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KNOWLEDGE OF NURSES ABOUT CHILDREN WITH SICKLE CELL DISEASE

CONHECIMENTO DE ENFEMEIRAS SOBRE A CRIANÇA COM DOENÇA FALCIFORME

CONOCIMIENTO DE ENFEMEIRAS SOBRE EL NIÑO CON ENFERMEDAD FALCIFORME

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Objective: to know the perception of nurses about the child with sickle cell disease. Method: qualitative Convergent-Care research, occurred in a public pediatric hospital, in which 12 emergency nurses participated from July 2020 to April 2021, after submission to the Ethics Committee. The data collection techniques were: survey of knowledge by semi-structured interview, convergence groups and participant observation. The data were analyzed according to the referential of the Convergent-Care Research and its phases, being them conception, instrumentalization, theorization, transfer and analysis. Results: the nurses recognized the disease by the main clinical manifestation, the pain crisis, which was cited as a striking characteristic of the child with sickle cell disease. Final considerations: the nurses working in the pediatric emergency know some aspects of sickle cell disease and revealed incipient knowledge about the pathophysiology of the disease.

Descriptors: Sickle cell anemia. Emergency Hospital Service. Pediatrics. Nursing. Knowledge.

Objetivo: conhecer a percepção das enfermeiras sobre a criança com doença falciforme. Método: pesquisa qualitativa Convergente-Assistencial, ocorrida em hospital público pediátrico, da qual participaram 12 enfermeiras da emergência no período de julho de 2020 a abril de 2021, após submissão ao Comitê de Ética. As técnicas de coleta de dados foram: sondagem do conhecimento por entrevista semiestruturada, grupos de convergência e observação participante. Os dados foram analisados conforme referencial da Pesquisa Convergente-Assistencial e suas fases, sendo elas concepção, instrumentalização, teorização, transferência e análise. Resultados: as enfermeiras reconheceram a doença pela principal manifestação clínica, a crise álgica, a qual foi citada como característica marcante da

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criança com doença falciforme. Considerações finais: as enfermeiras atuantes na emergência pediátrica conhecem alguns aspectos da doença falciforme e revelaram conhecimento incipiente sobre a fisiopatologia da doença.

Descritores: Anemia Falciforme. Serviço Hospitalar de Emergência. Pediatria. Enfermagem. Conhecimento.

Objetivo: conocer la percepción de las enfermeras sobre el niño con enfermedad falciforme. Método: Investigación cualitativa Convergente-Asistencial, ocurrida en hospital público pediátrico, de la cual participaron 12 enfermeras de la emergencia en el período de julio de 2020 a abril de 2021, tras sumisión al Comité de Ética. Las técnicas de recolección de datos fueron: sondeo del conocimiento por entrevista semiestructurada, grupos de convergencia y observación participante. Los datos fueron analizados conforme referencial de la Investigación Convergente-Asistencial y sus fases, siendo ellas concepción, instrumentalización, teorización, transferencia y análisis. Resultados: las enfermeras reconocieron la enfermedad por la principal manifestación clínica, la crisis álgica, la cual fue citada como característica distintiva del niño con enfermedad falciforme. Consideraciones finales: las enfermeras que actúan en la emergencia pediátrica conocen algunos aspectos de la enfermedad falciforme y revelaron conocimiento incipiente sobre la fisiopatología de la enfermedad.

Descriptores: Anemia Falciforme. Servicio Hospitalario de Emergencia. Pediatría. Enfermería. Conocimiento.

Introduction

Sickle cell disease (SCD) is one of the most frequent genetic alterations in Brazil and in the world, comprising a group of congenital hemolytic anemias characterized by the presence of hemoglobin S (Hbs), predominant among Afro-descendants[1].

The presence of the Hbs mutation predisposes hemoglobin to polymerization and damages the erythrocyte membrane, which assumes the aspect of sickle with reduced shelf life and results in hemolytic anemia, with painful vaso-occlusive manifestations, ischemic endothelial dysfunction and chronic inflammatory response[2].

These manifestations begin in childhood acutely and are perpetuated throughout life, which shows the relevance in the development of studies and strategies for people living with sickle cell disease.

At the level of care of the Urgency and Emergency Network, there is assistance to acute clinical complications. It is understood that the professionals of the intermediate levels of health care are unaware or ignore the disease that brings SCD within the lines of care, such as lack of information, being one of the main causes of inadequate care. Therefore, it is essential that health professionals are prepared to assist this public[3].

Therefore, the non-recognition of clinical signs of risk implies the limitation of the professional in assessing the care needs directed to this patient with sickle cell disease, which hinders the planning of a quality care to avoid complications, as well as to reduce mortality. Thus, the objective of this study was to know the perception of nurses about the child with sickle cell disease, given the gap in the literature on the subject.

This article is part of the master's research about the construction of a nursing care protocol to the child with sickle cell disease in the emergency, in which the object of study was the nursing care to the child with sickle cell disease in the emergency.

Method

This is an exploratory, descriptive, qualitative study of the convergent-care type, whose main characteristic is the intentional articulation of the research with the care practice, whose design presents a methodological character of proximity and distancing from the care know-how, which allows reciprocal exchanges of information throughout both processes[4].

The research took place in a public pediatric hospital in inland Bahia, in which 12 emergency

nurses participated, whose data were collected between July 2020 and April 2021. During the collection period, 22 nurses composed the staff of pediatric emergency professionals. The inclusion criteria of the purposeful sample were: to integrate the nursing team for at least six months in the urgency and emergency sector (considering this time as the minimum to have experienced the context of the emergency and, possibly, some child with SCD), to agree to participate in the research by reading and signing the Informed Consent Form (ICF).

The exclusion criteria were: being on health leave or vacation and/or absent from the sector in the period of data collection. Of the nurses who met the inclusion criteria, all received the invitation to participate, because the purpose was to reach the maximum number of participants. These, in turn, accepted until the end of the stages of research, thus there was no withdrawal.

The data collection techniques were: survey of knowledge through semi-structured interviews, convergence groups (CG) and participant observation. The data were analyzed according to the Convergent Care Research (CCR), as well as the following methodological trajectory: phases of conception, instrumentalization, theorization, transfer and analysis.

Regarding ethical aspects, all stages of this research were developed according to the criteria of Resolution n. 466/2012, which regulates the principles of bioethics[5]. Thus, it was submitted and approved by the Research Ethics Committee (REC) of the State University of Feira de Santana. After the approval of the REC, the study proposal was clarified to the possible participants of the research through the ICF.

When considering the involvement of the researcher as a nurse in the field, it is emphasized that, during the data collection and later stages of the research, the researcher was not working in the emergency sector and, at the end of the research, therefore, ethical principles were maintained at all times.

In conjunction with the coordination of the emergency and sector of permanent education and research, a previous scale was elaborated with the dates, name of the possible participants and times established for the interviews.

Moreover, the nurses received a virtual message from the researcher, with a brief presentation about the research and the beginning of the data collection, making them aware that they would be called to the interviews.

In the first stage of data collection – interview – participants chose random fictitious names that were not part of the emergency team, to maintain identity secrecy, with subsequent collection of sociodemographic data. The interviews were recorded in order to preserve the reliability of the data collected, and the participants were always asked if they wanted to hear the content or modify something in the speeches, however, no modification was requested by any of the interviewees.

The interviews lasted on average 9.5 minutes for each participant, were recorded only once at a previously agreed time, following the COVID-19 protocols in force in the period. The first interview was conducted as a pilot of the interview guide, and, since it reached the objectives, was included in the results.

The Interview Script included questions such as: tell me a little about sickle cell disease; tell me about sickle cell disease in pediatrics. What do you think about nursing care to the child with sickle cell disease? What do you think about nursing care to the child with sickle cell disease in the pediatric emergency?

The CG were conducted remotely by the Google Meet application, still in the context of the COVID-19 pandemic, recorded in real time by the researchers. These are small groups whose participants met in order to develop theoretical knowledge to benefit the care practice studied[6]. The meetings lasted one hour and were previously scheduled with the participants. The observation, in turn, was performed with Observation Script and recorded in Logbook.

In the data analysis, the processes of grasp, synthesis, theorization and recontextualization were carried out.

In the CCR, the grasp process initiates data collection with the organization and codification

of the information; the synthesis process consists of subjectively examining the data and performing associations and variations of the information found in the grasp process; the theorization process consists in discovering the values contained in the information collected during the synthesis process[6].

The information obtained was encoded in Interview Notes (IN), Convergence Group Notes (CGN) and Observation Notes (ON). Regarding the participants, the use of fictitious names throughout the textual corpus was maintained, as well as the acronyms of the other notes already mentioned.

After the interviews, the audios of the recordings were listened repeatedly and the transcription was made in full, maintaining the fidelity of the speeches.

The data were organized in an analysis framework made in Microsoft Publisher, in which categories were separated according to the objectives of the research. Within each category, the information was compiled in order to "show essential data to unveil the phenomenon"[6:55]. The grasp and synthesis processes allowed the elaboration of assumptions and theories from the observed, with constant resumption of the theoretical framework and discussion in the light of the scientific literature.

In order to ensure quality in qualitative research, the guidelines of the Consolidated Criteria for Reporting Qualitative Research – COREQ were adopted[7].

Results

The participants were 12 emergency nurses from a public pediatric hospital, predominantly female (91.6%), being only one male (8.4%). Most are from 28 to 45 years, with time since college between 1 and 11 years and acting in Pediatrics in a period between ten months and nine years.

Regarding professional qualification, seven had at least one postgraduate degree, among which the most cited was Urgency and Emergency. It is also noteworthy that none in the area of Pediatrics, since all worked in a pediatric hospital.

The triangulation of the data collected through the interviews, convergence groups and observation after their organization and classification allowed the creation of two categories of analysis: *Category I* - Knowledge of nurses about Sickle Cell Disease (SCD); *Category II* - Knowledge of nurses about children with Sickle Cell Disease.

Category I – Knowledge of nurses about Sickle Cell Disease (SCD).

Examining the nurses' knowledge about sickle cell disease was an essential step, since the care depends on how much the nurse knows about the aspects of the disease and then plan the care of each patient with his/her team.

For most participants, SCD is a genetic disease and is characterized by altered hemoglobin and/or red blood cell shape:

> *Sickle cell disease is a condition in the hemoglobin that forms a sickle shape, which justifies the name, and this sickle shape generates some complications.* (GABRIELA, E)

> *It is basically a disease at the hematological level, in which hemoglobin acquires a sickle shape, which is why it is also called sickle cell.* (PAULO, E)

> *Sickle cell disease for me is a genetic disease that is transmitted through an alteration in hemoglobin.* (LETICIA, E)

> *It is a genetic disease that is passed from mother and father to child.* (ANA, E)

However, some statements showed misconceptions when pointing to SCD as an autoimmune disease, hematological or caused by other factors:

> *When I hear sickle cell disease, we understand that it is an autoimmune disease.* (NAIARA, E)

> [...] *which could also be a disease acquired due to a lack of vitamins, a lack of proteins, I don't know if I'm answering correctly. But I believe it could be that this lack of protein, iron supplementation, sometimes due to an inadequate diet, can cause the child to develop a type of anemia and this anemia can also have some traces.* (SOFIA, E)

Regarding the knowledge of professionals about the heredity of sickle cell disease, which

consists in the genetic presence of the trait of the disease, it is an occurrence that was not completely clear to the participants:

> *They may have sickle cell trait or sickle cell anemia. This will depend on whether the parents have this gene to distinguish between sickle cell disease and the trait.* (PEROLA, E)

> *When either the father has the trait or he has the disease, or the mother has the trait and the father has the trait and when they combine,* [...] *the child ends up being born genetically with sickle cell anemia.* (LETICIA, E)

> *So, sickle cell disease, we know that it is a genetically hereditary disease, inherited through genes from parents or a family member who already has the underlying pathology.* (JAMILE, E)

> *But, it really is a disease that, I think it is a hereditary disease that has families, that sometimes from your ancestor ends up passing on to all generations, and then each one, with a classification.* (SOFIA, E)

The nurses showed to know the relationship of race/color with the occurrence of sickle cell disease, including historical aspects of the disease found in only one speech of the participant Naiara:

> *Generally, those who have this genetic change are black people.* (PEROLA, E)

> *They are generally black patients, black patients who arrive most often with this pain condition.* (CARLA, E)

> *It is more related to black patients, who have a greater predisposition.* (MARIA, E)

> *And then, we will say that it is generally a disease that affects black people more, whose emergence was in this population and ended up appearing in other countries too, not only in Africa, but it came to Brazil and other places.* (NAIARA, E)

Regarding the pathophysiological aspects, they were not clearly mentioned by the participants. However, the complications resulting from the pathology were addressed in the speeches:

> *It is a disease that will cause the patient to have a greater problem in relation to oxygen uptake.* (MARIA, E)

> *One of these* (complications) *is the number of red blood cells that, generally, because they are poorly formed, end up decreasing, developing some other consequences such as thrombus formation. And these thrombi can cause anything from a local complication to a systemic complication.* (GABRIELA, E)

> *And from this deficiency, the patient can progress with respiratory discomfort, abdominal pain... they have liver changes, changes in the system, in their hemodynamics...* (SOFIA, E)

> *Consequently, the patient, due to the different shape of this cell, has a change* [...] *in an intense fever, pain as well, chest pain, abdominal pain. It has repercussions, in a certain way, on the body with some symptoms.* (PAULO, E)

Although little cited, the diagnosis of SCD performed through the Guthrie test appeared in the interviewees' speeches, as well as the importance of its early performance and the monitoring of the person with SCD throughout life and the investigation of families:

> *The family always has to be investigated. Which is investigated today in the Guthrie test.* [...] *When it is diagnosed early in the child's life, they have a certain amount of control not to evolve to greater severity.* (SOFIA, E)

> *And, generally, we can identify this disease right when the child is born, with the Guthrie Test. We can identify it and from there, the right thing to do is to refer for follow-up for the correct care throughout life.* (NAIARA, E)

> *Sometimes the mother doesn't even know that the child has the trait. Some patients arrive without a diagnosis of SCD, due to the vulnerability that some families experience or that do a Guthrie test, but they did not see or show the results of the exam to anyone.* (GABRIELA, GC)

> *But, unfortunately, today, not everyone was able to complete the screening. Today, it's easier, but in the past I thought it was more complicated.* (SOFIA, E)

One of the participants highlighted the chronicity of the disease, but also the lack of knowledge about the cure:

> *It is a disease that has no cure, so the person will need to remain under care and receive assistance for the rest of their life.* (NAIARA, E)

Thus, nurses working in the emergency of the research scenario recognized sickle cell disease in its main biological characteristic, the alteration of hemoglobin in sickle form, as a hereditary disease and present in the black population. They also revealed incipient knowledge about the pathophysiological aspects, but cited possible systemic changes.

Category II – Knowledge of nurses about children with sickle cell disease

This category consists of nurses' knowledge about SCD in the pediatric context, considering that all work in the pediatric emergency. In addition to knowing the pathology, it was

evidenced how they perceive it in children, bringing some particularities to this age group.

Most participants reported pain crisis or pain as a striking characteristic of the child with SCD:

> *These are children presenting with pain crises, pain, both abdominal pain and chest pain, pain in the upper and lower limbs, in other words, pain. They arrive complaining of a lot of pain.* (JOAO, E)

> *These are children who live in pain crises.* (LETICIA, E)

In addition to the presence of pain, other complications that may occur in childhood and/or adolescence were mentioned, such as splenic sequestration, cerebrovascular accident (CVA), pulmonary thromboembolism (PTE), jaundice and the need for transfusions.

> *These are children who may be at risk of splenic sequestration due to the amount of red blood cell production. This spleen starts to increase in size due to these production issues, the need for blood flow. It is generally one of the most serious complications, without removing the thrombi, and can range from a local complication, to a PTE, to a CVA. This thrombus can move, go to the heart, brain, several other places in the body, lungs.* (GABRIELA, E)

Nevertheless, the questioning of SOFIA about the presence of noticeable jaundice in the sclera revealed the lack of knowledge about the pathophysiology and clinical repercussions of the disease in the body of children:

> *I have worked in the emergency department for many years [...] and I observe that children with SCD generally have jaundice. Why do they have this clearly visible jaundice in the sclera?* (SOFIA, GC)

In addition to the biological aspects, of some symptoms or complications associated with sickle cell disease, which were mentioned, the interviewees did not bring other aspects of children's lives that have an impact with SCD, except the speech of PEROLA, which describes some of them:

> *In relation to behavior, many of them are highly irritable due to the pain, their physiognomy has an expression, some of sadness or nervousness. They have a certain aversion to healthcare professionals because they spend a lot of time in hospital, some returning repeatedly, many do not attend school regularly because they leave or stay in hospital for long periods, as I have already mentioned. And sometimes, you don't have that same social interaction. Many people also do not have this understanding and end up not understanding this behavior of children, generating social distancing, instead of trying to understand a little about the disease.* (PEROLA, E)

Although the socioeconomic distinction of children with SCD was not affirmed, due to the general condition of the population assisted in the public hospital institution, one participant highlighted the fact that it is associated with low income:

> *So, to talk about social, in reality here it is a bit, how do I say it? Restricted. Because most of the public here are really low-income, so for me to say that they are apparently low-class children is very, perhaps insignificant, because most people here are like that.* (CAMILE, E)

At another time, the difficulty of the professional in recognizing the repercussions of SCD in childhood and the need for qualification to meet this public were also pointed out:

> *In adults, I know, as I've seen some other cases, there are ulcers and it affects women's sexuality a lot. But, in children, we still cannot observe how it will affect the "whole" because they are still small and often end up not understanding the reality of the disease.* (LETICIA, E)

> *Professionals must be qualified to care for these children. (PEROLA, GC)*

This category highlighted the main characteristic of sickle cell disease in children, represented by painful crises, in addition to the various signs and symptoms triggered by clinical manifestations, which nurses identify in the hospital emergency. In addition, the need to strengthen the knowledge of professionals about SCD was revealed, especially its repercussions in childhood, as essential to establish quality care in Pediatrics.

Discussion

According to the participants, nurses working in the emergency of the research scenario recognized sickle cell disease in its main biological characteristic: the alteration of hemoglobin into sickle form, hereditary and predominant in the black population.

The speeches evidenced that, despite knowing that SCD is a disease of genetic inheritance, some professionals did not fully elucidated that this condition can be inherited from parents and other relatives, and not only from parents to children.

The mutant hemoglobin responsible for SCD is designated as hemoglobin S or Hb S, whose most frequent sickle cell disease is sickle cell anemia (HbSS), homozygous form – most cited by professionals –, but there are S beta thalassemia and double heterozygous SC, SD and E, fewer incidents. The forms HbSS and Hbs beta thalassemia are clinically very similar and have the most severe clinical manifestations[8].

The fundamental characteristic of this genetic issue is that "individuals with SCD must inherit a maternal and paternal mutation"[9:9], according to the following situations: parents have the trait, that is, heterozygotes for S, C, E or beta thalassemia, or have SCD.

Having knowledge about the types and genetic condition of SCD is important for the professional, because it allows differentiation between the most severe clinical forms, despite the similarities of the forms, and may provide correct explanations and guidance to the family of the child with SCD about the diagnosis of the disease.

In a study by Loiola and others[10], which evaluated nurses' knowledge about sickle cell anemia, the findings converge with the current research, while also pointing out the deficit in relation to information related to SCD; some misconceptions were found in the statements of the interviewees who pointed to SCD as an autoimmune, hematological or caused by other factors, such as in some types of anemias.

Similarly, in the study of Jenerette and Wells[11], nurses had difficulty responding correctly about the disease, demonstrating the lack of understanding of the sickle cell as a hemoglobinopathy that results in red blood cells in sickle form. This confirms the need for health education about the subject to clarify important points that can influence the care of people with SCD.

At another point, most participants recognized the predominance of sickle cell disease in the black population. According to Serjeant[12], the Hb S mutation originated in Africa in areas affected by malaria, in which individuals with sickle cell trait presented survival advantages over those with only hemoglobin Hb A, whose prevalence of sickle cell trait varies between different regions but reaches high levels in some areas of sub-Saharan Africa, eastern Saudi Arabia and central India. In addition to being present in different proportions on all continents of the world and endemic also in the Caribbean and Americas[13].

This public health problem, with relevant epidemiological data, is something that should be known by health professionals who work in the service as a way to contribute to the improvement of assistance to this public. Therefore, despite the process of miscegenation and the presence of the disease in other races, recent studies show the prevalence of SCD in black people in Brazilian territory, especially in the state of Bahia, the first in expressive numbers of people with trait of and with SCD[14-15].

Regarding the knowledge of the pathophysiological process of sickle cell disease, it was incipient in the research group. The lack of knowledge about the pathology constitutes a barrier to the execution of comprehensive and adequate care for people with this illness, therefore, there is a need for theoretical and technical basis to obtain quality care[16].

On the other hand, the importance of the Guthrie test was recognized, which is part of the Neonatal Screening Program and should be performed in the first days of life in all children in the Brazilian national territory. It consists of the collection of blood drops from the heel for neonatal screening of diseases such as phenylketonuria, congenital hypothyroidism, cystic fibrosis, biotinidase deficiency, congenital adrenal hyperplasia and sickle cell disease[9].

Despite all the progress resulting from the insertion of the test in neonatal screening, the shared one reflected the fragility still existing in the coverage, in the examination and in the early diagnosis, being necessary greater guidance for families before and soon after birth, beyond the investigation of the families.

Participants cited the need to monitor people with SCD. The National Program of Comprehensive Care for People with Sickle

Cell Disease and the National Policy of Care for People with Sickle Cell Disease and other Hemoglobinopathies are also responsible for the care and monitoring of people with this disease, which rely on the performance of the multidisciplinary team.

Like other chronic diseases, SCD requires prolonged treatment, hospitalizations and continuous monitoring, which results in drastic changes and affects the routine of those who live with the sick[16], whose treatments, hospitalizations and follow-ups begin in early childhood.

Despite the speech that cites SCD as incurable, there is the possibility of cure by hematopoietic cell transplantation, but its use is limited by the availability of an adequate HLA-compatible donor and the lack of knowledge of the benefits of transplantation[17].

That said, there is a need to rethink the discussion of sickle cell disease in the training disciplines of health professionals, especially in Brazilian states with higher prevalence of the disease, as well as permanent education strategies in the services to guarantee the quality of care to this public.

Regarding the second category, pain was the main characteristic mentioned by the participants. Pain is usually the first symptom of the disease in children from six months of life. According to the study by Carvalho[18], pain was also the main characteristic of people with SCD, pointed out by health professionals.

The observational study of Machado and other authors[19] found the high intensity of pain in children and adolescents with SCD. This corroborates the perception of pain as synonymous with the disease, including for the sick individuals themselves, with global repercussions and different locations[20].

Regarding complications, the pathophysiological mechanism of SCD is related to hypoxia situations that generate hemolysis, with release of proinflammatory agents, cytokines and consumption of nitric oxide determining vasoconstriction, ischemia and infarction of target organs, which predisposes to CVA, both ischemic and hemorrhagic[21].

The pulmonary involvement may be acute or chronic, whose acute complications are represented by bronchial hyperreactivity, pulmonary thromboembolism (PTE) and acute thoracic syndrome (ATS). Of these, the most incident is the ATS, which is the second most serious cause, the first being splenic sequestration[22].

Splenic sequestration is characterized by a decrease in hemoglobin concentration equal to or greater than 2g/dl compared to the baseline value of the patient, an increase in erythropoiesis and spleen dimensions, which is more common in children from 1 to 4 years with HbSS with a prevalence of 7 to 30%[22].

Thus, the perception of participants about the severity of clinical complications of SCD in children demonstrates the knowledge to be acquired by professionals for management, care and prevention of acute conditions of this pathology in emergency.

Concerning the non-biological aspects of SCD in children, irritability, the physiognomy of "sadness" or "nervousness", the long time of hospitalization, with recurrent returns, irregular school frequency and the impairment of children's social interaction were highlighted. Moreover, aspects of stigma to children with sickle cell disease, such as social distancing and the expression "sickle cell" in several speeches, were identified, related to lack of understanding about the disease.

In a study by Pereira and others[23], a relevant percentage of children with SCD who present behavioral changes, which are attributed to specific characteristics of SCD (such as the unpredictability of the disease, painful crises and restrictions imposed by the disease) and with other aspects of life of different study populations (such as socioeconomic status, emotional support and quality of life).

This idea is confirmed by Salih[24], whose research showed that patients suffered from being absent from school, provocation, embarrassment due to nocturnal enuresis, embarrassment due to

jaundice, failure to contribute to school activities, such as sports and depressive symptoms; reinforces the negative impact that the disease has on behavior.

In this sense, Campelo and collaborators[25] report that, in the approach of nurses to children with SCD, professional skills in providing support and knowing how to identify these feelings that arise during hospitalization are important, and highlight as a measure assistance not only for pain, but focused on psychological aspects, offering support and attention also to the caregiver and transmitting safety to the child.

Although the socioeconomic distinction of the child with SCD was not affirmed, due to the general condition of the population assisted in the public hospital institution, one participant highlighted the fact that it is associated with low income, according to the epidemiological characterization of other studies with children with SCD[26].

The results of this study cannot be generalized, since they are a specific location. However, as discussed, it corroborates the little literature already existing and strengthens the evidence on the need for further research on sickle cell disease involving its aspects in childhood and adolescence, both in Brazil and in the international scenario.

Final considerations

When elaborating the final thoughts of this research, after readings, reflections and analyses directed to the object of investigation, inserted in a context of pediatric care and associated with the experiences of nurses in the emergency, focusing on the sickle cell disease, I am able to conclude that the objective proposed by this study was achieved.

In addition to knowledge of the disease, it is necessary to develop skills to evaluate and identify non-verbal and subjective aspects present in pediatric patients; whose professional qualification is responsible for providing subsidies to the nurse and team to assist this specific population.

Therefore, health professionals need to be able to add this knowledge in the pediatric emergency, because the deeper the knowledge about a certain pathology, the more appropriate care is and the more relevant the guidance provided to children and their family, as forms of prevention of acute conditions during care and discharge planning.

Collaborations:

1 – Conception and planning of the project: Juliane Batista Costa Teixeira, Aisiane Cedraz Morais, Juliana Freitas de Oliveira Miranda and Evanilda Souza de Santana Carvalho;

2 – Analysis and interpretation of data: Juliane Batista Costa Teixeira, Aisiane Cedraz Morais, Evanilda Souza de Santana Carvalho;

3 – Writing and/or critical review: Juliane Batista Costa Teixeira, Aisiane Cedraz Morais, Vivian Ranyelle Soares de Almeida, Caroline Fernandes Soares e Soares, Luana Santana Brito;

4 – Approval of the final version: Juliane Batista Costa Teixeira, Aisiane Cedraz Morais, Vivian Ranyelle Soares de Almeida, Caroline Fernandes Soares e Soares, Luana Santana Brito, Juliana Freitas de Oliveira Miranda and Evanilda Souza de Santana Carvalho.

Competing interests

There are no competing interests.

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