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# Internalization of care: a qualitative study with schoolchildren living with sickle cell disease

## *Internalização do cuidado: um estudo qualitativo com escolares que convivem com a doença falciforme*

## *Internalizacion del cuidado: un estudio cualitativo com niños que viven con enfermedad de células falciformes*

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## ABSTRACT

**Objective:** to analyze the internalization of body care by the schoolchildren with sickle cell disease based on Vigotski's development theory and Collière's concept of care. **Method**: Qualitative study with 15 schoolchildren living with sickle cell disease, followed in an outpatient clinic in the city of Vitoria - ES. The technique was the individual interview and thematic analysis. Body hydration, playing, prevention and management of the sickle cell crisis, food and clothing were the thematic units that emerged. **Results**: Participants reported ingesting various types of liquids. The games were predominantly active. The medications were repair and maintenance of health. It was observed no consumption of healthy foods. The use of clothes suitable for the cold was evidenced. Pain was a sign of the internalization of care and knowledge for games. The decrease in liquids and inadequate clothing triggered the sickle cell crisis. **Final Considerations**: The internalization of knowledge and care mediated by pain and the unpreparedness of teachers due to lack of knowledge were highlighted. **Implications for practice**: this study can support the best articulation between health professionals, children and school.

**Keywords:** Anemia; Sickle Cell; Child; Self Care; Qualitative Research; Child Development.

## RESUMO

**Objetivo:** analisar a internalização do cuidado com o corpo pelo escolar com a doença falciforme com base na teoria do desenvolvimento de Vigotski e no conceito de cuidado de Collière. **Método:** Estudo qualitativo com 15 escolares que convivem com a doença falciforme, acompanhados em ambulatório na cidade de Vitoria – ES. A técnica utilizada foi a entrevista individual e a análise temática. A hidratação corporal, o brincar, a prevenção e manejo da crise falcêmica, a alimentação e as roupas foram as unidades temáticas que emergiram. **Resultados**: Os participantes referiram ingerir variados tipos de líquidos. As brincadeiras foram predominantemente ativas. Os medicamentos foram de reparação e manutenção da saúde. Não se evidenciou consumo de alimentos saudáveis. Observou-se a utilização de roupas adequadas ao frio. A dor foi um signo da internalização do cuidado e do conhecimento para brincadeiras. A diminuição de líquidos e roupas inadequadas desencadearam a crise falcêmica. **Considerações Finais:** Evidenciaram-se a internalização do conhecimento e dos cuidados mediados pela dor e o despreparo dos professores pela falta de conhecimento. **Implicações para a prática:** este estudo poderá subsidiar a melhor articulação entre profissional de saúde, criança e escola.

**Palavras-chave:** Anemia Falciforme; Criança; Autocuidado; Pesquisa qualitativa; Desenvolvimento Infantil.

## RESUMEN

**Objetivo:** analizar la internalización de la atención por parte del escolar con la enfermedad de células falciformes basado en la teoría del desarrollo de Vigotski y el concepto de atención de Collière. **Método**: Estudio cualitativo con 15 escolares que viven con la enfermedad de células falciformes, monitoreados en una clínica ambulatoria en la ciudad de Vitoria - ES. La técnica fue la entrevista individual y el análisis temático. La hidratación corporal, el juego, la prevención y el manejo de la crisis falcémica, la alimentación y la ropa fueron las unidades temáticas que emergieron. **Resultados**: Los participantes informaron de la ingestión de varios tipos de líquidos. Los juegos fueron predominantemente activos. Los medicamentos fueron de reparación y mantenimiento de la salud. No se ha demostrado el consumo de alimentos saludables. Se observó el uso de ropa adecuada para el frío. El dolor fue un signo de la internalización de la atención y el conocimiento para los juegos. La disminución de líquidos y la ropa inadecuada desencadenaron la crisis falcémica. **Consideraciones finales:** Se señalaron la internalización del conocimiento y la atención mediados por el dolor y la falta de preparación de los maestros debido a la falta de conocimiento. **Implicaciones para la práctica**: este estudio podrá subsidiar la mejor articulación entre los profesionales de la salud, los niños y la escuela.

**Palavras clave**: Anemia de Células Falciformes; Niño. Autocuidado; Investigación Cualitativa; Desarrollo Infantil.

## INTRODUCTION

The term sickle cell disease comprises several hemoglobinopathies around the world, among which sickle cell anemia is the majority.[1] In Brazil, it is estimated that 60 to 100,000 people live with the disease, mainly in regions that have received large numbers of Africans.[2]

Historically, the disease arose in the African continent and was brought to Brazil by enslaved blacks, and some states have an incidence of one newborn diagnosed with sickle cell disease for every 13,500 births, such as Santa Catarina and Paraná, probably influenced by the lower number of blacks in the southern region of the country. In the same context, the incidence of sickle cell disease may reach 1:4,000 in São Paulo, 1:1,800 in Espírito Santo, 1:1,400 in Minas Gerais and Goiás states, 1:1,300 in Rio de Janeiro, up to 1:650 in Bahia.[3]

Sickle cell disease progression includes ischemia and infarction of any organs and hemolysis resulting from sickle cell disease,[4] and the signs and symptoms are varied, with greater or lesser intensity. Children have frequent complications.[5]

Sickle cell attacks can be triggered directly by situations that alter the state of hydration and oxygenation,[6] and the clinical framework usually includes pain anywhere in the body, edema in the feet and hands, paleness, jaundice, lower limb ulcers, stroke, and priapism.[5]

From school age onwards, the child begins to develop more concrete thinking, which gives him/her greater understanding of the mechanisms of the body's own functioning and of the pathophysiology of the disease, and provides him/her with the possibility of apprehending preventive and curative care. At this age, the child is sensitive to anything that threatens or suggests injury, and may be able to identify changing health patterns and act on their behalf.[7]

Children must learn at an early age to take care of their own body, which needs to be internalized, so that they become active subjects in maintaining their health. The care of the body, when it exists, appears weakened, fragmented and focused only on issues related to pain or acute crises. This was evidenced by the literature review for this study, performed in LILACS, Medline, ScieLO, CINAHL and CAPES data sources. There is a lack of other care besides pain identification and intervention, as well as a need for children to get more knowledge about sickle cell disease and internalize body care, object of this study, for a healthy life.

Caring is an individual act that we perform for ourselves and serves to maintain and sustain life.[8] The process of internalizing care is an operation that initially represents an external activity, which is reconstructed and internally transforms concepts through the use of instruments and signs. It is an interpersonal process transformed into intrapersonal, the result of various events that occur throughout its development.[9]

The sign relates to psychological activity and serves as an aid to attention, memory and accumulation of information. The instrument, on the other hand, assists in concrete actions, enables man to act on nature, with the function of regulating actions on objects.[9]

Thus, this study sought support in Vigotski's Developmental Theory[9] to support the levels of development of school-age children and the internalization of body care, and in Collière[8] to underpin the discussion related to the typology of care developed by the schoolchildren.

In order to contribute to the construction of an autonomous subject, co-responsible for maintaining his health, the purpose of this study was to analyze the process of internalization of body care by schoolchildren with sickle cell disease.

## METHOD

Qualitative study, performed in the pediatric hematology outpatient clinic of a general hospital in Vitoria - Espírito Santo, in which 9 girls and 6 boys whose ages ranged from 6 to 12 years old participated, selected through the follow-up agenda in the referred institution during the planned period of data collection.

They were considered as inclusion criteria were: having been diagnosed with sickle cell disease and having been hospitalized at some point in his life as a result of the disease. Exclusion criteria were established as the presence of some occurrence at the time of data collection. There was no exclusion, refusal or withdrawal of participants in this study.

The interviews were recorded after the school signed the Informed Consent Term (ICF), the Free and Informed Consent Term (FICT) by its responsible and the approval of the Ethics in Research Committees (ERC) of the proposing and cooperating institutions, under the numbers 825,549 and 850,125. All ethical aspects were respected in accordance with Resolution 466/201210,[10] of the National Health Council. No compensation was granted to participants in the study. Only, at the end of the study, all received a school kit containing a box of colored pencils, black pencils, pointers, erasers, glue, rulers and ballpoint pens as a form of thanks.

The data were collected in the period from November 2015 to May 2016 by means of a participant characterization form and an open-ended question script about body care. These tools were validated through an initial interview whose information was discarded after the identification of the need for adjustment in a script question.

The collection was carried out in the outpatient clinic itself, in a private room, and each interview was transcribed within 48 hours and checked by a single researcher, author of the study. A single interview was carried out with each participant, in the presence of the responsible person for the child. The interviews lasted an average of 26:33 minutes each, with no space to avoid later sharing for comments or corrections by the participants.

During the interview technique, posters containing various figures found in electronic media related to body care or lack of them in the context of sickle cell disease were used. The posters contained figures of several kinds of liquids to be ingested, several toys, children in active and passive situations and games, medications, food considered healthy and unhealthy, clothes and utensils used on hot and cold days, which were used only to activate the memory of those surveyed. Each school individually answered open questions related to care considered essential to maintain and recover the health of children living with sickle cell disease. Schoolchildren were identified by the letter C and the interview sequence number, that is, C1, C2, onwards. Words related to trademarks were replaced by generic terms at the time of data transcription.

The sample was defined by theoretical saturation which corresponds to the finding that there were no new elements in the statements collected so far. The regularity of the findings in the collected testimonies was sought using the colorimetric coding system. Thus, the themes were identified by colors and the passages of the statements could be grouped according to each theme. In this way, it was possible to identify the constancy and consistency of the statements. The interviews were followed by the presence of new elements according to each theme.

In this context, it can be stated that the theme related to the use of clothes was the first to reach theoretical saturation, which occurred after the second interview. The last one to reach the theoretical saturation was the theme related to body hydration, starting from the eleventh interview.

The thematic analysis made it possible to discover the meaning nuclei of the material obtained and occurred according to the precepts of Minayo,[11] in three stages: pre-analysis, exploration of the material, and treatment of the data, inference and interpretation.

The pre-analysis consisted in understanding and interpreting the material and organizing initial ideas. The constitution of the textual corpus was sought, and it was verified that the material covered the aspects raised that met the objectives of the study.

In the second stage, exploring the material, we sought the link established between the assertions and the statements of the participants, making it compatible with the use of instruments and signs, interpersonal and intrapersonal relationships, and internalization of knowledge for the care of Vigotski[9] and Collière,[8] considering that these were the theoretical references used.

The stage of processing the results obtained and interpretation was to highlight the information obtained. From this stage, inferences and interpretation of the material were made in light of the theoretical framework proposed for this study. The presentation of the results was organized according to the analysis of the empirical material and pointed out the following thematic units and subunits: Body Hydration; Play; Prevention and Management of Falcemic Crisis; Food and Clothing.

## RESULTS

Twelve schoolchildren were diagnosed by foot test, eight with sickle cell anemia (SS), five with sickle cell SC disease and two with S-talassemia.

a) Body hydration

In this analysis topic, the different types of liquids frequently ingested by schoolchildren participating in the study will be presented.

All respondents reported drinking water, as well as other liquids, according to their needs and times of day. They stand out in the following statements:

> *Sometimes milk, water, soda. At school it is juice (C2, 7 years).*
>
> *At home I drink coffee, juice box or soda (C8, 12 years).*

Although everyone mentions water consumption at home and/or at school, this liquid did not feature prominently in most lines. However, thirteen schoolchildren described some consumed liquids that know how to harm their health, such as: industrialized, sweet and fat-rich liquids. Some of them associated the ingestion of these other liquids with the experience of bladder and abdominal pain, according to the lines of C8 and C9:

> *Chocolate products gives me a tummy ache. (C8, 12 years old).*
>
> *Chocolate products makes the gallbladder hurt because of the stone (C9, 12 years).*

The ingestion of a certain liquid, which causes some kind of discomfort, has led schoolchildren to associate cause and effect and to internalize this knowledge, according to their experiences. They also informed the importance of liquids in crisis prevention:

> *Without water, I have a pain crisis, the arteries clog. (C1, 12 years old).*
>
> *We have a discomfort if we don't drink much water. (C2, 7 years old).*
>
> *To improve the belly. (C6, 6 years).*
>
> *It's to circulate the blood. It's a business in the vein that stops and has no way to pass the blood, it hurts (C9, 12 years).*

In addition to the importance of fluid intake for the prevention of falcemic crises, those surveyed demonstrated knowledge about the occurrence of congestion of the blood vessel in the face of decreased body hydration. It was also mentioned the difficulty of fluid intake and the difficulty of elimination at school:

> *It's hard there. It's got time (C4, 12 years)*
>
> *The teacher won't let her. My colleague peed her pants. (C7, 6 years old).*
>
> *After lunch I ask the teacher (C9, 12 years old)*
>
> *No water (C12, 10 years)*
>
> *You have the right time, in the third and last class (C13, 12 years).*
>
> *You have to ask (C15, 6 years)*

It was evident in this study that, at school, the child does not have his needs for hydration and elimination fully met. It is worth mentioning that children with sickle cell disease are recommended to drink more liquid, which makes them use the bathroom more often. If the teacher forbids them to leave, the school may start ingesting less liquid than necessary. Still regarding this aspect, C7's statement reveals that when the school can't wait for the teacher's release, he may urinate on clothes and be embarrassed before the whole class, which incurs in violation of his right.

b) Playing

The schoolchildren talked about the games, physical and leisure activities in different contexts, as well as the types of games and games, exposure to sun and cold water.

As for the kind of jokes and games, they referred to active and passive activities:

> *Hide and seek and ball at home, the boys kick and I try to grab. In the hospital, in Ben 10's doll, with a ball (C2, 7 years old).*
>
> *At school I play catch-pike, and hide and seek (C5, 10 years old).*
>
> *Pool, my brother's video game and on the computer (C10, 12 years old).*

The diversity of activities developed by the school requires energy expenditure. The house and the surrounding spaces were the most cited places to play. Schoolchildren interviewed showed that they play the same kind of games as pediatric population in general, and that having sickle cell disease is not an obstacle to limit it in their activities at first.

On the other hand, they cited sun exposure, contact with cold water, and activities that require physical effort as crisis triggers:

> *In the sun, my head hurts. In the pool, my arms (C4, 12 years old). If I play in the sun, my back, belly, arm, leg and headache from sickle cell anemia. (C7, 6 years).*
>
> *A lot of exercise gives pain in the legs, arms (C8, 12 years).*

Schoolchildren correlate excess physical activity during play, exposure to certain environments where these games take place, exposure to the sun and water, as triggers of sickle cell crisis, demonstrating the internalization of their care in crisis prevention, as highlighted by the statement of C8 and C9:

> *I don't even work out much. I end up having a bad time, with pain in my arm and legs. Then I go to bed, and my mother puts on a thermal bag to warm up where it hurts (C8, 12 years old).*
>
> *I pass gel. Lots of pain... I stop playing (C9, 12 years).*

Ceasing physical activity, keeping at rest or lying down, applying warm compresses or gel on the part affected by the pain are the main care developed in order to alleviate the discomfort at the time of the falcemic crisis.

c) Prevention and management of falcemic crisis

Repair and maintenance medications used by schoolchildren with sickle cell disease and the mediators of such care are presented in this thematic unit.

When asked about care in the face of pain crises, three schoolchildren cited the use of analgesics:

> *Dipyrone when I feel headache, bellyache (C3, 10 years). Stomachache, bellyache... I take ibuprofen, I take dipyrone. Only when I'm in pain. I know how to take it myself (C4, 12 years).*
>
> *Dipyrone, when I have a headache (C9, 12 years).*

Of the fifteen interviewees, only three reported the reason for using analgesics in pain crisis, showing that this repair care is internalized in schoolchildren who are often in this situation.

To maintain health, schoolchildren reported regular use of medications such as hydroxyurea and folic acid:

> *I've been taking this (hydroxyurea) for a long time. Always at night and in the morning, I take medication for sickle cell anemia (C2, 7 years).*
>
> *Because of my anemia, I've been taking folic acid since I was little... at night, Monday, Wednesday and Friday (C4, 12 years old).*
>
> *Hydroxyurea and folic acid for a long time, for sickle cell anemia... the time I don't know. All I know is that I take it at night, I'm the one who gets it (C5, 10 years).*

It highlights that of the schoolchildren interviewed, seven cited the medications used and their schedules for maintaining their health, however, the statements indicate that they do not effectively know their actions, as can be seen in the following statements:

> *I take hydroxyurea to avoid hospitalization, avoid crisis (C1, 12 years).*
>
> *It helps me to improve sickle cell anemia (C2, 7 years).*
>
> *It is a vitamin to help the disease, to cure the disease (C4, 12 years old).*

The people who contribute to the internalization of knowledge and therefore to the maintenance of health are the parents, the nurse and the doctor, cited by six schoolchildren:

> *My mother talks and the nurse said it is to improve (C2, 7 years).*
>
> *The doctor said she has to take it (C5, 10 years).*
>
> *The doctor takes care of me, teaches me what I have to do. I follow the doctor's and my father's orders... (C9, 12 years).*

> *My mother asks: did you take the medication today? Not to get sick and not be hospitalized (C11, 10 years).*

The school receives information from other people to take the maintenance medication, with the justification of not getting sick or for health improvement, however, they do not seem to understand that, even if they take the medication regularly, the falcemic crisis can occur, because other conditions interfere in its manifestation.

d) Food

The types of food consumed by schoolchildren and their knowledge of healthy foods have also been addressed and are described below.

All reported eating variations of food groups, such as carbohydrates, proteins, sweets, cereals, vegetables, fruits and vegetables, as described below:

> *Bread with butter, stuffed biscuit... rice, beans, meat, eggs, instant noodles (C3, 10 years).*
>
> *Salt bread, rice, beans, meat, banana... lettuce salad, carrot, tomato... at school I eat cake. (C14, 11 years old).*

Schoolchildren report consuming predominantly rice, beans and meat at large meals, but on the other hand most consume other foods they consider unhealthy, such as those rich in fat, sugar and salt:

> *French fries, biscuit with filling, chips, ice cream, chocolate, lollipop, snacks, and biscuit, because it has a lot of sugar (C2, 7 years).*
>
> *I eat it almost every day. It gives stomachache, tooth decay, toothache (C8, 12 years).*
>
> *Fried salty, biscuit. These things with a lot of fat hurt the gallbladder (C9, 12 years).*

These data showed that even though they were aware of the damage to health caused by unhealthy foods, they continued to eat them. In this context, it can be said that schoolchildren internalized the knowledge about food consumption and health, however, they were not able to stop consuming the food considered unhealthy, showing that they had not internalized the care of their own body with regard to food.

d) Clothing

This thematic unit presents the use of clothing suitable for the climate. All the schoolchildren highlighted the importance of wearing clothing appropriate to the climate:

> *If I feel too cold I might have a crisis. If I feel too hot, it happens. I start to feel bad, feeling short of breath (C1, 12 years).*
>
> *I put on pants, jacket. If I get too cold, I may get an arm pain, a headache (C8, 12 years).*
>
> *I put on cold blouse and long pants because of the pain. In the heat, dress, blouse and shorts because it can also give pain (C13, 12 years).*

The care with the choice of clothes in winter or on the coldest days was shown to the one of greatest concern, considering that it was in the cold environment that most of them reported pain when they were not dressed properly. Thus, it can be said that this care was internalized through the experience of pain.

## DISCUSSION

In the last decades, policies aimed at providing integral health care to people living with sickle cell disease have been progressively strengthened, which has contributed to reduce the invisibility of the disease, which has been cultivated throughout the last century.

In the case of children, early diagnosis of sickle cell disease may mean the opportunity of access to adequate care already in the first months of life. As children grow up, they have the opportunity to be assisted by a multidisciplinary and humanized team so that, together with their family, they are prepared for self-care.[12]

In this sense, some precautions are recommended to avoid dehydration, such as wearing clothing suitable for the climate, maintaining a higher frequency of water intake, avoiding intense physical exercise to minimize insensitive loss and oxygen demand. These are examples of care that can be learned and implemented by the child.

Dehydration is a factor that precipitates flares in children with sickle cell disease, as they have more body water than adults and require more water to eliminate water-soluble waste through the kidney.[7,13] Body hydration is very important, as red blood cells become sickle-shaped when they lose water, increasing the risk of vaso-occlusion, causing pain, stroke and damage to organs.[14]

The maintenance of body hydration by schoolchildren with sickle cell disease is usually achieved by means of various liquids, as evidenced in this study. On the other hand, although water has been the most cited liquid, its value has been discredited by schoolchildren in terms of first choice to avoid sickle cell crisis. It is also noteworthy the capacity of some schoolchildren to have internalized the knowledge about liquids that are not good for health, through repeated negative experiences, as in relation to abdominal pain. On the other hand, they have not internalized the care related to this issue, because despite knowing that they are harmful, they continue consuming such liquids. In this context, it should also be considered that the unavailability of healthy liquids was not mentioned by the participants.

It is through repeated experiences that the child learns, mentally, to plan his activity and, throughout his development, presents an increasing ability to control his own behavior. This is possible because external activities and interpersonal functions are transformed into internal, intrapsychological activities, that is, internalization mediated by the use of signs and instruments occurs.[9] In this context, it is important to highlight that liquids were the mediators of learning about the importance and effects of liquids on the body of the schoolchild.

In addition, bladder elimination is directly related to the ingestion of water, because the more liquid ingested, the greater the need for elimination. In the school context, schoolchild elimination with sickle cell disease is usually not attended, which may result in less fluid intake and higher risk of sickle cell crisis, or even renal failure over time.

Water deprivation in sickle cell patients associated with low O2 concentration, hypertonicity, and low pH of urine triggers deformation of the red blood cells (sickling process), a result of increased blood viscosity, edema, and vascular obstruction that predisposes to ischemia and renal microcirculation infarction.[15] As a result of kidney damage, a person with sickle cell disease has difficulty concentrating urine and produces large amounts of diluted urine. Therefore, they need to go to the toilet more often and this should not be limited.[14]

On the other hand, pedagogical teams need to be enlightened as to the particularities of those living with sickle cell disease, recognizing the child's right to meet its elimination needs as many times as necessary, regardless of fixed hours. Strategies should also be considered to make it easier for children to go to the bathroom without causing discomfort or embarrassment to the child.[14]

The reality of living with a disease such as sickle cell anemia does not prevent the child from developing play/playing activities according to the types of play performed by children in general. At the same time, for Vigotiski,[9] playing broadens children's possibilities of interaction with other children, people and the world, establishing themselves as learning mediators in the children's universe.

In this context, based on their experiences, the surveyed students demonstrated that they internalized some activities developed and the time of exposure to certain temperatures as triggers of falcemic crisis, which encouraged them to cease activity and rest.

By modifying behavior during play or playing in an attempt to avoid a crisis of pain, the schoolchild demonstrates having internalized a care that, according to Collière,[8] is maintainer of his health.

Children with sickle cell disease are able to demonstrate their ability to distinguish triggering factors from pain, which may serve as a protective mechanism for them,[16] and it is from the age of six that children are able to understand their responsibilities towards sickle cell disease and recognize that this condition of chronically ill patients forces them to adopt certain behaviors, unlike other children,[17] which was not evidenced in the present study.

Infections, cold and humid climate, pollution, dehydration, intense physical activity, stress, and sudden changes in temperature are the main precipitating factors of pain crises in sickle cell disease, so it is recommended to keep it warm and not to engage in intense physical activity.[14]

In the imminence of the falcemic crisis, schoolchildren reported using analgesics as a healthcare remedy. According to Ministry of Health guidelines, people living with sickle cell disease are advised to take this group of medications when necessary.[3] Dipyrone, for instance, is an analgesic and antipyretic widely used by this population.[18] On the other hand, the use of hydroxyurea and/or folic acid in continuous use to maintain the health of children with sickle cell disease has been mentioned.

Hydroxyurea is a drug used in sickle cell disease, leading to clinical and hematological improvement, reducing vaso-occlusion episodes by increasing fetal hemoglobin (HbF) concentration in 60% of treated people and decreasing polymerization of defective red blood cells and vascular adherence.[18] Although HbF protection mechanism in sickle cell patient has not been fully established, there is a positive association between HbF and oxygen saturation (SpO2). Thus, considering the pathophysiology of the disease, it can be said that increasing HbF reduces the severity of the disease in part by increasing SpO2.[19]

Folic acid is essential for the cellular multiplication of all tissues, including the figurative elements of blood[20] and is regularly recommended for patients with sickle cell disease,[21] however, not all of them necessarily make use of it.

Faced with the care of health maintenance and repair through the use of medication, it was contacted in this study that schoolchildren were able to internalize the use of analgesics directly related to the cessation of pain, that is, schoolchildren are aware of the use of hydroxyurea and/or folic acid, however, they are unaware of the action of these medications.

In this context, the interaction with the mother, the nurse, the doctor and the father, highlighted in the speeches of the participants, contributed to the internalization of this knowledge, considering that learning is a joint action that initially occurs on the external level, in the interaction with other people and, later, on the individual, internal level. This, in a certain way, drives the child's development processes, which would not be possible otherwise.[9]

In addition, in relation to their care, schoolchildren mentioned the need for a healthy diet, as a fundamental care for their growth and development and cited the various food groups that are part of their daily diets. However, it was found that foods such as sweets, savories and fried foods are often consumed by many of them, even though they are considered to be harmful to health. It has been found that schoolchildren have been internalized in their knowledge of the quality of food consumed, but have been unable to change their eating behavior for the benefit of their health. In this context, it should also be considered that the availability of healthy food depended not only on the interviewees, considering the complexity of the subject. Nevertheless, no participant associated the use of inappropriate food with their difficulty to obtain certain foods.

Although sickle cell disease itself does not require a differentiated diet, it must be balanced and rich in micro and macronutrients to minimize the risks of chronic malnutrition and delayed growth and development, which would negatively affect the prognosis of the disease.[22]

Finally, with regard to health care through the use of clothing appropriate to the climate, schoolchildren showed greater concern for the cold climate. Clothing can be considered a tool, a mediating element, used by the child as a link with the environment for the acquisition of knowledge[9] on how to dress properly to avoid pain.

Thus, the study points out that the school has internalized the care with the use of appropriate clothing, mediated by the experience of pain.

Exposure to cold is a triggering factor of the falcemic crisis. Children and adolescents with sickle cell disease may get sick when exposed to extreme heat or cold. Cold can make your health worse, and wearing clothing appropriate for the climate is a measure that helps prevent the crisis.[14]

The study showed that the internalization of care was due to the experiences of pain caused, in general, by the reduction of the ingestion of liquids, excess of play/playing and the choice of clothes inappropriate to the climate. Also, the use of analgesics was internalized for its immediate effect on pain. The care related to the elimination, the quality of food ingested and the use of maintenance medications such as hydroxyurea and folic acid are reproduced and not internalized, because schoolchildren do not know the reasons for the need for these other cares, and they maintain their conduct.

It can be seen that the signs and instruments used for the internalization of care were: liquids, jokes, medicines and clothes. The internalization happened in the interaction of the child with the parents, mainly the mothers who demand from their children the necessary care, but without explaining the reasons for such care.

Even so, adjustments are observed in the daily routine of families of children with chronic diseases, who find different strategies to ensure child care.[23]

It is considered that the process of internalization occurs throughout the development and consists in transforming an interpersonal process into an intrapersonal one. The functions in the child's development appear initially at the social level, in the interaction with the people of his coexistence, after that, the transformation occurs, internally, in the child. The internalization originates from the real relationships between people who interact with each other.[9]

In this context, it is important to note the low involvement of health professionals in education actions, which is generally directed towards the legal responsible, resulting in little appreciation of the school as a subject capable of taking care of himself.

Thus, it is necessary to better develop the relational aspect of the care provided to children with chronic diseases to contribute to the process of internalization of body care.[24]

## FINAL CONSIDERATIONS

The internalization of care occurs or is effected by the experience of pain, the main sign of internalization and has occupied a transversal space in this process, because those who have had more frequent falcemic crises have internalized some care more easily. In other words, schoolchildren internalized care for fear of having the crisis, not for the knowledge they had about the disease or for observing the care they received. In addition, the signs and instruments used were mainly built in the context of the home, with the parents, especially the mother, being the main mediators.

It is concluded that schoolchildren are not valued as subjects capable of caring for themselves, especially in the hospital context, when health professionals make the guidelines directing them to the person responsible for them, omitting even the pathophysiology of the disease and all the care that may cause or prevent the sickle cell crisis, resulting in the reproduction of what they should or should not do, the family member being unable to justify certain care to the schoolchildren. On the other hand, school is not thought of as a place to maintain care for children with sickle cell disease because teachers are unaware of the clinical situation children may experience when limited to drinking liquids and using the bathroom. In this way, it is necessary to articulate the hospital with the school, through permanent actions of continuous education, aiming to better instrumentalize the teacher.

Thus, by revealing the process of internalization of care by the schoolchild, it is hoped to contribute to a better targeting of individual assistance provided to children, valuing them as subjects of rights, as well as helping in the construction of public policies, especially with regard to school health, so that they protect vulnerable populations and help to achieve comprehensive health care, especially for children with chronic diseases, such as the population studied.

Among study limitations, the complexity of internalizing school care with sickle cell disease in a socially complicated context stands out. Therefore, it is proposed to carry out new studies, broadly addressing the social context.

It is recommended the development of new studies on the subject and theoretical-methodological approach in order to contribute to the nursing care practice meeting the needs of children, particularly schoolchildren with sickle cell disease.

## AUTHOR'S CONTRIBUTIONS

Study design. Acquisition, data analysis and interpretation of results. Writing and critical review of the manuscript. Approval of the final version of the article. Responsibility for all aspects of the content and integrity of the published article. Luciana de Cassia Nunes Nascimento. Tania Vignuda de Souza. Data analysis, interpretation of results and critical review of the manuscript. Approval of the final version of the article. Responsibility for all aspects of the content and integrity of the published article. Isabel Cristina dos Santos Oliveira. Rita de Cássia Melão Morais. Maria Angélica Carvalho Andrade.

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