

# Drawing pain for children with sickle cell anemia: the pain that hurts, really hurts

*O desenhar da dor para as crianças com anemia falciforme: a dor que dói, dói muito*

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## ABSTRACT

**BACKGROUND AND OBJECTIVES:** Painful crises are part in the evolution of sickle cell anemia, is the more dramatic picture of variable intensity and location, caused by chronic hemolysis and vaso-occlusion, which alter the daily life of the patients. The objective of this study was to understand, by means of drawing, the repercussions and the coping strategies in situations caused by the painful crises of the sickle cell anemia, from the children's perspective.

**METHODS:** Exploratory, qualitative study, carried out in a pediatric referral hospital of Ceará, with five children diagnosed with sickle cell anemia. Data collection was performed from May to July 2016, by means of observations and drawings-story by Trinca. In the analysis, it was used the analysis of drawings content by Coutinho.

**RESULTS:** Two categories emerged: the pain that hurts and coping with pain. Every child identified its bigger meaning, evoking the repercussions of pain as the most striking element and more present in its life.

**CONCLUSION:** In face of the sufferings confronted by children with sickle cell anemia, it is necessary to create strategies that promote the implementation of public policies to prevent crises and treat the disease, modifying the course of the disease and improving the quality of life.

**Keywords:** Child, Pain, Sickle cell anemia.

## RESUMO

**JUSTIFICATIVA E OBJETIVOS:** As crises dolorosas fazem parte constante na evolução da anemia falciforme, é o quadro mais dramático, de intensidade e localização variáveis, ocasionados pela hemólise crônica e vaso-occlusão, que alteram o cotidiano dos pacientes. O objetivo deste estudo foi compreender, por meio do desenho, as repercussões e as estratégias de enfrentamento em situações ocasionadas pelas crises dolorosas da anemia falciforme, a partir da perspectiva das crianças.

**MÉTODOS:** Estudo exploratório, qualitativo, realizado em um hospital de referência pediátrica do Ceará, com cinco crianças diagnosticadas com anemia falciforme. A coleta de dados ocorreu de maio a julho de 2016, por meio de observações e desenhos-estória de Trinca. Na análise, foi utilizada a análise de conteúdo para desenhos de Coutinho.

**RESULTADOS:** Emergiram duas categorias: a dor que dói e enfrentando a dor. Cada criança identificou o seu significado maior, evocando as repercussões da dor como elemento mais marcante e mais presente em suas existências.

**CONCLUSÃO:** Diante dos sofrimentos enfrentados pelas crianças com anemia falciforme, se faz necessária a criação de estratégias que favoreçam a implantação e implementação de políticas públicas com esforços de prevenir as crises e tratar a doença, modificando positivamente o curso da doença e melhorando sua qualidade de vida.

**Descritores:** Anemia falciforme, Criança, Dor.

## INTRODUCTION

The sickle cell disease (SCD) is part of the group of chronic diseases, and one of the main and most frequent inherited hematological diseases that affect the human population<sup>1</sup>. A genetic mutation affects the DNA and causes erythrocyte distortion by a type of mutant hemoglobin that replaces the glutamic acid by a valine at position six of the beta chain, resulting in an abnormal hemoglobin, forming the hemoglobinopathies<sup>2</sup>.

Of the hemoglobinopathies, sickle cell anemia (SCA) is the most serious, with the highest clinical significance<sup>3</sup>, of more impacting epidemiological character<sup>4</sup> and more frequent morbidity and mortality in the human population, especially in developing countries<sup>5</sup>. In Brazil, it is estimated an incidence of 1-3:1,000 live births with this type of disease<sup>6</sup>, with a tendency to achieve increasingly significant portions of the population due to the high degree of racial miscegenation, reaching blacks, browns, and whites<sup>7</sup>.

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Characterized as a public health problem, the SCA has a great diversity of clinical manifestation that appears during the life of the people affected, caused by chronic hemolysis and vaso-occlusion<sup>8</sup>. Such processes are related to the painful crises that occur unexpectedly, involving any organs or tissues, producing pictures of great severity and pain intensity that impact directly on the quality of life of the patient.

In the face of the SCA complexity of symptoms and complications, it is necessary that the family seek immediate care at health centers in order to evaluate the picture and prevent complications. However, when the pain intensifies, patients need to look for treatment at urgency or emergency units which may involve successive and frequent hospitalizations<sup>9</sup>. This period of illness impairs and changes the daily life of children and adolescents, being, according to the World Health Organization<sup>10</sup>, a chronic condition that requires continuous management, treatment, and care for many years or even decades.

The repercussions of a chronic disease and the treatment of children afflicted with SCA require constant care in relation to the therapy and to the determinants that may aggravate their health<sup>11</sup>. Thus, it is necessary that both the families and health professionals be knowledgeable about the disease, its manifestations and implications, as well as being inserted into the process of care to provide a better service.

In order to contribute to the understanding of the meaning that this chronic disease has for a child, this article aims at sharing revelations that can lead to reflections both for health professionals, who need to catch up on, and the families, with the purpose of rethinking care to better meet the unique needs of this population.

Given that, the objective of this study was to understand, by means of drawing, the repercussions and the coping strategies in situations caused by the painful crises of the SCA, from the children's perspective.

## METHODS

It is a qualitative, exploratory, descriptive research, carried out in a tertiary unit of the State of Ceará, located in the city of Fortaleza, a referral center for the treatment of children and adolescents with serious and high complexity diseases.

Five children participated in the study, with ages varying from 5 to 11 years, with a diagnosis of SCA, undergoing outpatient follow-up, who agreed to participate in the study. In order to ensure children's anonymity, letters with a number were used to identify them as C<sub>1</sub>, C<sub>2</sub>, C<sub>3</sub>, C<sub>4</sub>, and C<sub>5</sub>.

Data collection was performed from May to July 2016. We used the observations and drawing-story constructions by Trinca<sup>12</sup> since it is considered the best material by which one can understand the children's subjectivity involving their lives, history, their way of looking at and thinking about the reality. The Free and Informed Acknowledge Form (FIAP) was signed by the children and adolescents, and the Free and Informed Consent Form (FICT), by their legally responsible person.

The drawing-story technique was applied after establishing a contact with the researcher who explained this technique to the child. Next, the child was asked to produce one single drawing, focusing on what it meant to the child to have SCA. This happened in only one moment, in a free and individual manner, on a sheet of paper, and the duration varied from child to child. When finished, the child was invited to speak, clarify and/or explain what was produced, so assigning its meaning.

Data analysis was based on the assumptions of drawings content analysis by Coutinho<sup>13</sup>. This method meets the following analysis procedures: systematic observation of the drawings and themes; floating reading of the stories content; selection of drawings by graphic similarities and/or proximity to the themes; exploration of the material, identification of core sense, categorization, and processing of the results. After the data decoding and categorization, two broad categories emerged: **The pain that hurts and coping with pain.**

The study complied with the ethical principles of research with humans, being approved by the Research Ethics Committee of the State University of Ceará (UECE) and the Children's Hospital Albert Sabin (HIAS), under the opinion number 1.547.314.

## RESULTS

When the children were asked to draw their perceptions of coping strategies in relation to SCA, it was found that each has identified its bigger meaning, evoking pain as the most striking and more present element.

### The pain that hurts

In the first category, children represented in their drawings their personal experiences, with special emphasis to their representations in relation to pain, as noted in figure 1.

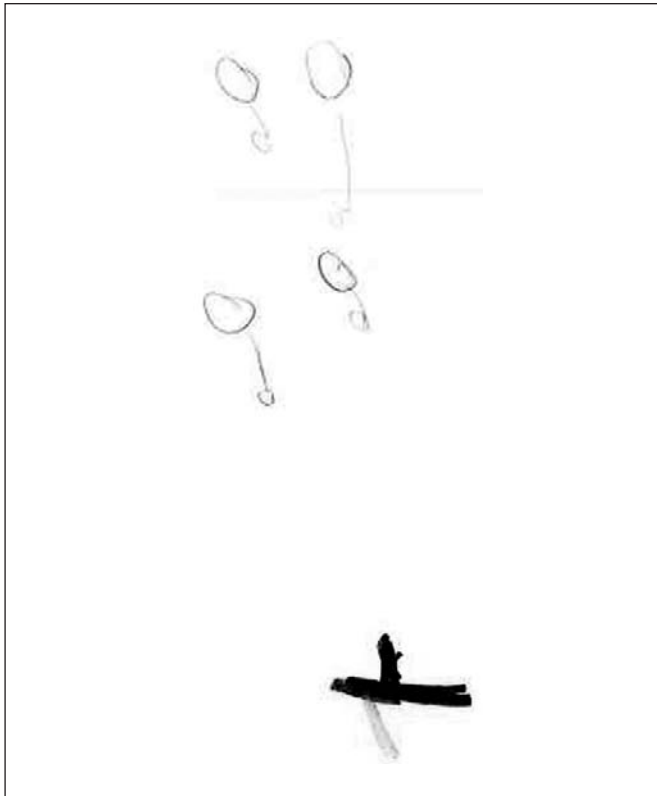
Figure 1 was produced by a 5-year old child who represented pain in the form of drops, with lines coming from above on the upper part of the sheet of paper. The drops reach his body directly, as shown by the line on the bottom of the paper.

When invited to talk about the production, he first pointed to the drops and said: - "that's the pain [...]". Then, pointing to the bottom part of the paper, he continued: - "[...] and this is me. It is my leg and my foot".

When asked about the reason of the drawing, C<sub>1</sub> he pointed again to the bottom part and answered: - "[...] it hurts here." Then he took the pencil in his hand, and started moving it upwards and downwards touching his foot, and said: - "[...] it's like this, see [...] like this [...] like this [...] and it hurts."

Another 5-year old child represented her pain showing the feeling she has when attacked by a painful crisis.

C<sub>2</sub> did something like a pain monster, which is on the right side of the paper, involving her and her mother. It's like an involvement, in the form of a balloon. The child drew herself twice, once alone and then she drew herself again in the arms



**Figure 1.** Drops of pain  
Source: 5-year-old child (C<sub>1</sub>).

of her mother, sitting on a rocking chair inside the balloon on the left. It is interesting of notice in this drawing that in the same way the child marked the monster, she also marked her own face as if she was emphasizing that she has been hit. When asked to talk about her work, the child, very casually started to tell what she feels when in pain: *it hurts, and the baby is sad and cries [...] it hurts, a lot [...] the baby is crying [...]* (Figure 2).

Then, she pointed to the girl with the marked face and continued:

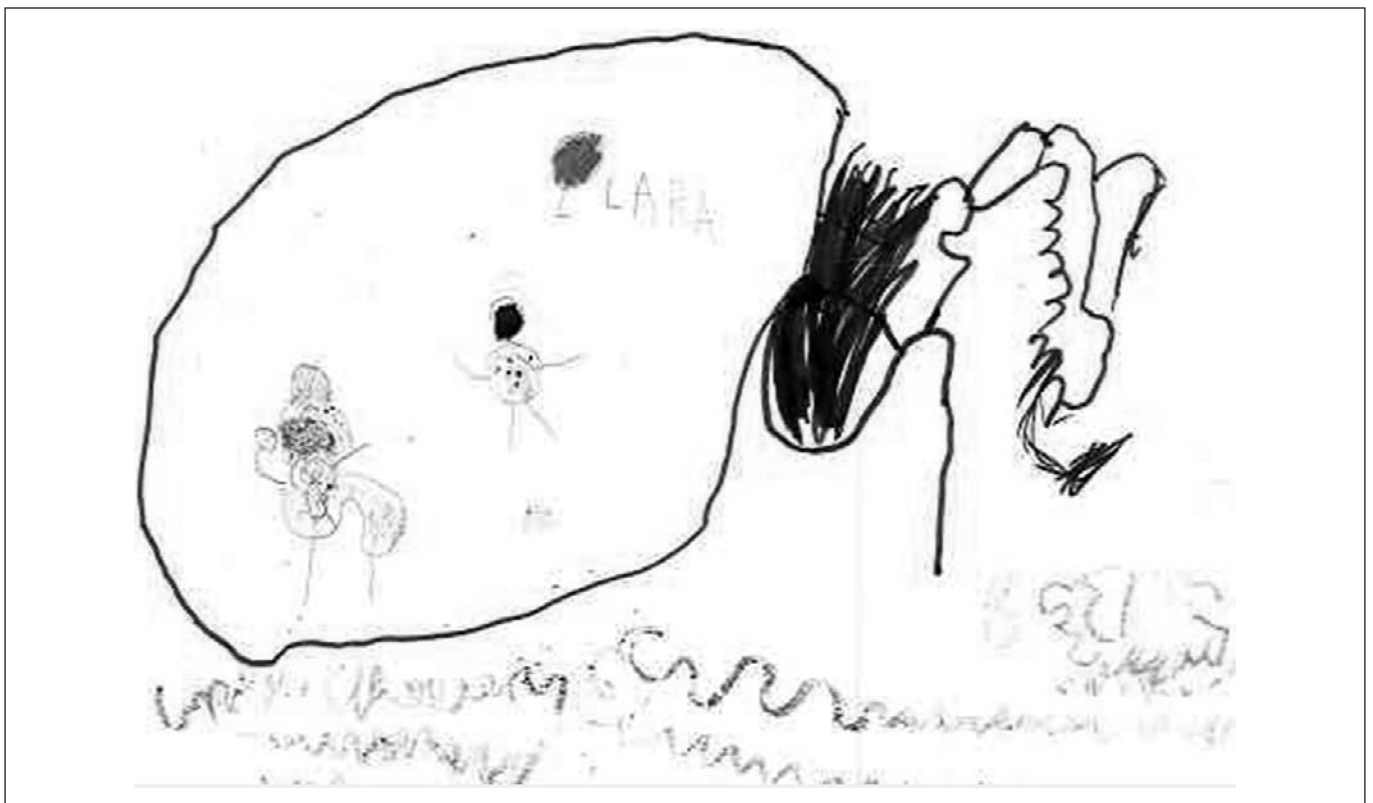
*"It hurts and the baby is sad and cries [...] it hurts, a lot [...] the baby is crying [...] then, her mom gives the soother medicine in the arm, in the other arm and feet [...] then, mom goes to the chair and takes the baby in her arms, sits and starts rocking to make the baby sleep [...] and [...] gives the baby the pacifier [...] and the baby sleeps and the pain goes away".*

When asked what would be the line that was involving her, on the right of the paper, C<sub>2</sub> looked at it and said: - *"[...] it hurts, is bad, makes the baby cry."*

In the third drawing, we see, once again, another child representing its pain (Figure 3).

The explanation was straightforward with few words, as shown in the author's own speech: - *This is a girl crying, she is in pain [...] much pain [...], she was in school, but she had to leave. She couldn't stand the pain".*

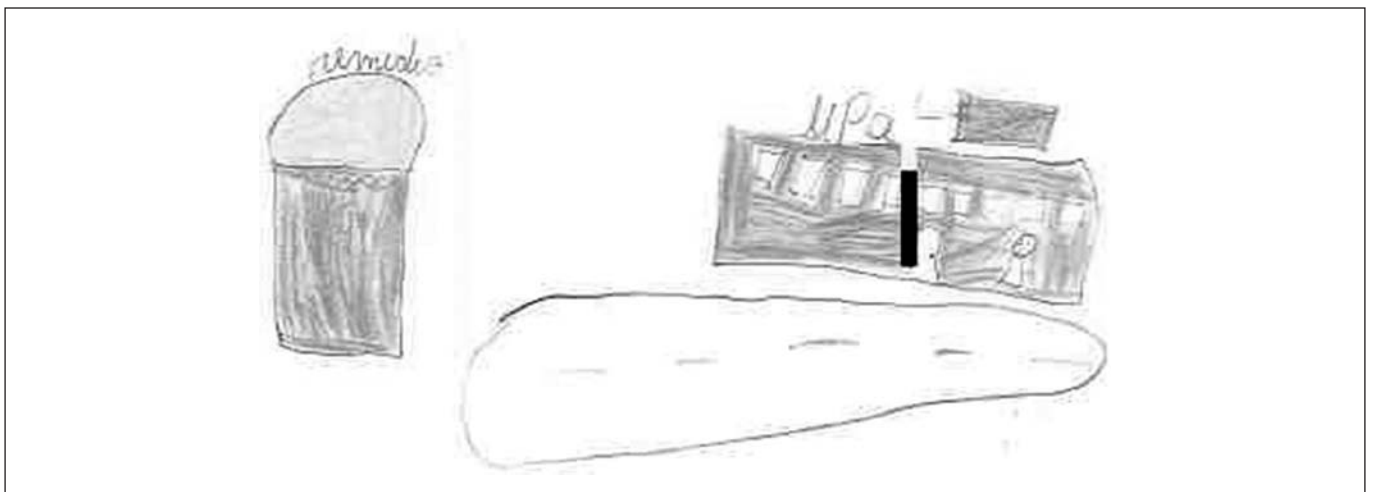
Later, the child ended up saying: *"[...] This is me, crying in pain."*



**Figure 2.** Involved by pain  
Source: 5-year-old child (C<sub>2</sub>).



**Figure 3.** Crying in pain  
Source: 9-year old child (C<sub>3</sub>).



**Figure 4.** The urgent care unit and the medication  
Source: A 7-year old child (C<sub>4</sub>).

In the second category, it was possible to grasp how each child faces its process of pain crisis due to SCA, as we can see in figure 4.

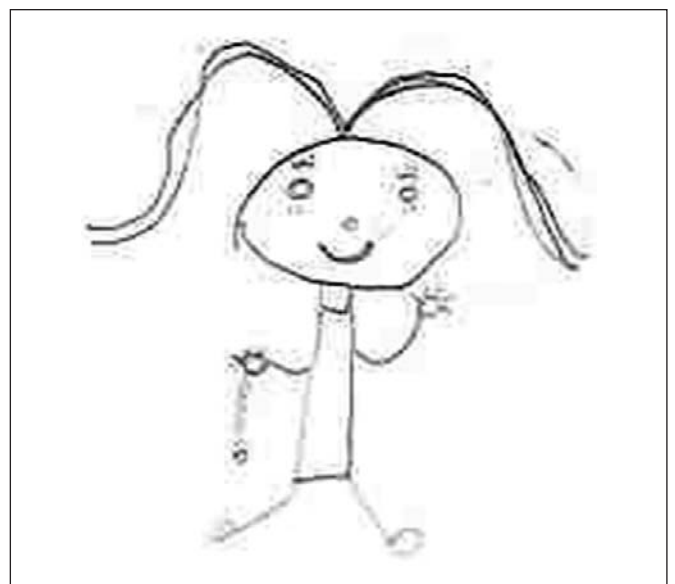
The way C<sub>4</sub> copes with pain is expressed searching for help, apparently alone and crying next to the door of an urgent care unit, called UPA, on the right side of the paper. She drew a road below and a gigantic medication on the left side.

When explaining its production, C<sub>4</sub> first pointed to the person crying inside of UPA and said: *Here, it's me crying and feeling much pain, then I go to UPA] ... I always go there [...] it is where I take my medication*". Then, pointing to the medication: - "[...] *this is the medication, it helps me to feel better.*"

Another way of coping with SCA pain was shown by an 11-year old child (Figure 5).

The drawing shows an apparently happy girl holding a rosary in her right hand, she explains: "[...] *This is me. I do that when I'm sick, in pain*".

And she was asked: -"Do that what? And she added: "*I take my rosary and pray [...], and I get better*".



**Figure 5.** Spiritual support  
Source: 11-year old child (C<sub>5</sub>).

## DISCUSSION

The analysis was established from the elements that emerged from the data about the children's perception by means of their drawings and the researchers' observations. Therefore, the child drawing and its symbolic language were considered instruments through which children establish contact with their inner world, being able to express their feelings by means of graphic representation, articulating their problem or their emotional conflict, or the stress that arises in that moment of life<sup>13,14</sup>.

Several meanings attributed in the children's drawings were noticed, mainly related to the painful crises due to SCA. According to the first category, the pain appears as a common symptom among participants, in line with a study<sup>15</sup> that compares the perception of SCA painful episodes among 27 children and their caregivers. The results revealed differences in relation to the type and intensity of pain. In terms of the pain location, the majority referred to the trunk region followed by the limbs. In the first two drawings, the experience of a painful episode was expressed in its physical aspects, probably by a manifestation related to dactylitis. C<sub>1</sub> makes its approach in a solitary way, indicating the pain site; whereas C<sub>2</sub> draws itself involved by pain, but the mother appears, embracing the child, giving the medication, taking her in her arms until "the baby sleeps and the pain goes away."

The way C<sub>2</sub> copes with pain is in line with a survey<sup>16</sup> carried out in two referral centers for pediatric cancer treatment in the Midwest of the state of São Paulo, where 66.7% of the cases showed that the mothers were the primary caregivers.

The attempt to have a regression to improve and neutralize the experience of physical discomfort caused by the painful crisis is delegated to the mother, as shown in another survey<sup>17</sup>, whose results show that when the children are sick and/or hospitalized, they become the focus of the attention, requiring exclusive dedication and, it is in the family, especially the mother, that the child has its references assured.

Indeed, in the third drawing, the girl did not identify nor her caregivers either the specific location of the pain but drew herself crying because of a painful crisis she had when in school, and because of that she had to leave.

The impact of pain affects the daily life of the children, in such a way that C<sub>3</sub> had to leave school, as in the study<sup>17</sup> aiming at identifying the impact of SCA in the daily life of adolescents that demonstrated frequent reports of pain, fatigue, and limitations to social interaction. Corroborating this idea, in the study<sup>18</sup> on the experience of people with SCA, it confirmed the limitation in these people's lives causing physical and emotional destabilization.

In the second category, the children expressed the way how they face the episodes of SCA painful crisis. In drawing four, C<sub>4</sub> brings to the scene a healthcare unit where she seeks for care, she called it UPA; showing, as well as, a big bottle of medication.

It drew attention the representation that this kid did to the size of the medication in contrast to its own size and even to the size of the healthcare unit where she is treated. The draw

of such a big medicine reminds the pain felt that was motivated by the disease. It seems to be a form of greater relief for the anguish felt.

The manifestations of pain in the individuals with hemoglobinopathies include episodes that require the administration of drugs aiming at the regression and improvement of the picture the soonest the possible<sup>19</sup>. Therefore, analgesia should be in line with what the patient presents, with the particularity of each case. The initial orientation is to do it at home, and if there is no improvement or other symptoms arise, caregivers need to go to the hospital<sup>20</sup>.

In the study<sup>21</sup> carried out in an emergency care unit in the interior of the state of Bahia, it was noticed, in the speech of the multi-professional team, that the patients look for the service when they have clinical complications or when they do not know what to do facing these complications. Another finding showed that there was a priority and focus solely on pain control, underestimating the physical examination as a chance for other episodes.

The way C<sub>5</sub> coped with her pain was with spiritual support, possibly learned at home with her parents or someone close, recognizing in her faith in God a way to overcome the difficulties of the complications imposed by the disease.

Spiritual practice is one of the alternatives for confronting and overcoming, being a positive aspect to alleviate the disease, as shown in the study<sup>22</sup> conducted in a tertiary hospital with 61 patients in dialysis treatment that identified the religious practice in the majority of the individuals.

The meaning presented shows that both to patients and family members and/or their accompanying person, "spirituality and religiosity help the experiences related to the disease and treatment, acting as a source of balance and strengthening the struggle for life"<sup>23</sup>.

## CONCLUSION

Children have a trajectory marked by multiple adversities that directly impact their lives. Therefore, we can conclude that in face of the sufferings confronted by children with SCA, it is necessary to create strategies that promote the implementation of public policies establishing a line of care, with efforts to prevent the crises and treat the disease, modifying the course of the disease and improving the quality of life.

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