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Relatives of Children Bearing Sickle Cell Anemia: Knowledge and Practice

O Familiar da Criança com Doença Falciforme: Saberes e Práticas.

El Familiar del Niño con Enfermedad Falciforme: Saberes y Prácticas

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ABSTRACT

Objective: This work aims to describe the type of care provided by relatives for children with sickle cell anemia according to Collière. **Methods:** It is descriptive study with a qualitative approach, which was carried out with relatives of children bearing sickle cell anemia in a general hospital in *Vitória* city, *Espírito Santo* State, Brazil, by using semi-structured interviews. Data were interpreted in light of the Collière's Theoretical Reference and submitted to Thematic Analysis. **Results:** Families had to deal with the health care professionals' lack of skill needed to convey the diagnostic. Also, there was a predominance of the maintenance care related to the time of diagnosis, playing, daily medication, body hydration, diet, elimination, and clothing. Nonetheless, repair care was restricted to emergency situations. **Conclusion:** It is necessary to train the professionals who care for children with sickle cell anemia to better meet their needs and those of their families.

Descriptors: Sickle Cell Anemia, Child, Family, Knowledge, Health Care Education.

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RESUMO

Objetivo: Descrever a tipologia do cuidado realizado pelo familiar à criança com doença falciforme segundo Colliére. **Método:** Estudo qualitativo, descritivo, desenvolvido com familiares de crianças com doença falciforme, em um hospital geral de Vitória por meio da entrevista semiestruturada. Os dados foram interpretados à luz do Referencial Teórico de Collière e submetidos à Análise Temática. **Resultados:** a família se deparada com profissionais despreparados no momento da descoberta da doença. Quanto aos cuidados, houve predomínio dos cuidados de manutenção relacionados ao momento do diagnostico, brincadeiras, medicação diária, hidratação corporal, alimentação, eliminação e roupas. Já os reparadores ficaram restritos a situações emergenciais. **Conclusão:** é necessário capacitar os profissionais que atendem as crianças com doença falciforme para melhor satisfação das suas necessidades e de sua família.

Descritores: Anemia Falciforme, Criança, Família, Conhecimento, Educação em Saúde.

RESUMEN

Objetivo: Describir la tipología del cuidado realizado por el familiar al niño con enfermedad falciforme según Colliére. **Método:** Estudio cualitativo, descriptivo, desarrollado con familiares de niños con enfermedad falciforme, en un hospital general de Vitória por medio de la entrevista semiestructurada. Los datos fueron interpretados a la luz del Referencial Teórico de Collière y sometidos al Análisis Temático. **Resultados:** la familia se deparó con profesionales despreparados en el momento del descubrimiento de la enfermedad. En cuanto a los cuidados, hubo predominio de los cuidados de mantenimiento relacionados al momento del diagnóstico, bromas, medicación diaria, hidratación corporal, alimentación, eliminación y ropa. Los reparadores quedaron restringidos a situaciones de emergencia. **Conclusión:** es necesario capacitar a los profesionales que atienden a los niños con enfermedad falciforme para mejor satisfacción de sus necesidades y de su familia.

Descriptores: Anemia de Células Falciformes, Niño, Familia, Conocimiento, Educación en Salud.

INTRODUCTION

Sickle cell anemia is a genetic and inherited disease characterized by a hemoglobin alteration making the red blood cells have a sickle-like shape.[1] In Brazil, this disease has a high prevalence and important incidence in all regions. In *Bahia* state, one child per 650 live births is diagnosed with sickle cell disease. This proportion is 1:1,300 for *Rio de Janeiro* State; 1:1,400 for the States of *Pernambuco*, *Maranhão, Minas Gerais* and *Goiás*; 1:1,800 for *Espírito Santo* State; 1:4,000 for *São Paulo* State; 1:11,000 for *Rio Grande do Sul* State; and 1:13,500 for the States of S*anta Catarina* and *Paraná*.[2]

In Brazil, although sickle cell anemia is one of the diseases diagnosed by the heel prick, some cases are still discovered late. In this sense, early diagnosis is essential for the children living with sickle cell anemia because the early care provided their relatives directly influences their quality of life.[3]

The complications of sickle cell anemia go beyond pain and interfere with the daily life of the child and his or her relatives, who are often not prepared to face the conditions imposed by this chronic disease[4] and specific care that in most cases are delivered by the child's own family in order to prevent complications.

A study, which aimed at identifying the scientific knowledge about families of children with sickle cell anemia, demonstrated that the family is the main caregiver. The children's relatives face challenges to deliver comprehensive care and fight for a better quality of life for them. It is necessary for the team to understand the demands and desires of the family, as well as identify elements that hinder the daily management of the disease. Additionally, this study highlighted the scarcity of Brazilian publications (especially in nursing) and the need to fill the gaps that still exist in this area.[5]

In this sense, to fill the gaps that still exist regarding the care for children with sickle cell anemia and their families, this study was based on the conceptions of care according to Collière's viewpoint, which defines the maintaining and repairing care as necessary for every human being.[6]

Maintenance care needs to last a lifetime. Maintenance care supports and maintains the acquired capabilities for meeting the daily life needs, such as food, sanitation, elimination, dressing, and moving. Lacking this care leads to regressions that can be very serious. Repairers are responsible for restoring the integrity of the health of the person being cared for.[6]

Hence, this study aims to describe the type of care for children bearing sickle cell anemia provided by their relatives according to Collière.

METHODS

This descriptive study with a qualitative approach was conducted in the pediatric infirmary of a general hospital in the metropolitan region of *Vitória* city, *Espírito Santo* State, over the period from March 2015 to May 2016. Five relatives (four mothers and one father) of children with sickle cell anemia admitted due to a sickle cell crisis participated in this study by accepting and signing the Informed Consent Form (ICF). Relatives of children with severe clinical symptoms were excluded.

Data were collected through semi-structured interviews with guiding questions about child care. The theoretical saturation was used to finish data collection because there were no new elements in the family statements.[7]

The collected data were discussed in light of Collière's concept of care[6] and analyzed by the thematic analysis technique, which is composed of three stages: pre-analysis; exploration of the material and treatment of the results; and interpretation.[8]

This study was approved by the research ethics committees from the proposing institution under the Legal Opinion No. 816.700/14, and from the co-participant institution under the Legal Opinion No. 850.125/14. It is

worth mentioning that the participants' anonymity was preserved, and they were labeled by the letter I (interviewee) followed by a number according to the order in which the interviews were analyzed.

RESULTS AND DISCUSSION

The following thematic units appeared after the interview analysis: "The disease diagnosis", "Maintenance care" and "Repairing care".

The disease diagnosis

This thematic unit revealed how children's relatives received the diagnosis of sickle cell anemia by the health professional and their lack of skill to manage it. In addition, they reported that these professionals explained the disease incorrectly to the family members, who consequently became frightened and feared their child's prognosis, and lacked sensitivity while communicating with them. However, after the child's transference to the specialized service, their relatives had access to more information about the disease and better prospects for the child's health.

> *"The person who said that she had the disease did not even know it, because she put so much terror into the disease, that I thought she would live on the bed. The nurse didn't say anything about the care, just the bad part." (I2)*
> *"At the time, the instructions they gave were minimal." (I1)*
> *"He said I had to take care of it, that it's a serious thing (...) that I have a different son." (I4)*
> *"All he said was: your son's test was a problem; you have to go to Vitória. Just like that. She was very rude. She treated me very badly. When my child was referred directly to APAE [Association of Parents and Friends of the Exceptional] I was already worried. After I got there, I got a wonderful consultation with an excellent professional. He said my child would listen, talk, and walk (...) there would only be some complications." (I5)*

On the other hand, one caregiver reported that she was very well guided by the pediatrician at the time of knowing their child's diagnosis.

> *"The pediatrician explained his illness to us, explained everything to us efficiently." (I3)*

Maintenance care

In this thematic unit, the relatives reported the care related to playful and physical activities done by the children in different contexts. They mentioned running and bathing in a pool as factors that may cause the child discomfort in addition to triggering complications that may lead the child to be hospitalized.

"We guide him, we tell him not to run too much, tell him to take it easy. If you feel exhausted, stop." (I1)

> *"Avoid running... She has to exert herself less during physical education classes, she can't exert herself the same way as others because she gets tired more easily. That's what I tell the school staff. I tell her to be careful with certain games so she doesn't fall and get hurt." (I2)*
> *"Beach, swimming pool, the time is controlled. One time he was bathing in the pool and got to the hospital because of a pain crisis. When he goes back to school, I ask him to do nothing during the physical education classes. I always tell him not to run too much. Depending on the effort, he already gets tired." (I5)*

Another maintenance care refers to the importance of body hydration. The family members pointed out the importance of stimulating the children with sickle cell anemia to keep themselves hydrated by consuming water, juice, fruits or coconut water even if there are no thirst. Moreover, the relatives sought strategies for delivering this care in the school environment, such as providing water bottles for the children and instructing teachers to not let them drink cold water.

> *"Water, lots of water. Juices, do you understand? Fruits, oranges, which have plenty of water. Coconut water and plenty of normal water. Drinking water all the time, even if there's no thirst." (I1)*
> *"Plenty of liquid so his blood won't thicken, so his blood will stay always good." (I2)*
> *"He needs to drink plenty of water. Before school, I tell him to get some water and put it in that little bottle. He's going to school with the bottle full, and there he drinks water and fills the bottle again. I told the teacher that he can't drink water too cold. I feel it's not good, he starts coughing." (I3)*

Feeding problems were also evident in the family members' speech. They try to offer their children healthy food, which makes them strong and avoid the greasy and industrialized ones. Despite this, children with sickle cell anemia still face situations in which their fathers offer them inappropriate food.

> *"To make her stronger, I avoid food too greasy and artificial." (I2)*
> *"I don't cover the beans with water. I use the blender to chop cabbage and instead of water, I cover the beans with cabbage. I mix spinach into the minced meat, cook the beets and beans together, but he can't know it otherwise he won't eat. Dad gives too much soda, too much salty." (I5)*

Another point in this thematic unit refers to the care regarding elimination needs. The family members highlighted the teachers' failure at understanding that the children with sickle cell disease need to go to the bathroom many times,

and when this request is not met they urinate in the classroom, which causes them embarrassment in front of the other schoolmates, which is why these children are referred to a psychologist.

"He has to go to the bathroom when he asks. He's different from the other kids. I've already talked to the teacher (...) to pee a lot, whenever he wants." (I4)
"One time he wanted to use the bathroom and the teacher forbade him to do it. He did [urinated] it in the classroom. He did that a lot, and I even took him to the psychologist. Last year I was a little harsh with the teacher. She didn't allow him to go to the bathroom as a form of punishment. I told her: you can give him any punishment, but don't do that. And then the other students see it and really abuse it. Another time she called me and asked me to bring a pair of pants, she said he didn't do his homework so she grounded him and didn't let him go to the bathroom. I was angry at her. I said 'you can leave him without a break, without a snack, but he can't be left without water and can't be forbidden to go to the bathroom. Besides the sickle cell anemia, he has kidney stones, he takes a lot of water and has to put out what he puts in." (I5)

The environment temperature and the type of clothes were also present in the family members' speech. According to them, it is important for children with sickle cell anemia to dress themselves warmly during cold days in order to avoid pain crisis and the need to have clothes for both the types of weather, if necessary. They also pointed out that wearing too many clothes on hot days can cause discomfort for the child.

"When it's cold, put on cold clothes, wear socks to avoid feeling joint pain... wear a pair of pants, warm clothes (...). It cools the bones and she's in pain." (I2)
"Wear clothes properly, put on socks if it's cold. Wrap up because of the cold. The cold makes the anemia more dangerous; it gives joint pain." (I3)
"Always take an umbrella before going out, take clothes, because when it's hot when going out. On the way back it may be raining (...) bring two clothes for children, one for hot weather and the other for cold weather." (I4)
"Never take your shirt off. One time it happened and caused pain. Don't walk barefoot at all, not even in in the drizzle." (I5)
"If it's hot, get cooler. If she gets too stuffy, she's going to feel sick, feel shortness of breath, because if she put on warmly clothes in hot weather (...) it will lower the pressure. She sweats too much." (I2)

The use of medications for controlling the disease was also pointed out by the family members as a type of care. These medications can be used since childbirth until the child reach a certain age or can be used indefinitely.

"He had been taking just Benzetacil® since he was a little baby until he was 5 years old." (I3)
"He takes hydroxyurea and the doctor said he/she didn't know for how long he's going to be taking it." (I5)

Repairing care

Although maintenance care predominates in the results of this study, this thematic unit shows that repair care was also present in the family members' speech. Seeking medical care when the child has pain or fever was mentioned, in addition to orienting the child about the importance of medicines for improving his/her condition before being discharged from the hospital.

"Sometimes he gets knee pain, sometimes he gets a fever (...) so you can seek a doctor." (I2)
"You have to take the medicine to get better, stay here [hospital] until you get healed because if we go home, you will have to come back." (I3)

The impact of the diagnosis causes anger, shock, sadness, despair, and fear of the unknown. The skills of the professional who conveys the diagnosis may interfere with the relatives' perception of the disease.[9] Also, these skills can negatively influence the health care for the child who needs it regularly, which in turn can lead to complications.[10]

In this sense, the results of this study brought important reflections about the moment of sickle cell disease diagnosis for the child's relatives, making it evident that it is necessary for the health professional to be sensible during such moment, as well as to welcome them by clearing their doubts and preventing complications through appropriate guidance.

Despite facing the limitations imposed by the disease, children bearing sickle cell anemia need to play. Nonetheless, they can experience some discomfort if they do it excessively, such as fatigue. In such case, the family members instruct the child to avoid actions, such as running too much or swimming in a pool for a long time, that can bring about these consequences.

It is necessary to emphasize that, despite the risks presented, playing is natural, necessary and favors the children's development.[11] Playing is also a source of vitality, which would become life-giving care according to Collière.[6] On the other hand, the practice of intense physical activities should be avoided, as it can cause pain crisis.[12] To this end, the skills of the children for avoiding these risky situations depend mainly on their development.[11]

Another care mentioned by the interviewees was body hydration, since maintaining good hydration is important for organs and systems to function properly since this guarantees that the group and species continue to live, and is essential to maintain the vital functions of children.

In the case of patients with sickle cell anemia, hydration plays an even more important role because a vaso-occlusive

crisis can also be avoided if the patient is well hydrated. Furthermore, poor hydration associated with other factors can trigger deformation of the red blood cells, increased blood viscosity, edema and vascular obstruction that can lead to ischemia and renal microcirculation infarction.[13]

The need for providing healthy food for children with sickle cell anemia was highlighted by the interviewees. This is important because consuming good food, such as physical and mental well-being, brings benefits not only for sickle cell patients but for the general child population.

According to Collière, feeding is a type of routine care that aims to maintain life, contributes to the development and survival of human beings, and builds and maintains their bodies, images, and relationships with the environment.[6] Thus, it is necessary that both nurses and nutritionists develop a nutritional plan for children with sickle cell anemia according to their particularities.

Inadequate nutrition, both in terms of micronutrients and macronutrients, has a great impact on the quality of life of children living with this disease. Sickle cell anemia affects the requirements of some nutrients and consequently its prognosis. Children are potential victims because they need to absorb large amounts of energy for speeding their growth.[14]

It should also be noted that sickle cell anemia is often mistaken for iron deficiency anemia. Ferrous sulfate for patients with sickle cell anemia should be used only in proven cases of iron deficiency anemia, and the importance of adequate nutrition should always be emphasized. However, it is necessary to carry out new studies to better understand the effects of iron administration in these patients. [15]

For good dietary guidance, the results of blood tests should be analyzed, and if the amount of iron is high, the diet should include iron-poor foods.[16] It is also important to prefer folate-rich foods, which plays a key role in increasing bone marrow activity and producing more red blood cells.[15]

Regarding the need for elimination, the family members pointed out the teachers' lack of skill in dealing with the particularities of the sickle cell anemia, such as the constant need to go to the bathroom. Children with this disease need to drink plenty of liquid to maintain hemodilution and avoid pain crisis.

Children with sickle cell anemia are more likely to develop chronic kidney disease. Necessary care should be taken to maintain body hydration as soon as possible since these patients have the worst prognosis if they contract a chronic disease.[17]

Therefore, the teachers' knowledge of the specificities of care for children with sickle cell anemia is of great importance for providing better assistance and for creating an appropriate pedagogical plan for their development.[18]

Teachers who know this disease can help to prevent seizures, recognize early signs and symptoms, and ensure support to children living with this pathology.[18]

Another maintenance care mentioned by the family members is using clothes appropriate to the weather. In this context, children with sickle cell disease may become ill when exposed to heat, extreme cold, and sudden temperature changes, requiring the use of appropriate clothing so that they avoid situations that may trigger pain crisis and even hospitalization.[12]

In addition to the care related to the children's needs, the interviewees highlighted the use of medications as a type of maintenance care because they prevent complications. Nevertheless, these medications are not used in emergencies.[6] Penicillin is mainly used in children up to 5 years of age to prevent the onset of pneumonia[19] and hydroxyurea.[20]

Some recent studies have proven the efficacy of hydroxyurea for improving the health of patients with sickle cell anemia by reducing the effects of a vaso-occlusive crisis. Hydroxyurea can be used in children who are three years of age or older following some criteria: having had three or more episodes of vaso-occlusive crisis in which medical care was necessary, acute thoracic crisis, one or more strokes, recurrent priapism or persistent severe anemia.[20]

Repair care, even if not as evident as the maintenance care, is present in the family members' speech. When dealing with pain and fever, they resort to medical and hospital services for immediate intervention, aiming to avoid sickle cell anemia complications.

Intervention in the light pain is often initiated at home with medications, heating compress, rest and increased water intake. For mild to moderate pain, instructions are to take painkillers or non-steroidal anti-inflammatory drugs, such as ibuprofen. For acute, rapid onset pain, orally administrated or intravenous medications are used. Regarding the latter, due to the multifactorial nature of the pain crisis, in most severe cases more than one painkiller may be used simultaneously. When the pain persists or becomes severe, opioid drugs may be needed, but their use for an extended period of time must be avoided.[20]

CONCLUSIONS

This study brought valuable contributions to the subject of care for children living with sickle cell anemia by describing the type of care provided by their relatives.

It showed the health care teams' lack of skill when announcing the diagnosis and their difficulty in guiding the family members through the disease, as well as the lack of knowledge of the school staff about the limitations of children with sickle cell anemia.

The family members contributed by playing, administering medications daily, and promoting hydration, feeding, elimination, and the use of clothes appropriate to the weather. Most of these are maintenance care actions, which are important for survival and life.

Furthermore, it is evident that this study has gaps that will stimulate the creation of new strategies for the instrumentalization of children and their relatives for preventing

pain crisis and improving the children's health in face of complications.

The fact that there were few children hospitalized during the period of data collection was a limitation of this study. Nevertheless, the results led to reflect on the necessity of developing new studies on training school staffs and primary health care teams for meeting the needs of and accepting the children with sickle cell anemia and their families.

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