



## Search for the treatment of pain crises in sickle cell disease: mothers' conceptions *Busca pelo tratamento da crise algica na doença falciforme: concepções das genitoras* *La búsqueda por el tratamiento del dolor de la enfermedad falciforme: concepciones de las genitoras*

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### ABSTRACT

**Objective:** To know the aspects involved in the search for treatment of pain crisis in sickle cell disease based on mothers'/caregivers' conceptions. **Methods:** This qualitative descriptive study was carried out between the months of July and November 2017 at the Center for the Care of People with Sickle Cell Disease in Feira de Santana, Bahia, Brazil, with six parents/guardians of children and adolescents aged 6-18 years. The data were collected through semi-structured interviews. The data were analyzed based on thematic content analysis criteria and presented in four categories: "Reasons that lead to the search for specialized centers", "Difficulties encountered in the path to the health center/logistics", "Infrastructure/lack of professional awareness for urgent care", and "Conditions for hospital discharge/feelings at hospital discharge". **Results:** The main reasons for looking for a specialized center were pain crises, fever, and previous infections. The difficulties encountered in the path/logistics refer to the long path between home and hospital, lack of own vehicle, and the delay in service provision. The hospital infrastructure was considered comfortable, but cases of disregard of pain and lack of comprehensive care were associated with lack of professional awareness of the problem. The discharge conditions were related to pain relief, bringing feelings of joy at hospital discharge. **Conclusion:** The findings reveal factors related to the difficult access to health services due to social vulnerability and a need need for effective health education strategies to train parents/guardians in home care with the aim of preventing crises in addition to creating new specialized centers to facilitate the provision of humanized care to the patient and family.

**Descriptors:** Children's Health; Sickle cell anemia; Pain; Therapeutic.

### RESUMO

**Objetivo:** Conhecer os aspectos envolvidos na busca por tratamento da crise algica na doença falciforme, a partir das concepções das genitoras/responsáveis. **Métodos:** Pesquisa descritiva, de abordagem qualitativa, realizada entre os meses de julho a novembro de 2017, no Centro de Atendimento à Pessoa com Doença Falciforme em Feira de Santana, Bahia, Brasil, com seis mães/responsáveis de crianças e adolescente entre 6 a 18 anos. A coleta de dados se deu por meio de entrevistas semiestruturadas. Os dados foram analisados pelos critérios da análise de conteúdo temática e apresentados em quatro categorias: "Motivos que levaram à procura de unidades especializadas", "Dificuldades encontradas no trajeto à unidade de saúde/logística", "Infraestrutura/falta de sensibilização profissional para o atendimento de urgência" e "Condições para alta/sentimentos na alta hospitalar".



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**Resultados:** Os principais motivos para procura de uma unidade especializada foram as crises algícas, bem como febre e infecções progressas. As dificuldades encontradas no trajeto/logística referem-se ao longo percurso entre o domicílio e o hospital, falta de veículo próprio e a demora no atendimento. A infraestrutura hospitalar foi considerada confortável, porém casos de subjugação da dor e falta de atendimento integral foi associada à falta de conscientização profissional para o problema. As condições de alta foram relacionadas ao alívio da dor, trazendo sentimentos de alegria na alta hospitalar. **Conclusão:** Os achados revelam fatores relacionados à dificuldade de acesso aos serviços de saúde devido a vulnerabilidade social, havendo necessidade de estratégias efetivas de educação em saúde para capacitar os pais/responsáveis no cuidado domiciliar, visando a prevenção das crises, além de criação de novas unidades especializadas para facilitar atendimento humanizado ao paciente e familiar.

**Descritores:** Saúde da Criança; Anemia Falciforme; Dor; Terapêutica.

## RESUMEN

**Objetivo:** Conocer los aspectos de la búsqueda por el tratamiento del dolor de la enfermedad falciforme a partir de las concepciones de las genitoras/responsables. **Métodos:** Investigación descriptiva de abordaje cualitativo realizada entre los meses de julio y noviembre de 2017 en el Centro de Atención a la Persona con Enfermedad Falciforme de Faria de Santana, Bahía, Brasil, con seis madres/responsables de niños y adolescentes entre 6 y 18 años. La recogida de datos se dio a través de entrevistas semiestructuradas. Se ha analizado los datos por los criterios del análisis de contenido temático y se les ha presentado en cuatro categorías a continuación: "Motivos que llevaron a la búsqueda de unidades especializadas", "Dificultades encontradas en el trayecto hacia la unidad de salud/logística", "Infraestructura/falta de sensibilización profesional para la atención de urgencia" y "Condiciones para la alta/los sentimientos de la alta hospitalaria". **Resultados:** Los principales motivos de la búsqueda de una unidad especializada han sido las crisis de dolor así como fiebre e infecciones anteriores. Las dificultades encontradas en el trayecto/logística se dan por el largo recorrido entre el domicilio y el hospital, el hecho de no tener un vehículo propio y la tardanza de la atención. La infraestructura hospitalaria ha sido considerada confortable pero los casos de la dominación del dolor y la falta de la atención integral se han asociado con la falta de concienciación profesional del problema. Las condiciones de la alta se han relacionado al alivio del dolor con sentimientos de alegría en la alta hospitalaria. **Conclusión:** Los hallazgos revelan factores relacionados con la dificultad de acceso a los servicios de salud debido a la vulnerabilidad social con la necesidad de estrategias efectivas de educación en salud para la capacitación de los padres/responsables del cuidado domiciliario con el objetivo de prevenir las crisis además de la creación de nuevas unidades especializadas para facilitar la atención humanizada del paciente y su familia.

**Descriptor:** Salud del Niño; Anemia de Células Falciformes; Dolor; Terapêutica.

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## INTRODUCTION

Sickle cell disease (SCD) is the term used to define genetic alterations characterized by the presence of an abnormal hemoglobin called hemoglobin S (HbS). These morphological changes cause deformities in the shape of red blood cells, thereby limiting their lifespan<sup>(1,2)</sup> and resulting in several clinical manifestations, such as severe pain in the joints, back and abdomen, frequent lung infections, cerebral infarction, splenic sequestration, priapism, hand-foot syndrome, retinopathy, and other morbid occurrences that an individual may experience<sup>(3)</sup>.

The early diagnosis of SCD is a positive measure to reduce the morbidity and mortality of SCD. It consists of the heel prick test performed on every newborn in the first week of life, as determined by the National Neonatal Screening Program, provided for in Ordinance 2.829 of December 14, 2012<sup>(4)</sup>. It is indispensable for monitoring, quantifying, and reducing the morbidity and mortality related to cases as there is no cure for the disease<sup>(3,5)</sup>.

The disease is a serious public health problem that originated in Africa and then spread to southern Italy, the Arabian Peninsula, India and, later, to the Americas following the immigration of African slaves. It is the most prevalent genetic disease worldwide, with 300 thousand new cases annually and a prevalence rate of 25% to 40% in African countries. In Brazil, the Hb S gene is found in 0.1% to 0.3% of the black population, mostly in the Southeast and Northeast regions<sup>(6,7)</sup>. SCD lethality rate is 80% in children under 5 years of age who do not receive adequate health care. The mean life expectancy of people with SCD has already reached 48 years<sup>(3)</sup>.

Due to the occurrence of involuntary immigration of African peoples to Brazil, the country has become so miscegenated that SCD currently affects all racial groups, including self-declared Whites. However, its prevalence is higher in the black population<sup>(5)</sup>.

SCD causes several symptoms in individuals, and scientific evidence shows that pain is the main reason for seeking medical care and hospitalizations in childhood, which can compromise social and family interaction due to reduced participation in daily activities, relationships with little affection, aggressive discussions, and lack of control

over the behavior of adolescent children. In the school environment, these individuals are subject to constant absences, constraints due to symptoms such as urinary incontinence and jaundice, pain crises, inability to participate in certain sports activities, and social and emotional disorders<sup>(8-11)</sup>. In adolescence, given the various psychological and somatic changes inherent to the growth process, individuals react better to the symptoms of SCD as they perform activities to improve their health and well-being and usually follow specific medical guidelines<sup>(12,13)</sup>.

It is important that family members seek to understand the pathology and the correct medical advice to minimize pain and reduce the risk of secondary hospitalizations as crises are frequent throughout life and vary in intensity. In most cases, understanding is considered imprecise and generally comes from unreliable sources, such as social media groups, which can jeopardize the health of children and adolescents with SCD. Thus, there is a need to evaluate the attitudes to be adopted while delivering care since they can prevent suffering, hospitalizations and deaths<sup>(14)</sup>.

In addition to the considerations outlined above, it should be noted that the present study is in line with the National Health Promotion Policy (*Política Nacional de Promoção da Saúde – PNPS*) as it reiterates the process of construction and production of health and fully complies with the guidelines and principles of other policies and technologies developed in the Brazilian health system with its intense participation in information provision for execution of policies and services<sup>(15)</sup>. Thus, in view of the difficulties faced by families and the manifestations of pain in individuals with SCD, which involve a daily routine that demands caution with the care that must be delivered, there is a clear need to resort to treatment in health institutions with the due technical and scientific support for that.

Thus, our research question is: what perceptions do mothers/guardians of children and adolescents with sickle cell disease have about the search for treatment of pain crises? The present study aimed to understand the aspects involved in the search for the treatment of pain crises in sickle cell disease from the perspective of mothers/guardians.

## METHODS

This descriptive study used a qualitative approach, which was considered the best strategy to meet the proposed objective as its main characteristic involves obtaining data through direct contact between the researcher and the situation studied, with emphasis placed more on the process than on the product. This approach is concerned with portraying the participants' perspectives<sup>(16)</sup>.

The study took place at the Center for the Care of People with Sickle Cell Disease in Feira de Santana, Bahia, Brazil. Located in Mid North Bahia, circa 116 km away from the capital Salvador, the city had an estimated population of 614,872 thousand inhabitants in 2019<sup>(17)</sup>. The center, which was implemented in 2012, serves an average of 430 patients with SCD of all ages and provides the following services: immunization, multidisciplinary care delivered through specialized consultations, health education, laboratory tests, and treatment of related diseases<sup>(18)</sup>.

Six mothers/guardians of children and adolescents with SCD participated in the study. They were individually invited to participate while waiting for the outpatient consultation during the period from June to November 2017 on the premises of the aforementioned institution. All the participants agreed to collaborate with the research, and no one refused to participate.

Inclusion criteria were: being a mother/guardian of children and adolescents aged 6-18 years with SCD receiving care at the Center for the Care of People with Sickle Cell Disease. Exclusion criteria were: parents/guardians of children and adolescents with other comorbidities and who were unable to participate in the study due to cognitive difficulties.

Data were collected through semi-structured interviews<sup>(16)</sup> using the following guiding question: what are your perceptions of the search for the treatment of your child's pain crisis? The interviews were recorded using smartphones after obtaining the participants' consent.

Sampling was terminated when the research objective was achieved based on thematic saturation criteria, which implies, according to the researchers' evaluation, a repetition of response patterns in the interviews<sup>(19)</sup>. The audios were then transcribed, organized, coded and categorized according to thematic content analysis criteria (pre-analysis, material exploration and treatment of results)<sup>(20)</sup>.

In the pre-analysis, the main concepts listed are systematized. The second phase, exploration of the material, consists in coding operations, appreciating the text excerpts into registration units, the meaning of collection rules, and the classification and association of information into categories. The third and final phase consists of the treatment, inference and interpretation of results, in which the information is condensed and highlighted for analysis in a reflexive and critical way, thereby resulting in inferential interpretations<sup>(20)</sup>.

The results of this study portray the categories that emerged from the study: Reasons that led to the search for specialized centers, "Difficulties encountered in the path to the health care center/logistics", "Infrastructure/lack of professional awareness for urgent care" and "Conditions for discharge/feelings at hospital discharge".

This study is part of the project titled "Internalizing and externalizing behavior problems in children and adolescents with sickle cell disease" approved by the Research Ethics Committee of the Bahia Adventist College (Approval No. 2.968.064). Participants who consented to collaborate signed an informed consent form that guaranteed anonymity and followed the principles of bioethics established in Resolution 466/2012 of the National Health Council. Participants were identified using the letter I, referring to "interviewee", and then numbered sequentially following the random order of the interviews – I1, I2... and so on.

## RESULTS AND DISCUSSION

This section describes the categories that emerged from the study "Reasons that led to the search for specialized centers", "Difficulties encountered in the path to the health care center/logistics", "Infrastructure/lack of professional awareness for urgent care" and "Conditions for discharge/feelings at hospital discharge". These will be analyzed in the light of the literature that discusses the theme.

### Reasons that led to the search for specialized centers

This category describes the main reasons for the search for a specialized center by parents/guardians of children/adolescents with SCD. The reasons include intense and persistent pain crises and fever. The parents said that in the face of these situations they care more about their children and seek help to alleviate the children's symptoms and suffering. In addition to these reasons, presence of past infections (urinary, respiratory or intestinal) was also mentioned, thus justifying the occurrence of fever, as highlighted in the following statements:

*"We go to the hospital in the following circumstances: when the pain doesn't go away or when there's fever of 38°C because I always worry when it comes to fever, I don't wait for it to reach 39°C. In these situations, there was always an association with some infection: urinary, respiratory or intestinal, which had already occurred previously and lasted an average of ten to fifteen days." (I1)*

*"When the pain is intense, I take him to the hospital." (I2)*

It is known that pain crises are the most common manifestation of SCD and the main cause of hospitalization. Pain crises generally last from four to six days, but they can persist for weeks. Pain management in children is particularly difficult, both due to the challenge of measuring the intensity of this subjective symptom and the lack of efficient and specific guidelines<sup>(21)</sup>.

A study carried out in Cotonou, Benin, Africa, with 204 emergencies related to sickle cell disease in patients aged 5 to 59 years showed that various manifestations can occur and, in some cases, endanger the patient's life. Complications were, in most cases, acute, and the main cause of hospitalization was vaso-occlusive crisis (63.7%) with presence of severe pain localized in the osteoarticular region (70.1%), abdomen (12, 7%), chest (4.9%), penis (4.9%), and brain (1%). Infectious complications were also found and represented mainly by bacterial infection with no localized focus (27.9%) and lung diseases (18.6%)<sup>(22)</sup>.

In line with these findings, a study carried out in Al-Madinah Al-Munawarah, Saudi Arabia, with 739 children with SCD over a 6-year period found that the main reasons for hospitalization were vaso-occlusive crises (49%), acute chest syndrome (20.9%), infections (17.5%) and acute anemia (8.1%)<sup>(23)</sup>.

In addition to the clinical condition of pain in the search for specialized centers, it is known that patients with SCD are more likely to acquire infections, one of the main indicators of this condition being periods of fever, a worrying factor that should be considered an emergency and receive immediate medical attention for proper management upon clinical suspicion and laboratory confirmation.

Infections lead to constant hospitalizations and are highlighted as the third most common cause in children with SCD (17.5%)<sup>(18)</sup>. Increased susceptibility to bacterial infections is a major factor in cases of morbidity and mortality in patients with SCD, especially in early childhood. In that regard, a study carried out in 36 pediatric hospitals in the Metropolitan Region of the United States of America (USA) with 4,853 consultations of children aged three months to 18 years with SCD and fever highlighted that the average length of hospital stay was two days and that procedures such as blood count (91.7%), reticulocyte count (93.5%), blood cultures (93%), radiographs (68.5%) and use of parenteral antibiotics (91.7%) were performed<sup>(24)</sup>.

Accordingly, a study carried out at the Child Emergency Service of the University of Calabar Teaching Hospital, in Southern Nigeria, with 633 children concluded that the main symptom presented was fever (73.9%). The study also highlighted that children under five were most vulnerable to infectious diseases, with the most common diagnoses at admission being respiratory tract infections (53.7%) and malaria (52.4%). Additionally, the average length of hospital stay was 48 hours. It was also observed that children who received alternative care before admission had a longer average hospital stay, which reinforces the importance of health education for adequate treatment at home<sup>(25)</sup>.

A national study carried out in a university hospital in Juiz de Fora, Minas Gerais, Brazil, corroborates these data as it concluded that the pain crisis is the most frequent reason for seeking emergency medical care and hospitalization, with the main triggers of the crisis being infections, exposure to cold, local trauma and dehydration<sup>(26)</sup>. Another study that was also carried out in Minas Gerais, Brazil, with the aim of describing hospital admissions of children with SCD screened by the State Neonatal Screening Program in hospitals of the Unified Health System (*Sistema Único de Saúde – SUS*) found that the most frequent cause of pediatric hospitalization was pain crisis, with an average length of stay of five days<sup>(27)</sup>.

### Difficulties encountered in the path to the health care center/logistics

This category clearly shows that the long path between home and the hospital and the lack of a vehicle for transportation were the main difficulties mentioned by the participants. They said that they used public transport or a neighbor's car due to their precarious financial conditions. Moreover, when the situation was extremely critical, they resorted to a taxi as a faster alternative. In addition to these problems related to means of transportation, there was also a delay in the provision of care at health care services, as described in the following statements:

*“As it is a long path to reach the hospital, I ask the child's father to borrow the car from the neighbor, as the hospital is far away. The father accompanies us when he can, but he is not the one who drives. He calls a driver, and we all go together. [...] Sometimes, when she feels pain, I quickly administer dipyrone or paracetamol before leaving home. When I get to the center, I tell the doctor about the medicine she took.” (13)*

*“If he reports a slightly intense pain, I will just take the bus since, given my financial conditions, I am unable to afford a taxi. However, when it is urgent, I hire someone I know to take us there, as I can pay them later.” (14)*

*“I take the bus to the Children's Hospital, which is located in the neighboring city, as there is no adequate service close to home for his care.” (15)*

*“When we arrive at the center, sometimes the service takes a while, but in the polyclinic, as the professionals already know us, it lasts on average 30 minutes.” (13)*

Such difficulties have been reported by other researchers in a study carried out in Lublin, Eastern Poland, with 540 parents of children and adolescents. The study concluded that inhabitants of rural areas face greater difficulties in accessing the service due to longer distances in relation to the inhabitants of urban areas<sup>(28)</sup>.

Another study conducted in Northeastern Myanmar, Asia, with 4,235 participants, found geographical barriers, gender diversity and financial burdens to be the main causes that significantly restrict access to health services in that region, which requires a system of adequate primary health care delivery, financial protection strategies and special health care<sup>(29)</sup>.

Furthermore, in a study conducted in 97 villages in Lahe Township, Myanmar, Asia, poverty was a barrier to access to health services due to the costs and lack and/or difficulty of getting transportation to get to the health center. In addition to long distances, people also faced the uneven distribution of transport infrastructure, with a limited number of dangerous roads and terrain conditions, which made villages inaccessible during heavy rains<sup>(30)</sup>.

In addition to these factors, a study carried out in Southern California with 39 parents to analyze the barriers to care and the quality of primary care services for children with SCD reported other difficulties, such as the inability to contact doctors or clinics to schedule appointments, prolonged waiting time for care and failure to take a day off from work to accompany the child<sup>(31)</sup>.

It should be noted that the difficulties are present at all levels of complexity. A study carried out in the municipality of Janaúba, Minas Gerais, Brazil, with 14 community health workers (CHW) who covered areas where people with SCD lived concluded that the demand for a primary health care center is minimal and nonexistent for some professionals. The main reasons that lead people with SCD to seek the primary health care center were the scheduling of exams, scheduling of specialized consultations, growth and development consultations, and situations of complications (pain crises and fever). In these situations, the demand for care was associated with the fact that the health center was the place that was closest to their homes<sup>(32)</sup>.

### Infrastructure/lack of professional awareness for urgent care

This category addresses the infrastructure and the lack of professional awareness for urgent care. Regarding the infrastructure of health services, the results are positive, with reports of comfortable hospital environment. However, there are reports of lack of professional awareness, such as disregard of pain, lack of comprehensive assessment and variable service duration. Reports were dichotomous:

*“The hospital environment is comfortable: there is a chair for me, but, as I am thin, sometimes I lie in bed with him, as he does not like to sleep alone.” (14)*

*“When my daughter is experiencing a pain crisis and I need to take her to the emergency, there is a delay in the care. Triage is quick, but the service takes a long time. Once she had an intense pain crisis and her father took her to the emergency room without going through triage. His conduct was questioned, which generated discussion at the reception. The father explained that his daughter suffered from severe pain and could not wait while getting worse and worse. There was another time when he had to break into the on-call room due to the delay in the service and found doctor sleeping. During the service, the father argued with the doctor, who said he would call the police. Because of that, I realized that the medical care was not the same, he did not have the same commitment. When the shift changed and a new doctor came in, my daughter was assessed in a more appropriate way and then referred for blood transfusion.” (16)*

A study carried out with children admitted to a University Hospital in Juiz de Fora, Minas Gerais, Brazil, found that the time taken to intervene on pain crises is long, with a 25.2-hour waiting time, which portrays the difficulty of accessing the health service and the lack of awareness regarding the need for quick care. The care provided to patients with SCD can be improved through the implementation of an individual care plan and effective regulation of emergency care, thereby helping users more quickly and effectively<sup>(21)</sup>.

Issues related to infrastructure are also reported by other researchers in a study carried out at the Bugando Medical Center, in Mwanza, Tanzania, with 20 caregivers of pediatric patients receiving palliative care and 14 employees of the multidisciplinary team. The study used participant observation to highlight that the main barriers encountered are related to financial needs (100%), such as resource constraints and low household income, which inhibits the team from providing basic medical care and comfort at the end of life, and infrastructure barriers (86%), such as deficiencies in hospital resources, which negatively affect the ability to provide satisfactory care. However, the study identified strengths and resources in the community that could help overcome such barriers, such as the wealth of intangible resources in the wards, exemplified by the spirit of collective action between patients and staff in order to raise awareness and increase respect and fight for better access to medications. In addition, the religious focus of both parties can serve as a source of comfort and resilience, which are necessary to continuously provide palliative care in precarious places<sup>(33)</sup>.

Health institutions also need to establish as a priority goal the integral and safe care for the needs of their patients, with activities based on effective scientific, philosophical and methodological precepts to guarantee a quality care model considering the constant improvements in practices that seek comprehensive care to solve health needs<sup>(34)</sup>.

### Conditions for discharge and feelings at hospital discharge

This category highlights that the conditions for hospital discharge are related to pain relief, bringing joy to family members in being able to return home, as described below:

*“After a few hours, when she no longer reports any pain, we are discharged and return home.” (13)*

*“When the doctor says he is discharged, we get very happy, because we want to leave.” (14)*

This feeling is described by other researchers who studied this issue. A study carried out in a public pediatric hospital in Bahia, Brazil, analyzed the perception of 10 family members/caregivers of children with loss of skin integrity and concluded that the feelings expressed at the time of discharge were antagonistic, i.e., there was certain relief for the possibility of returning to their routines, joy, tranquility, fear, concern and impotence in the face of maintaining the child's care at home<sup>(35)</sup>.

Nursing professionals who monitor the process of hospitalization of children and adolescents also experience a series of feelings, expressing joy at the recovery and discharge of these individuals<sup>(36)</sup>. It is understood that hospital discharge causes several feelings, but it is essential that this moment happens properly, with the child in safe conditions to return home in order to avoid any risks of aggravation of the clinical condition already installed. Thus, there is a

need for an effective dialog between caregivers and medical professionals and health education actions delivered by the multiprofessional team in order to prevent complications and continue the proposed treatment appropriately.

A study carried out in Rio de Janeiro, Brazil, with 11 family members/caregivers of children with special health needs (CWSN) pointed out that hospital discharge occurred through a medical program that does not add family participation and a social practice marked by the preparation of mothers based on the forecast of discharge and a multidisciplinary approach focused on health education, in which nurses play a fundamental role as educators to help the family provide the necessary care at home<sup>(37)</sup>.

Although extrapolation of data is not feasible, it is possible to replicate the study so that similar perceptions can be identified in parents of children and adolescents with SCD from other locations, since the population with the highest prevalence of the disease has similar socioeconomic profiles, clinical aspects and care needs, as shown in the results presented by other researchers<sup>(8,38)</sup>.

The impact of this study for the PNPS refers to the need for managers and professionals to have an expanded view of social inclusion, which presupposes actions that guarantee access to the benefits of life in society for all people in an equitable and participatory way with the aim of reducing inequities<sup>(15)</sup>. In the case of children and adolescents with SCD, access to health services must be facilitated from leaving their homes to entering the health service so that they can have access to a more humanized service from the time they enter the service to discharge.

Some limitations of the present study should be highlighted, such as the fact that the data collection was carried out in a single Center for the Care of People with Sickle Cell Disease. This makes the pertinent narratives and characteristics of the members limited, but the possibility of reproducing these findings in other care institutions should not be ruled out since it is a comorbidity inherent to vulnerable populations. With regard to the scientific literature, there was a shortage of studies on the topic addressed in terms of categories, which limited a more comprehensive discussion.

## FINAL CONSIDERATIONS

This study showed that the main aspects related to the search for the treatment of pain crises in children with SCD by mothers/parents involve several factors. First, the search is linked to the difficult access to health services due to the social vulnerability of the interviewees.

Thus, it is suggested that health education strategies be effectively incorporated into outpatient centers to train parents/guardians in home care, thus reducing the number of readmissions. For the authorities and government officials, there is an urgent need for more specialized centers in regions with a higher number of cases of SCD to facilitate users' access. There is also a need for strategies aimed at facilitating accessibility to specialized centers and greater awareness among professionals in order to provide humanized care to the family and the patient with SCD.

## CONFLICTS OF INTEREST

The authors declare that there are no conflicts of interest.

## CONTRIBUTIONS

**Gabriel Santos da Silva** and **Karoline Dias Martins** contributed to the analysis and interpretation of data; and the writing and/or revision of the manuscript. **Brendo Vitor Nogueira Sousa**, **Elenilda Farias de Oliveira**, **Viviane Silva de Jesus** and **Ohana Cunha do Nascimento** contributed to the study conception and design; the acquisition, analysis and interpretation of data; and the writing and/or revision of the manuscript.

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