v. 2, n. 76, 2022

International Journal of Health Science

THE PERCEPTION OF PARENTS OF CHILDREN AND ADOLESCENTS WITH SICKLE CELL DISEASE IN RELATION TO TREATMENT

Sara Bruno Torres Rêgo
Universidade Federal do Amazonas, Manaus-AM, Brazil
http://lattes.cnpq.br/1390110259551257

Davi Bernardino Barroso
Universidade Federal do Amazonas, Manaus-AM, Brazil
http://lattes.cnpq.br/9971966493848623

Arinete Véras Fontes Esteves
Female Nurse. Doctor of Science in Psychology. Professor at the Manaus School of Nursing /Universidade Federal do Amazonas, Brazil
https://orcid.org/0000-0002-3827-6825

Isabela Santos Gomes
Universidade Federal do Amazonas, Manaus-AM, Brazil
http://lattes.cnpq.br/2561101350384267

Carolina Simões Pereira
Universidade Federal de Mato Grosso, Cuiabá-MT, Brazil
http://lattes.cnpq.br/2010554077702226

Davi Vicente Félix da Silva
Universidade Federal do Amazonas, Manaus-AM, Brazil
http://lattes.cnpq.br/1263294710959435.

Drielly da Silva Galvão
Universidade Federal do Amazonas, Manaus-AM, Brazil
http://lattes.cnpq.br/7449173955289609

Priscila de Oliveira Lima
Universidade Federal do Amazonas, Manaus-AM, Brazil
http://lattes.cnpq.br/9743586050857241

Ellen Rocha de Abreu
Master in Nursing. Institution nurse: Universidade Federal do Amazonas. Manaus, Amazonas, Brazil
https://orcid.org/0000-0002-5005-5793

Anne Grace Andrade da Cunha Marques
Female Nurse. Master in Nursing. Professor at the Center for Health and Sport Sciences / Universidade Federal do Acre. Rio Branco, Acre, Brazil
https://orcid.org/0000-0001-5266-689X

Marcos Vinícius Costa Fernandes
Male Nurse. Master in Nursing. Nurse at the Amazonas State Health Department
0000-0001-7921-6530

Marcos Vinícius Gusmão da Silva
Male Nurse. Specialist in Urgency and Emergency. Nurse at INDSH in Manaus, Amazonas, Brazil
https://orcid.org/0000-0002-4888-4795

Abstract: Sickle cell disease (SCD) is a genetic disorder of autosomal and recessive origin, being prevalent in people of African origin and with low education, impairs the quality of life of its patients, as it causes limitations in occupational activities in a physical and emotional way, causing reclusion and non-acceptance of treatment, especially among children and adolescents. **Goal:** To describe the perception of parents/guardians of children and adolescents living with sickle cell disease. **Methodology:** Descriptive and exploratory qualitative approach research, with children and adolescents aged 6 to 18 years, who undergo treatment at the HEMOAM Foundation from December 2021 to June 2022, with data collection through semi-structured interviews and content analysis. Results: It was possible to identify, through the scientific evidence published in the databases on the subject, that the role of caregiver of the child with sickle cell anemia demands great responsibility, and it bears a great psychosocial weight, but the proximity to support networks, with family members, churches, organizations and also the health team, proved to be positive for coping with the disease, its complications and aggravation. **Discussion:** It is found in the perception of parents of children and adolescents living with sickle cell disease, their knowledge about their children's health condition, care routines in relation to treatments, as well as their concerns and anxieties arising after diagnosis of sickle cell disease, enabling a better understanding of how health professionals approach this population, resulting in positive repercussions in the scientific environment through educational actions. **Conclusion:** The mother is the integral caregiver of the child and adolescent in their treatment trajectory, resulting in critical mental exhaustion for performing so many activities with little or no help from outsiders.

Keywords: Sickle cell anemia; Pediatric Nursing; Chronic diseases.

INTRODUCTION

Sickle Cell Disease (SCD) is a disease of genetic, autosomal origin and chronic nature, resulting from the mutation of the β-Globin gene, responsible for encoding the molecule Hemoglobin A (HbA), which, through a point mutation, starts to encode Hemoglobin. S (HbS). HbS is found in low concentration in patients with SCD, but due to its characteristics of low affinity for O2, and ability to form polymers when there is low concentration of this gas, its effects are expressed at a cellular and systemic level (AZAR, 2017; ZAGO), 2007; BRAZIL, 2015).

The polymerization of HbS gives the erythrocyte the sickle shape, characteristic of Sickle Cell Anemia (SCA), which has a greater ability to adhere to the vascular endothelium, causing obstruction of the vessels, ischemia of adjacent tissues and, when the event that triggered the polymerization is prolonged for a long time, there is hemolysis of red cells and the emergence of inflammatory reactions (AZAR, 2017; ZAGO, 2007).

FA presents with several symptoms, such as skin ulcers, osteonecrosis, splenic sequestration, priapism, kidney problems and increased susceptibility to stroke. Symptoms vary with age, eating habits, lifestyle and the treatment performed by the patient, however the main complication reported by patients with SCA is pain in the extremities of the limbs, caused by vaso-occlusive obstruction (BRAZIL, 2012; SOUSA et al. al., 2015; ZAGO, 2007).

In Brazil, the diagnosis of FA is made through the "Foot Foot Test", using the sickling technique of the cell in a medium with low oxygen concentration, in addition to this, there are other methods such as blood count and electrophoresis. In the state of Amazonas, the test is carried out at the Fundação de Hematologia e Hemoterapia do Amazonas (FHemoam) (ALMEIDA, 2017; BRAZIL, 2015; HEMOAM, 2021).

Drug treatment of FA is performed with Hydroxyurea (HU), which stimulates the production of another hemoglobin, Fetal Hemoglobin (HbF), which prevents painful vaso-occlusive symptoms by not making polymers such as HbS, but is not curative. Other medications are also used to relieve the patient's suffering, such as analgesics, anti-inflammatory drugs and even opioids (FERREIRA & GOUVÊA, 2018; SOUSA et al, 2015).

In Brazil, 3,500 live-born children with SCA are registered annually, a disease that affects 8% of the Brazilian population, mainly the black population and lower income, who have greater socioeconomic and nutritional vulnerability, which makes it difficult to adhere to treatment and the biological development of these patients (BRAZIL, 2012; CANÇADO, 2007; JESUS, 2018).

In the context of the Unified Health System, the right of patients with SCA is guaranteed by the National Program for Comprehensive Care for People with Sickle Cell Disease and other Hemoglobinopathies, established by Ordinance No. 1,391/05 of the Ministry of Health. It is also worth mentioning that neonatal screening, with tests that identify Sickle Cell Anemia, is guaranteed by the National Neonatal Screening Program (PNTN), established by Ordinance No. 822/01 of the Ministry of Health (BRAZIL, 2005; CANÇADO, 2007).

Focusing on the family nucleus of patients with SCD, they are usually single-parent families, led by the female figure, and who, when they receive the diagnosis of a new member with SCA, especially a child, go through an exhausting process of reorganization and adaptation to the family.

new reality and routine (ATAÍDE & RICAS, 2016; GESTEIRA, 2016).

The care process requires a lot of responsibility, which falls mainly on the mother, who almost exclusively assumes the role of caregiver of this child, and who, in the face of the new reality, seeks to reconcile home and work life with daily care (GESTEIRA, 2016).).

Being an exhausting situation, due to the family's resignification dynamics, adaptations, uncertainties and psychological stress when thinking about this person's future, the overload ends up causing damage to the mother's social network, or circle, which may have its ties weakened with the mother. environments such as work, but strengthened with those who help with care, such as siblings, mother, and health system professionals (MORAIS, 2018; NEVES, 2018).

To alleviate suffering, some environments and relationships proved to be positive for the caregiver. Talkgroups, non-profit organizations, churches and religious faith proved to be good ways to share pain and suffering, seeking motivation to continue care and material support (MORAIS, 2018; VIEIRA, 2020).

Good relationships with family members were also positive, as the division of care is something that usually happens in these relationships, in which the mother can temporarily leave the healthy children with aunts or grandparents to dedicate herself to the care of the sick child, or alternate the care of the mother. child with PA with other sisters, to have a little rest (MORAIS, 2018; VIEIRA, 2020).

In addition, a good relationship with health professionals is also important, because through this relationship valuable information is obtained that helps the mother to take better care of the child with SCA (MORAIS, 2018; VIEIRA, 2020).

Given the context of Sickle Cell Anemia, and how caregivers are placed in this scenario, it is concluded that it is important to understand how caregivers deal with patients with SCA, how they promote their children's quality of life, and which factors facilitate or hinder caring, in the perception of these caregiver parents.

Therefore, this research proposal asks the following question: How do parents or guardians of children with Sickle Cell Disease, treated at Fundação Hemoam, face the care of sickle cell children?

GOALS

General goals

- Understand how parents and legal guardians deal with the care of pediatric patients with Sickle Cell Disease.

Specific objectives

- Search with the participating caregivers, which are the main obstacles faced for the treatment of Sickle Cell Disease.
- Identify, together with caregivers, which aspects facilitate the treatment of Sickle Cell Disease.

METHODOLOGY

TYPE OF STUDY

It is a qualitative study of the descriptive type, which according to Polit (2011) "These studies present comprehensive summaries of the phenomenon or event in everyday language".

PLACE

The research was carried out at the Fundação de Hematologia e Hemoterapia do Amazonas (HEMOAM), located in the South Zone of the city of Manaus/Amazonas. The foundation assists people of different ages with blood disorders, performing tests, monitoring, treatment, consultations and hospitalizations, in addition to being a reference center in the

treatment of Sickle Cell Disease, the subject of study of this research proposal.

RESEACH PARTICIPANTS

Parents and/or legal guardians who accompany children and adolescents diagnosed with Sickle Cell Disease, aged up to 18 years, who are in the waiting room of the Hemoam outpatient clinic and who agree to participate in the research, could participate in the research.

Characterizing the sample obtained, all participants were female, being the patient's mother, they do not live with their spouse, as they are single or divorced.

Those who were not in the waiting room of the Hemoam outpatient clinic during the data collection period or who, for whatever reason, wish to remove their data from the research were excluded from the research.

APPROACH TO THE PARTICIPANT

The person responsible was approached in the waiting room before or after the medical appointment, and was explained about the research, the research objective, the data collection process and how to participate. The Consent and Free Clarification Term (TCLE) was also presented to the person in charge, available in two copies, which is read to the participant, giving them time to ask questions and decide on their participation. Volunteers who consented to be interviewed were directed to the reserved room in the clinic, where the interview took place. All participants had the right to deny participation, without penalty for attendance or embarrassment.

STUDY PERIOD

The project started with data collection in August 2021 and was completed in July 2022.

DATA COLLECTION

To collect the data, the semi-structured interview method was used with a script previously prepared and already tested in other previous researches in the same area, containing 23 open questions, because "The semi-structure follows a script that is physically appropriated and used by the researcher" and that "assures, especially to less experienced investors, that their hypotheses or assumptions will be covered in the conversation" (MINAYO, 2014, p.267).

To facilitate the transcription of the data, a smartphone device, model Galaxy A50, SM-A505GT, with a voice recorder was used to record the answers in audios in mp3 format and obtain reliability of what was said, previously communicating the interviewee before recording. start.

The interviews lasted an average of 20 to 60 minutes, and were held in a reserved space at Fundação Hemoam, to avoid embarrassment and exposure of responses to third parties.

There is no defined number of participants, the data saturation technique was used to define when data collection must end (MINAYO, 2014).

Data analysis

The Thematic Content Analysis method was used, which "[...] consists of discovering the nuclei of meaning that make up a communication, whose presence or frequency means something for the intended analytical objective" (MINAYO, 2014, p. 316).). In the case of low demand from interviewees for any intercurrences, the work would be analyzed with the amount obtained.

For this, the pre-Analysis stages were followed, through floating reading, analysis and constitution of the corpus, and the reformulation of hypotheses, the Material Exploration stage, to search for the significant categories and organize them, and then the treatment of the results obtained from the raw data, revealing the most significant data (MINAYO, 2017, p. 316-318).

In order to comply with the consent form signed by the interviewee, and maintaining their anonymity, the participants were named after common fruits from the northern region, namely Açaí, Biribá, Bacuri and Cupuaçú.

ETHICAL ASPECTS

The project is approved by the Research Ethics Committee of the institution: ''Universidade Federal do Amazonas" (CEP-UFAM) and the institution: ''Fundação de Hematologia e Hemoterapia do Amazonas" (CEP-Hemoam), under the code CAAE 46313321.8.3001.0009, as well as the Term of Free and Informed Consent (ICF) is approved.

RISKS AND BENEFITS

For the participant, the risks are associated with the discomfort and fears generated by the questioning, as it is a qualitative research, seeking personal reports, some topics may be sensitive to the participant. In addition, due to the coronavirus pandemic, there was a risk of contamination from exposure to the environment.

Despite this, the research brought benefits to the academic community with the results obtained, showing researchers and readers the difficulties faced by those responsible for children with Sickle Cell Disease.

For the participant, there may be future indirect benefits, summarized in policies or actions that reduce the effects of the aspects reported as hindering.

SAFETY MEASURES

Due to the coronavirus pandemic, preventive measures were necessary to prevent the spread of the virus, to maintain this safety, hand hygiene is carried out before the interview, with washing between interviews and encouraging the use of alcohol in gel 70%, if the washing is not possible, safe distance of at least 1 meter between the interviewee and interviewer, as well as the use of surgical masks to prevent the spread of droplets in the environment (MINISTRY OF HEALTH, 2021).

RESULTS AND DISCUSSION

The interviews were carried out through a previously prepared questionnaire, resulting in relevant information about the care experience, from personal changes to the caregiver, to family changes to suit the needs of the child with sickle cell anemia.

In view of the interviews carried out after transcription and reading, the categories and subcategories were identified: "Receiving news from the sick child", "Psychological situation of the child's caregiver" due to "Changings in routine" and "Help from family members".

THE RECEPTION OF THE SICK CHILD'S NEWS

The literature points out that the caregiver task is mostly performed by a female figure, who alone must lead the family, promote care and also provide sustenance for her children, sometimes counting on the help of family members, as grandmothers, to share the care and when they cannot get this family help, all the sustenance of the house and the care provided depend on them, therefore, all the interviews were the mothers of the hospitalized children. (ATAÍDE, 2016).

The interviewees were asked about the shock when receiving the news of the diagnosis, and they report that it is news received with suffering, and that it brings fear when thinking about the future, because it is a chronic disease and that, according to the doctors informed the mothers, it could take your child to death.

Biribá: "I suffered a lot, I cried a lot, I even got into depression [...] they told me what it is, that there was no cure, mainly, that is the most suffered, knowing that it is a disease that

has no cure."

Cupuaçú: "[...] for me it was a very big shock, even I wanted to give up, even I got sick because of it, because of the two of them [...] because I thought they were going to die, right?"

Gesteira (2016) says that the mother feels guilty and incapable, afraid of the future and death due to the characteristics of the disease and the way it is described by doctors, and they expose the caregiver to a risk of depression.

PSYCHOLOGICAL SITUATION OF THE CHILD'S CAREGIVER

The report of psychological problems resulting from fear, the feeling of incapacity and the occurrence of the sickle cell crisis that she lives with her child, was found in the interviewees' speech, especially the participant Cupuaçú, who even reports hearing voices that remind her of crying and the request for help from their daughters.

Cupuaçú: "[...] I had an anxiety crisis that I didn't speak or write [...] the story never ends, because when they have a crisis I can't sleep [...] sometimes I hear them crying, I hear them calling me [...] I only sleep if I take medicine, if I don't take medicine, I don't sleep."

For BARBOSA (undated), child hospitalization is a very stressful process for caregivers, resulting in different levels of psychological impacts, especially when it comes to the development of pathological anxiety, emphasizing the importance of psychological help services to support them in these situations. situations.

ROUTINE CHANGES

Receiving the news of a sick child with a chronic illness also brings changes to the mother's life, in style, in customs, in the way she is interpreted, to direct all her attention and care to the child, and at the same time seek ways to financially maintain care, to ensure food and comfort for the child with sickle cell anemia. When there is a diagnosis of chronic disease, individuals and family members begin to have a significant change in their routine for the treatment of their disease, whether through physical, social and financial issues. (TRENTINI, 1990)

Açaí: "[...] right at the beginning, so I could work, I put him in a daycare, there in Macapá, so, like, I got it with my client, because he wasn't old enough to stay in daycare [...]] then I arranged with the owner (head of work) for me to have lunch at five o'clock in the afternoon [...] then at five o'clock he would leave the daycare [...] I adapted a bicycle [...] and I would take him [...]"

Hospital care in particular is the one that most affects the daily lives of caregivers of hospitalized children, because in addition to the child's own limitations, parents suffer in adapting to that regulated environment due to the impossibility and limits imposed in relation to the home care routine that is usually performed in a more comfortable and dynamic way for both (GOMES, 2014).

Biribá: "It used to be normal, well, not now, after that, it's a direct doctor, it's spent so you don't even talk, [...] he can't ride the bus if he doesn't get sick, it's uber here, uber there, so the cost has gone up a lot."

Change occurs not only in the mother who will perform the care, but often in the family, which acts in a secondary way in the care of the child, supporting the mother, whether emotional, to share care, help financially or offer a welcoming environment. The treatment of children with chronic diseases considers the relationship between their well-being linked to that of the caregiver and their form of care and family involvement through the child's illness process (MILBRATH, 2016).

Açaí: "[...] my son is very dear to the family, from my mother [...] everyone is very careful with him, despite being far away, but everyone

worries about him, wants to know about him [...] when he is hospitalized, they help me a lot, I mean a sister [...]"

Biribá: "[...] there are three girls at home, but he is the only one who has this disease, so the attention is all for him, one hundred percent."

Cupuaçú "The change in routine was like this together, our whole family changed, we have a large family, so everyone changed because of (daughter's name) [...] so the change was general, in everything, food, behavior, acceptance, because everyone accepted, no one rejected".

HELP FROM FAMILY MEMBERS

The family is understood as the foreground in the caregivers' network of relationships, as it is usually the family that the mother can count on to help with care, household activities, provide goods and services that help or allow the family caregiver to dedicate himself to the care of the family. child, or share care during work periods (MORAIS, 2018).

However, not all caregivers can count on the help of the family, as reported by the following interviewee.

Bacuri: "No, it's still as it was [...] nowadays nobody wants to take care of the sick, it's just the two of us, sometimes we have to spend two months hospitalized, three months hospitalized, it's just us, just the two of us. "

For HUERTA (1984), hospitalization is seen by mothers as a bad and traumatic process, as it is associated with the pain and suffering of the crisis, and despite being necessary in moments of vaso-occlusive crisis, the permanence is uncomfortable, as it is evidenced by the following statements:

Bacuri: "Here in the hospital it is bad, right, it's not like at home that we feel comfortable, right, at the house there [...] he sleeps well, thank God, he sleeps well all night, just doesn't sleep well when he's in crisis like this [...]"

Cupuaçú: "Yes, here I think that the hospital environment is good, yes, for the recovery of many, but on the other hand, if you spend a lot of time here, you get sick, you get sick because (daughter's name) was hospitalized here once, she acquired dengue here [...] we were here like this, and a gentleman died on our side [...] he had a cardiac arrest right here and died on our side, I mean, for them, the patients, this is horrible."

CONCLUSION

Through the interviews carried out, it was possible to identify the main difficulties faced by those responsible for children with Sickle Cell Disease when observing the role of caregiver, which in general is exercised by the child's mother, who gives up her routine and customs to dedicate herself integrally to the care of the sick child, providing means to support the child and adhere to treatment, in addition to playing the role of mother. It is a triple task, which requires a lot of time, dedication and effort, leaving psychological marks mainly due to the concern for the child's future, which can lead to the mother's own mental illness, as she completely assumes the role of care, facing constant difficulty in treating the child and still work to maintain the costs of the house, in a context generally of poverty and difficult access to health services. Therefore, the importance of more research directed to this theme is highlighted, in order to provide psychological assistance, social support and indicate the main health treatments suitable for the follow-up of this caregiver.

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