

## NURSING CARE TO PEOPLE SUFFERING WITH SICKLE CELL DISEASE IN EMERGENCY UNIT<sup>1</sup>

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### ABSTRACT

This study aimed to identify how the nursing team perceives the care to the person with sickle cell disease at the emergency unit. This is a qualitative and descriptive study, developed in a specialized hospital in Rio de Janeiro with 12 members of the said sector nursing team. The Data production took place between April and September 2014 through semi-structured interview. Data were submitted to content analysis and the following category arised: The nursing staff in the care for the person with sickle cell disease in the emergency room. By taking care of the person with sickle cell disease in the emergency department, the nursing team faces some limitations, such as: pain management, the team's level of knowledge on the disease, the organization and structure of the service on the care demands. To take care of these people, members of the nursing staff must be prepared to learn to evaluate them considering their needs and their life histories with the disease, which involves numerous hospitalizations lifelong

**Keywords:** Nursing care. Sickle Cell Anemia. Emergencies. Nursing team.

### INTRODUCTION

Sickle cell disease is hereditary, and its prevalence is higher in people of black ethnic groups and African descent; however, the presence of black culture and the fact that 50.7% of the Brazilian population is composed of black people<sup>(1)</sup> have not been sufficient to put an end to inequality and racial stereotypes. Due to the population of miscegenation, which has its roots in colonization and the country's settlement process, there was the spread of genes that give rise to the presence of hemoglobin variants and determined diseases such as hemoglobinopathies and thalassemia<sup>(2)</sup>, making the sickle cell disorder the monogenic hereditary disease most common in Brazil<sup>(3)</sup>.

In Brazil, about 3,500 children are born each year with sickle cell disease or 1/1,000 live

births and there are 200,000 carriers of the sickle cell trait. Data of the Ministry of Health in 2008 revealed that, among the states that perform the neonatal test, Bahia has presented the highest incidence of carriers, 1:650 live births, whereas Santa Catarina and Parana had the lowest rates 1:13,500 live births<sup>(4)</sup>.

Sickle cell disease and its clinical complications have hierarchical levels of complexity in a continuum between periods of welfare and emergency care<sup>(3)</sup>. The clinical picture of the disease is characterized by pain syndrome, hemolytic anemia, organ failure, infections, and comorbidities. The vaso-occlusive crises are more frequent and start to even appear in the first year of life, between the third and fourth month, due to decreased fetal hemoglobin (HbF) and an increase in hemoglobin S (Hb)<sup>(5)</sup>.

In an integrative review study<sup>(6)</sup>, it was also

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found that there are few nursing productions related to the care of persons suffering with sickle cell disease as regards the assessment to mitigate the pain it causes. The scarcity of studies takes place, particularly in relation to prevention and self-care, involving family and the nursing staff, especially in the hospital setting. It is inferred, therefore, that there are gaps in relation to the nursing care to these people. A study on the epidemiology of the Sickle cell disease with 9,349 patients, developed in the states of Bahia, Rio de Janeiro, and São Paulo, from 2000 to 2002, found that the most frequent hospitalization of these patients were in the emergency room<sup>(7)</sup>. The emergency room is a service site available to the public for 24 hours a day, suitable for the care of patients with specific diseases, where there is a specialized team of organized labor in emergency care, emergency room, and emergency. It is the first place for receiving and caring for patients; an area in which individuals seek to solve their immediate health problems<sup>(8)</sup>. People with sickle cell disease who seek care in the emergency unit are in a health limit situation and expect resoluteness to their problems, which require special attention, with careful assessment of their clinical conditions and attentive listening to their physical, social, and psychological demands by a multidisciplinary team that is prepared to provide such care in an organized environment that is equipped with proper infrastructure<sup>(6,8)</sup>.

In this context, the main link between the patient and the hospital takes place with the nursing service, which is the largest group of health professionals, who, by the nature of their work, maintain a continuous and close contact with patients, promoting maintenance, recovery, and rehabilitation of health through care<sup>(9)</sup>. With regard to the people with sickle cell disease, this proximity to the nursing staff is important in light of the possibility of performing care procedures that may or may not meet the patient's needs and help in coping with the disease<sup>(10,11)</sup>. Therefore, to work in the emergency department, the nursing staff needs to have emotional stability, expertise, and skills for the decision making process in an environment in which the professional comes across everyday

with moments of despair, pain, death, and hope concomitantly<sup>(3,8)</sup>.

People with sickle cell disease at the emergency unit must be met as quickly as possible, in a warm and humane way, by a qualified team, especially because they arrive weakened because of the painful crises and/or the occurrence of other complications which limit their activities and repercussions on their quality of life<sup>(8)</sup>. The most common complications that lead the person with sickle cell disease to seek emergency services are pain, infection, anemia, and stroke that can occur simultaneously, implying a careful assessment and immediate intervention of the health and nursing staff<sup>(12)</sup>.

Thus, the care of the nursing staff to the person with sickle cell disease in the emergency unit requires complex interventions such as: individualized assessment, pain management, prevention and control of infection, and proper understanding of hematologic and immunologic issues<sup>(3)</sup> as well as willingness to accept and evaluate the person in accordance with their needs, to promote a targeted and thoughtful care practice that brings benefits to the patient and nursing<sup>(13)</sup>.

Given the above, the study presented its guiding question: how does the nursing team perceive the care provided to the person with sickle cell disease admitted at the emergency unit? To answer it, we defined the objective of this study: to identify how the nursing team perceives the care to the person with sickle cell disease at the emergency room.

## METHODOLOGY

This is a qualitative and descriptive study developed in a specialized hospital located in Rio de Janeiro, a reference in terms of care for patients with hematologic disease.

Data production occurred from April to September 2014, through semi-structured interviews scheduled according to the availability of the participants. The study included 12 members of the nursing staff who met the following inclusion criteria: work in the emergency department, of both sexes. The professionals on vacation and/or away from the sector in the period of data collection, and those

with temporary contracts in the institution were excluded.

The interviews were recorded on a digital device, fully transcribed by the researcher and identified with the letters N (nurse), NT (nursing technician) and NA (nursing assistant), followed by the identification number, as exemplified below: N1, NT1, NA1, and so on. Then the data were subjected to content analysis<sup>(14)</sup> in the stages of: pre-analysis, material exploration, treatment of results, inference, and interpretation. After the data content analysis, the following category has emerged: The nursing staff and the care provided to the person with sickle cell disease in the emergency room. The research project was approved by the Research Ethics Committee of the institution under the opinion No. 350/14, and all participants were informed of the research objectives and signed the consent form, as recommended in Resolution 466/2012 of the National Health Council (NHS), about research involving human subjects.

## RESULTS AND DISCUSSION

Of the 12 study participants, six were nurses; four were nursing technicians; and two, nursing assistants. Nine of them were female, seven were between 21 and 40 years of age; four were between 41 and 60 years; and one was over 60 years. Regarding marital status, five were single; four, married; one was separated; one was divorced; and one, a widower; nine reside in their own home; and four, in rented accommodations.

All nurses already had a postgraduate degree, and in relation to professional experience, four worked in nursing between 1 and 5 years of age; four, between 6 and 10 years; two, between 11 and 15 years; and two, for more than 15 years. Seven of them, including three nurses, three nursing technicians, and one nursing assistant also work in another institution.

### **The nursing staff and care to people with sickle cell disease in the emergency unit**

#### **The arrival at the emergency**

Upon arriving at the emergency room, people who suffer from sickle cell disease aspire that

their problems are solved, and for that, some situations that need immediate measures should be considered, such as: priapism, need for urinary catheter installation, intense analgesia, blood transfusion, intravenous hydration, water intake, and assessment with a urologist, expert for a better intervention<sup>(11)</sup>.

The Patients who look the emergency service of the institution are initially treated at Emergency Room (ER), after that they are forwarded to the reception. At the reception, they are received by the nurse for conducting the screening and risk classification by using the Modified Manchester Scale<sup>(2)</sup>, adapted to the needs and characteristics of the patients registered at the hospital, consisting of classification in four colors: red (patients in more serious condition); and yellow, green, and blue (for the least severe cases). After nursing and medical evaluation, patients are referred to the consulting room.

Thus, the dynamics of care aimed to people suffering with sickle cell disease at the emergency unit requires planning in which, initially, such patients should be accepted and then an initial assessment should be carried out in order to identify the problems and the clinical severity, and to provide support to family members who are in vulnerable situations<sup>(15)</sup>.

We talk to this patient; we identify him by name, registration, and the location of the pain he is feeling. We puncture him [...]. We often collect the blood, request the laboratory staff and forward him to the X Ray, you know? When he returns [...], as we evaluate the pain, we prepare the medication, and he remains here for a period of six hours, and then he is re-evaluated by the doctor. And then we check: if the pain ceased, he goes home. If the pain did not cease, he goes to the 5th floor. Besides medication, we also make a "talk therapy" to alleviate the pain of the patient. Well, I think, above all, I try to take care with affection, with love. It's not only the medication that we relieve their pain, often they arrive here screaming (NT2).

The patient arrives and we prepare the normal interview. We ask questions; make the pain scale [...]. Pay attention to what he says [...]. We try to listen to the patient [...], we measure the vital signs, and puncture. Sometimes he does not come with SPA access (NA1).

In the speeches of members of the nursing team, N1, N2 and NT1, the dynamics of care to the person with sickle cell disease in the emergency room follows the recommendations in the Protocol of Service to Acute Events of sickle cell disease of the Ministry of Health<sup>(4)</sup>.

We stay in the emergency sector, sorting, and we receive the patients. I check the vital signs and, [...] there is a text, a questionnaire, in which we ask the questions and mark the details about the patient. Then, in this evaluation, we get to know if he gets the green, red or yellow bracelet. In emergency, they usually arrive feeling a lot of pain, a lot of pain. And then, in the emergency sector, in the ER, the patient goes to the clinic to be assisted by the doctor and then goes to the medication room, for the application of the medication. There, that's the way the sickle cell disease is. I usually take care of the medication and the guidelines [...]; he usually takes a lot of medicine for pain (NT1).

We have to collect a series of tests; we have to monitor these tests, because the treatment is long and is chronic. So we make the visit, and use a specific form that we use to ask about the basic human needs of the patient, according to the degree of knowledge he has about his illness. Then we trace a care profile directed to these patients. They need immediate care. They come with pain and sometimes short of breath. Sometimes they arrive with a major infection. Then the service agility is crucial (N1).

Due to the worsening of the disease, it is essential that the multidisciplinary team keep monitoring, noting the signs: paleness, fever, behavior changes, pain, dyspnea, tachypnea, weakness, enlarged spleen, fatigue, and other health problems<sup>(8)</sup>.

We take care of the psychological condition of the patient because it is important. Providing support in this moment is important to humanize care, because this is part of the moment. You can serve the patient [...], prepare the medication, but if you don't provide good support, don't help the patient [...], something is missing for that patient (NT3).

You know, sometimes, when the sector is calm, I talk about day-to-day issues, as to the reason why he came to the emergency on family matters. But there are times when sometimes you cannot get to chat (N5).

To take care of the person with sickle cell disease, you need to know how to articulate the

technical dimension to the human dimension, establishing an ongoing relationship with the patient that is grounded on trust and empathy with structured services to provide therapeutic and preventive guidelines, considering the social, economic, and cultural conditions of each client<sup>(15)</sup>. In this context, people with sickle cell disease report various forms of physical signs and symptoms such as fatigue, weakness, sleep disturbances, fever, yellowing of the eyes and general malaise that characterize the beginning of the painful crisis<sup>(16)</sup>.

### Assessment and management of the pain

Pain is the hallmark of the disease and dominates the clinical picture of people with sickle cell disease throughout life. Their nature is unpredictable and can be precipitated by known factors or not, the most common cause of more than 90% of hospitalizations, leading to recurring visits and hospitalizations in emergency units<sup>(5,8,12)</sup>. The vision of the members of the nursing staff regarding the person with sickle cell disease refers directly to the presence of pain, which is the main complaint and requires speed in establishing actions to their relief in emergency<sup>(5)</sup>. The approach to the person with sickle cell disease in emergency with pain crisis should be the central focus of attention in the care and needs to be evaluated attentively in a comprehensive perspective, considering their physical and psychological repercussions.

These are patients who come here because of the pain. He is a chronic patient; he was born with it. It's an African disease. Sometimes it comes with so much pain that there are times when I'm in doubt. Care needs are, in my opinion, aimed to improve pain. Sometimes I talk with colleagues on both medicine pain they take and they still don't stop feeling pain, and wonder if they take the right medicine at home and some are left with a grin on their faces (N3).

They need care to relieve their pain. I also see that many have social problems. They don't have anything to eat here and they only provide after six hours of stay in the sector [...]. Difficult! (NT3).

It is a chronic disease that requires nursing care, especially at the head of the bed, because it requires a lot of care as they feel a lot of pain, a

lot of breathlessness. This is a very needy patient and requires even professional attention. And sometimes, I note that some patients receive care, take care of themselves, and others not. They forget medications. They exaggerate on drinks (N5).

They are unable to work, most are like this [...], the young, the younger work and all, but whenever they have any symptoms, they come to receive the medication to stop this pain that is usually in the cold [Quietly] because they feel a lot of pain (NT4).

The painful syndrome is described by these patients as "persistent" and "always present", "consistent" and "recurrent", "the pain that does not go"<sup>(6)</sup>, which can cause psychological changes, sleep disorders and psychopathology as: depression, anxiety, and personality disorders<sup>(12)</sup>. They may also have problems with self-image, with the self-concept and self-esteem, attributed to sexual retardation, physical maturation and growth, as well as its appearance, with the presence of jaundice and distended abdomen. Anxiety, aggressive behavior and fear are also present, often associated with repeated attacks of pain and hospitalizations<sup>(17)</sup>.

It is when the patient [...], he's a patient like [...], when he doesn't want to be helped, it is difficult even you insist. For example, there patients who are aggressive, but now they have improved well. Sometimes I talk to the people who, now that they are "domesticated" [laughing], they are much better than they were before. Patients would come here and used to be aggressive [...]. The problem is that if the patient, for example, fails to respect us, then surely things get bad (NT3).

When they are aggressive [...] that's where I'm more careful [...] sometimes they are aggressive because of the pain, and then I always double my care, you know? That's when I talk to them. It's like this, it is like that, you know? I double my attention. That's why I keep an eye on him [...], I double my attention to them (NA2).

Pain leads to an imbalance, people get nervous, aggressive, not knowing what to do, willing the pain to cease, and asking health professionals for medications all the time<sup>(12,18)</sup>. In the relationship with patients, the team describes that they have some knowledge in terms of the disease, arising from the experience of living with such a condition, which allows the understanding regarding how they deal with the

disease so it is possible to implement guidelines according to their expectations in an reliable and exchanging environment<sup>(18,19)</sup>.

They are patients who know and completely dominate the disease they have (N3).

Here they know more than us [laughing]. Many here [...] Wow! They know a lot. They teach us a lot (N4).

By taking care, you enter the world of people being cared for, opening a process of discovery and interaction mutual learning with the health team. In addition, other conditions are offered to join a growing need since it provides an opportunity to discover their own capabilities<sup>(6,15)</sup>. The nursing staff needs to know when there is pain and how it affects the patients with sickle cell disease, in order to help them through the use of communication techniques, which include, inter alia, respect for individuality and the establishment of an empathic relationship, in order to understand the world of those individuals using simple and direct questions, favoring their understanding in terms of their pain, which provides a humanized care<sup>(15)</sup>.

### **Knowledge of the nursing staff regarding sickle cell disease**

Recognizing the magnitude of the issues that permeate discussions of attention to people with sickle cell disease in order to take care of them is a challenge for the multidisciplinary team, which is not restricted to the identification of signs and clinical symptoms of the disease, but it requires knowledge to provide an approach integral, where interventions can contribute to overcoming the limits imposed by the disease<sup>(6,8)</sup>. However, members of the nursing staff reported lack of knowledge in terms of sickle cell disease as a limitation for the care aimed to these people.

So what limits me most; what sometimes limits me is not to have much knowledge about the disease! [...] And then some things arise and raise doubts regarding the disease [...]. That's it (N6).

What limits me [...], limits the assistance of the people, is that when I came across the patients here [...] I didn't know what sickle cell anemia was. They know more than us (NT4).

Therefore, caring for the person with sickle cell disease at the emergency unit involves fostering an environment which triggers an information exchange relation, where it is necessary to listen to people and recognize their physical and emotional needs as fundamental elements to be evaluated for planning effective interventions. These, therefore, should favor the comfort and recovery of the person seeking the service in anticipation of resoluteness to their demands of immediate attention, particularly in relation to painful crises, which have a direct impact on their emotional balance and interpersonal relationships<sup>(6)</sup>. However, the assistance directed to people with sickle cell disease in the emergency room has an incessant routine that is the source of physical and emotional distress to patients and professionals who need to promptly meet the needs of these people in the sector<sup>(8)</sup>.

### **The routine of the nursing staff in the care of people with sickle cell disease in the emergency unit**

In speaking of the care routine to people with sickle cell disease at the emergency unit, the members of the nursing staff noted that the available physical space is insufficient regarding the demand of patients, especially in painful crises, which also requires emotional support to confront this situation that leaves them vulnerable.

There is a great demand here for patients and also, like [pointed to the crowded sector]. Because it is a patient that requires rapid intervention, and if it takes long, he can get decompensated and have complications. We do not always have enough beds to prepare and accommodate them (N1).

I get nervous when they don't stop calling [...] it makes me nervous if the pain doesn't stop, then and I ask a colleague to assist them (N5).

Often when I put myself in that person's place, because I know it's a disease [...] which is bad for them, I do my best to ease the pain of these patients. That's why I do the "talk therapy" along with medication, to try to help. Get it? (NT2).

Caring for people with sickle cell disease, which is a genetic chronic disease, means understanding that living together and the relationship of these people with the health services will be permanent, and they will always return with different health demands. Therefore, it

is considered that these people need a prepared nursing, which, in our reality of health services, often involves the exercise of creativity, overcoming the difficulties imposed by services<sup>(8,18)</sup>. The daily life of the nursing staff in the emergency room is challenging and includes some limitations, such as knowing how to deal with the feelings and reactions of patients, who are aggressive at times, as well as issues related to the deficit of human and material resources.

Some patients are difficult to handle because of their personality. It is as if they reflected the blame of their disease in you. This limits our assistance because we are there to help, and the patient often does not want to be helped. This also generates limitations with respect to assistance and supplies. An example: we ran out of medication. Tramal is almost over; the stock of morphine was limited on Sunday. There is no ketorolac in the unit for quite some time. It also ends up limiting assistance very much, especially to the sickle cell patients, because of the pain. Ketorolac is one of the main medications and there is none at the unit. Then we end up using Tramal, which is the second option and is running out at the unit. So, this is it. You never know what you'll find on your next shift (N2).

The lack of material in health institutions, whose possible causes are numerous structural, organizational and individual problems, has a direct impact on the development of care for patients seeking services for treatment and these are elements that generate stress in nursing professionals<sup>(20)</sup>. Currently, overcrowding is configured as an ongoing challenge faced in the emergency department, and the structured screening (risk classification)<sup>(2)</sup> represents an alternative of the organization, since it allows prioritizing care for the most patients in more serious conditions.

However, for this, emergency services must have a team of qualified professionals in order to host these people, who often fail to receive care due to the lack of knowledge of workers concerning the disease and the non-existent connection with the hematological reference centers in which people with sickle cell disease should be monitored regularly in their area or in their home town<sup>(4)</sup>.

### **FINAL CONSIDERATIONS**

To take care of the person with sickle cell disease in the emergency room, members of the nursing staff must be prepared to identify and assess their needs, seeking their well-being and autonomy through a careful and sensitive listening to their physical, psychological and social demands. And from that, they must plan and implement effective care that provides clinical improvement, comfort and safety in the emergency room, which requires infrastructure of human resources and materials. Moreover, from the perspective of promoting a comprehensive and humanized care with increasing quality levels, we need to invest in continuing education programs on the magnitude of sickle cell disease, considering its cultural, economic and social aspects. Similarly, one should invest in updating regarding the systematization of nursing care in order to promote a safe and competent care, favoring the recovery and maintenance of the health of that population, preventing complications and

reducing readmissions with institutional programs for monitoring these people.

Thus, considering that individuals with sickle cell disease need continuous health care, it is essential to establish strategies to encourage and support self-care through educational activities that allow the promotion and maintenance of their health. In this sense, institutional programs and group activities, coordinated by the nurse, facilitator in the person's awareness process and self-care for the preservation of health and autonomy in activities of daily living, become relevant.

It is also evident the need for inclusion of themes focused on care for these people in the training of health professionals and the expanded discussion in terms of policies to improve working conditions and infrastructure in health institutions, identified as constraints to the full and humanized care in a safe environment to people with sickle cell disease in the emergency department.

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## O CUIDADO DE ENFERMAGEM À PESSOA COM DOENÇA FALCIFORME EM UNIDADE DE EMERGÊNCIA

### RESUMO

Este estudo objetivou identificar como a equipe de enfermagem percebe o cuidado à pessoa com doença falciforme na unidade de emergência. Trata-se de um estudo qualitativo e descritivo, desenvolvido em um hospital especializado no Rio de Janeiro com 12 membros da equipe de enfermagem do referido setor. A produção de dados ocorreu entre abril e setembro de 2014, mediante entrevista semiestruturada. Os dados foram submetidos à análise de conteúdo, emergindo como categoria: A equipe de enfermagem no cuidado à pessoa com doença falciforme na emergência. Ao cuidar da pessoa com doença falciforme em unidade de emergência, a equipe de enfermagem enfrenta algumas limitações, tais como: o manejo da dor, o nível de conhecimento da equipe sobre a doença, a organização e a estrutura do serviço diante das demandas de cuidado. Para cuidar dessas pessoas, os membros da equipe de enfermagem precisam estar preparados para saber avaliá-las considerando suas necessidades e suas trajetórias de vida com a doença, que implica em inúmeras internações ao longo da vida.

**Palavras-chave:** Cuidados de enfermagem. Anemia Falciforme. Emergências. Equipe de enfermagem.

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## EL CUIDADO DE ENFERMERÍA A LA PERSONA CON ENFERMEDAD FALCIFORME EN UNIDAD DE URGENCIAS

### RESUMEN

Este estudio tuvo el objetivo de identificar cómo el equipo de enfermería percibe el cuidado a la persona con enfermedad falciforme en la unidad de urgencias. Se trata de un estudio cualitativo y descriptivo, desarrollado en un hospital especializado en Rio de Janeiro-Brasil con 12 miembros del equipo de enfermería del referido sector. La producción de datos ocurrió entre abril y septiembre de 2014, mediante entrevista semiestruturada. Los datos fueron sometidos al análisis de contenido, surgiendo como categoría: El equipo de enfermería en el cuidado a la persona con enfermedad falciforme en urgencias. Al cuidar a la persona con enfermedad falciforme en unidad de urgencias, el equipo de enfermería enfrenta algunas limitaciones, tales como: el manejo del dolor, el nivel de conocimiento del equipo sobre la enfermedad, la organización y la estructura del servicio ante las demandas de cuidado. Para cuidar a estas personas, los miembros del equipo de enfermería necesitan estar preparados para saber evaluarlas, considerando sus necesidades y sus trayectorias de vida con la enfermedad, que implica en innumerables internaciones a lo largo de la vida.

**Palabras clave:** Cuidados de enfermería. Anemia Falciforme. Urgencias Médicas. Equipo de enfermería.

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