinical manifestations (Table 4) and in more than 95% of the times (Table 5) educators were unaware of that specific manual for teacher orientation regarding sickle-cell disease edited by ANVISA was available.

Table 3 - Educators' knowledge about sickle cell anemia versus knowledge about the existence of students with sickle cell anemia enrolled and attending the school

Educator knew or had already heard about sickle-cell disease	Knowledge about the existence of student with sickle cell anemia enrolled and attending schools			Total
	Yes	No	Did not answer	
No	37 (27.20%)	74 (54.41%)	2 (1.47%)	113 (83.08%)
Did not answer	3 (2.20%)	18 (13.23%)	1 (0.73%)	22 (16.17%)
Total	0 (0%)	0 (0%)	1 (0.73%)	1 (0.73%)
Total	**40 (29,41%)**	**92 (67,64%)**	**4 (2,94%)**	**136 (100%)**

Table 4 - Knowledge about the clinical manifestations of sickle-cell disease

Patient with sickle-cell disease can perform physical exercises	Educators (n)	%
Always	6	4.4
As indicated by the doctor	66	48.5
With restrictions	43	31.6
Never	5	3.7
Did not answer	16	11.8
Patients with sickle-cell disease need to go to the toilet	**Educadores (n)**	**%**
More often than the other students	56	41.2
As often as the other students	39	28.7
Less often than the other students	14	10.3
Did not answer	27	19.9
Sexual development and growth of students with sickle-cell disease	**Educadores (n)**	**%**
Better than the others	4	2.9
Similar to the others	48	35.3
Worse than the others	56	41.2
Did not answer	28	20.6
In case of pain, the student with sickle-cell disease should	**Educadores (n)**	**%**
I do not know	70	51.5
Rest, do not ingest liquid and be medicated	11	8.1
Stand, do not ingest liquid and not be medicated	1	0.7
Rest, ingest liquid and be medicated	42	30.9
Did not answer	12	8.8
Total	*136*	*100.0*

Table 5 - Educator's knowledge about sickle cell anemia versus knowledge about Teacher's Manual: Sickle-Cell Disease, by ANVISA

Do you know or have already heard about sickle-cell anemia	Do you know about the Teacher's Manual: Sickle-Cell Disease, by ANVISA			Total
	Yes	No	Did not answer	
Yes	4 (2.94%)	107 (78.67%)	2 (1.47%)	113 (86.2%)
No	0 (0%)	22 (16.17%)	0 (0%)	22 (16.17%)
Did not answer	0 (0%)	1 (0.73%)	0 (0%)	1 (0.73%)
Total	**4 (2.94%)**	**130 (95.58%)**	**2 (1.47%)**	**136 (100%)**

DISCUSSION

Awareness of students with sickle-cell disease SS (sickle-cell anemia) enrolled in their schools and the clinical characteristics that interfere with their behavior is of great value for educators in order to secure better assistance and proper educational development for these students. Educators have a fundamental role in this development given that they remain in direct contact with the carrier of sickle-cell disease for extended periods of time.

Teachers who know about sickle-cell disease are capable of adopting measures to help to prevent crises, recognize signals and early symptoms, and to secure the support to students affected by this disease, for the student's own safety, care and collective support actions for students and teachers.[7]

Attendance and regular participation in school is essential to the social and educational development of children with sickle-cell disease, as well as for their psychosocial well being. The school environment and experiences and the social relations with other children and adults are of critical importance in promoting autonomy and development of identity.[8]

It was observed in this study that 54.4% of the educators who had heard of sickle-cell disease were unaware of the presence of such students enrolled and attending their schools in the years of 2010 and 2011. Koontz et al. demonstrated similar lack of knowledge in their study, which is worrying due to the absence of a link between knowledge and reality.

It is common to find that doctors, carergivers, and parents of children with sickle-cell anemia do not give the school professionals detailed information about the disease.[7] Mukherjee et al.[9] demonstrate the importance and difficulty in obtaining information about health condition of students with chronic diseases. Educators can only identify students with sickle-cell disease, and duly care for them as prescribed by the ANVISA Teacher's Manual: sickle-cell disease if parents inform these educators of their children's condition. Educators can thus call families in situations of clinical need, implement special conducts for children with sickle-cell disease, such as ingesting more liquid and going to the toilet more frequently, restrict intense physical activity, and intervene favorably in the relationship between the student and the other classmates.

The parents are important in this bridge between educators and physicians, since they know the their children's needs and can request more educational assistance if needed. They are also able to measure the specific needs of children with sickle-cell disease in the school environment.

Teacher orientation manuals should be made better known, as well as medical reports, in pertinent cases and with the due consent of the patient or parents (or legal guardians). These can be efficient measures to help educators faced with the diverse situations experienced in schools.

Among the surveyed educators, 83.1% had already heard of sickle-cell anemia, the majority of which classified it as a hereditary disease (47.8%). However, a significant portion (39%) wrongly defined it as a nutritional deficiency.

The majority of the educators (64.7%) could not distinguish between sickle-cell trait and disease itself. Carriers of sickle-cell traits do not present anemia or hemolysis and, because of that, must be distinguished from students with the disease.[4]

Among the educators that answered the questionnaire, 65.4% did not know the symptoms of sickle-cell anemia. It was observed that 80.1% of the educators stated that the person with sickle-cell anemia can do physical activities with restrictions (31.6%) and following the doctor's instructions (48.5%). Many educators, therefore, believe that a doctor must authorize students with sickle-cell disease before they can engage in physical activities. However, there is no need for this report to be formal. These students should only

avoid activities that demand intense physical effort as this can precipitate a sickle-cell crisis. They can and should engage in light, moderate physical activities that permit interaction with the other classmates.[10] The teacher must also be advised to make sure that carriers of sickle-cell disease are not exposed to the cold after swimming and that they rest whenever tired.[11]

The majority of the educators (41.2%) stated that the people with sickle-cell anemia need to go to the toilet more often than the others. Teachers must allow them to go to the toilet more regularly than the other children because of their higher ingestion of liquid due to hyposthenuria.[11] It was recorded, however, that a significant percentage of the educators (19.9%) did not answer this question, showing their lack of knowledge on this subject.

The chronic condition of the sickle-cell disease can justify complaints of tiredness, apathy, and lack of concentration in school activities, which requires more attention from teachers and other educators to the carriers' clinical condition, so as to avoid unduly labeling of them as lazy, inattentive and undisciplined.

Analysis of the educators' answers in relation to sexual and statural growth of students with sickle-cell anemia detected that, even though many answered that there is a developmental delay in in relation to other students (41.2%), these educators show a certain lack of knowledge of this subject as 35.3% answered that they have similar development as the other students. Approximately 52.9% of the educators reported that the eye color of people with sickle-cell anemia is yellowish. However, a great number did not know (28.7%) or did not answer (9.6%) this question. Jaundice and low stature are typical effects of the disease and it is not uncommon for these differences to be noticed among the students, especially after the start of puberty.[12]

Among the educators, 87.5% did not know how to proceed in case of a pain crisis in people with sickle-cell anemia. Pain crises or other clinical complications can harm the education of carriers of sickle-cell disease.[10] The correct action in these cases is to recommend rest, ingestion of liquids, and analgesia.[4] Intense pain is a characteristic of sickle-cell anemia, and it is chronic throughout life, with intermittent worsening periods that cause great discomfort to many young people with this hemoglobinopathy, including during their time in school.[13,14] Generally, children with sickle-cell anemia during pain crises are not taken seriously by teachers, who tend to interpret the chronic pain as psychological, and not consider it as having a physical origin.[15] Positive attitudes by the teachers and classmates in treating the pain make the condition of the carrier of sickle-cell anemia easier.[16]

Children with sickle-cell anemia can have fatal complications, for instance, cerebral vascular accidents. School professionals must be aware of these clinical repercussions and of how to proceed when faced with them.[7]

Only 2.9% of the researched educators had already heard about sickle-cell anemia and knew about the *Teacher's Manual: Sickle-cell Disease*, by ANVISA (2002). This manual highlights that the teacher can contribute to the keeping students with sickle-cell disease healthier by observing some symptoms of the disease such as tiredness, apathy and pallor, and alerting the family for the need of medical evaluation and even hospital care. In case the student presents joint or lumbar pain, he or she must be allowed to lie down, ingest liquids and even be medicated using painkillers prescribed by her or his doctor. The student must be urgently taken to the hospital in case there is high fever. It is necessary, however, to promote more awareness of these manuals in schools.

Society in general is significantly uninformed about sickle-cell anemia, and educators are no different. In this sense, acting in the school environment by establishing strategies of health education for these professionals and improving the health assistance given by them are important challenges that can directly affect clinical evolution. In the school environment, "caring" educators need to pay attention to the minimal clinical manifestations of the disease, informing families of any signs of alteration in the students or referring them to medical care in case there are relevant clinical alterations.

Correct assistance to students with sickle-cell disease is essential for them to experience quality of life, social integration and learning opportunities similar to those of other students, allowing them to develop academically and to have better job opportunities.

CONCLUSION

There are few studies related to educators' knowledge about sickle-cell disease in the medical literature. Most studies approach cellular alteration and clinical manifestations of the disease. Few publications approach sickle-cell disease carriers within the social and school environments and refer to the

knowledge of educators in assisting the student with sickle-cell disease. The *Teacher's Manual: Sickle-cell Disease*, by ANVISA, reports that students spend more time with teachers in school than with doctors in the hospital, and that is these this professionals' help can greatly minimize the problems caused by the sickle-cell disease, especially the SS homozygous type (sickle-cell anemia). Thus it is possible for the child with sickle-cell disease to be respected, develop her or his potential in school and become a productive adult and valuable member of society.

COLLABORATORS

V.Q.O. Maia, J.P.S. Bispo and E.V.R. Urias worked in the conception, methodology, analysis and data intepretation and final drafting. M.H. Brandão worked in the conception and methodology and L.F. Teles worked in the final drafting of the article.

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