



Original article

## Perception of primary care doctors and nurses about care provided to sickle cell disease patients



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ABSTRACT

**Objective:** To analyze the perception of primary care physicians and nurses about access to services and routine health care provided to sickle cell disease patients.

**Methods:** This descriptive exploratory study took a qualitative approach by surveying thirteen primary care health professionals who participated in a focus group to discuss access to services and assistance provided to sickle cell disease patients. The data were submitted to thematic content analysis.

**Results:** Access to primary care services and routine care for sickle cell disease patients were the categories that emerged from the analysis. Interaction between people with sickle cell disease and primary care health clinics was found to be minimal and limited mainly to scheduling appointments. Patients sought care from the primary care health clinics only in some situations, such as for pain episodes and vaccinations. The professionals noted that patients do not recognize primary care as the gateway to the system, and reported that they feel unprepared to assist sickle cell disease patients.

**Conclusion:** In the perception of these professionals, there are restrictions to accessing primary care health clinics and the primary care assistance for sickle cell disease patients is affected.

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### Introduction

Longitudinality is an essential attribute of primary health care. This attribute is relevant in health care for people with chronic diseases such as sickle cell disease (SCD) because regular

monitoring by the healthcare team permits the provision of quality care.<sup>1</sup> In Brazil, the implementation of Family Health Strategy (FHS) teams has been specifically undertaken by multidisciplinary Family Health Strategy teams (FHS) that monitor and provide health care for registered beneficiaries, with an emphasis on preventive and health promotion activities. PHC

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professionals are considered to be essential in assisting SCD patients.<sup>2</sup>

The PHC teams have an important role in providing guidance to the family on various aspects. However, their training provides little preparation for assisting and monitoring SCD patients.<sup>1</sup>

It is a great challenge to train professionals to be competent providers of quality health care<sup>3</sup> in order to decrease morbidity and mortality, and to work to prevent risk situations.

To the best of our knowledge, there are no studies that focus primarily on analyzing access to services and assistance for people with SCD from the perspective of the doctors and nurses in PHC. This is the aim of the present study.

## Methods

This qualitative descriptive and exploratory study was conducted in eight primary care health clinics (PCHC) in the city of Montes Claros, in northern Minas Gerais, Brazil. This region stands out because it contains the second largest number of SCD patients in the state. At the time of this study, the city had 44 PCHC with FHS teams. Of these, 12 PCHC had SCD patients in their vicinities. In order to identify which PCHC had SCD patients in their vicinity, it was necessary to map the people with this disease in the municipality according to the PCHC closest to their homes using the Neonatal Screening Program Database.

Physicians and nurses met the following criteria and were eligible for the study if they: (1) had SCD patients in their health care team's vicinity; (2) were active at work during the study period; and (3) agreed to participate in the study. Eight nurses and five physicians participated in the study.

The data were collected using the focus group technique that allowed information to be extracted through dialog, interaction, and group discussion<sup>4</sup> on specific topics proposed by the researcher. A group meeting, lasting 1 h and 40 min, was held to better understand access to PCHC services and assistance for SCD patients.

The focus group discussion was based on the following topics: assistance to SCD patients and access to PCHC services for SCD patients. The discussions were tape-recorded.

The focus group was implemented by a moderator/coordinator with a Master's degree in the field, as well as two observers who recorded observations and behavioral reactions of the focus group participants in writing.

After the session, the material produced was carefully read, to confirm data saturation, ensuring that no new or relevant data were missing when data collection ended.

The data were submitted to thematic content analysis.<sup>5</sup> To ensure the anonymity of the 13 participants, they are referred to as interviewee I-1 to I-13. The recorded material was transcribed and recorded in a database that permitted the categorization of relevant themes and the creation of sub-categories.

All study participants signed informed consent forms. The study was conducted in accordance with the Helsinki Declaration as revised in 2008 and was approved by the Ethics Committee of Universidade Federal de Minas Gerais, registered under No. CAAE-0683.0.203.000-11.

## Results

Two categories emerged from the analysis of the interviews: "Access to PCHC services for people with SCD" and "SCD in the PHC routine: a challenge."

### Access to primary care health clinic services for people with sickle cell disease

It was observed in the professionals' statements that closeness/contact between the person with SCD and the PCHC is almost nonexistent: "*The patient always went directly to the hospital for help and made appointments at the blood center, and the PCHC was not involved. Another thing is that the PCHC did not conduct its own follow up*" (I-11). The professionals emphasized that the patients do not perceive the PCHC as a place where they can receive care, and directly seek care from the blood center and hospital. This lack of relationship is explained by the fact that the healthcare team does not conduct follow-ups on PCHC patients with SCD.

It was observed that some families did not seek assistance from the PCHC, even after the healthcare team scheduled appointments for them. The families' lack of involvement with the PCHC was evident in the statements that highlighted the efforts of some teams to follow-up. The professionals reported that some patients sought help from the PCHC when they had pain episodes, but this was not the case for all the professionals. Most of the time, the healthcare team felt excluded from care, with the patients only seeking help from the blood center and hospital. Here are some statements that exemplify this: "*The mother only considers follow up from the blood center to be important (I-7). The mother completely excludes us [PHC professionals] from this child's care*" (I-9).

It was observed that the role of the healthcare team in coordinating care was to schedule specialist consultations. This function provided minimum contact between the family of the person with SCD and the PCHC. There are even cases where the healthcare team does not know the patient, as they only receive the dates for specialist appointments and pass them on to the patient, as is observed in the statement: "*I do not know the patient, I just know that he went for the appointment, I just scheduled the appointments for him.*" (I-12).

The discussions included a description of the mother of a child with SCD who contacted the PCHC to inquire about vaccines. However, the healthcare team was not prepared to provide her with assistance due to their lack of knowledge about specific vaccine components for SCD.

Although families did not normally seek out the PCHC, some cases stand out where the family sought out the PCHC more frequently. This happened when there was follow-up from the healthcare team for a certain period: "*The patient is monitored not only for appointments, but whenever monitoring is considered necessary. The community healthcare agent is always educating, but follow up is only done when the patient visits us, spontaneously*" (I-2). In this case, it can be said that the family recognized the PCHC as a place where they could receive care. However, it is stressed that care was only a response to spontaneous demand, when the family sought assistance from the PCHC. Another case occurred when the mother of

the child with SCD contacted the PCHC for guidance about the genetic probability of having another child with the disease: "The mother of the child with SCD became pregnant again and was terrified that the next child would be born with the disease and went to the PCHC several times for information" (I-7).

### **Sickle cell disease in the primary health care assistance routine: a challenge**

#### **Subcategory 1: ignorance of the levels of assistance provided to sickle cell disease patients and primary health care as a gateway**

A lack of knowledge of both the physicians and nurses was observed regarding the levels of complexity of health care that are required by SCD patients. In addition, some professionals do not recognize that these patients should initially seek assistance from the PCHC: "I do not know where to direct the family to go first. I know they go to the PCHC, but I do not know if they went there initially, or because they were not able to get into the blood center" (I-3).

There were teams that directed their patients to initially seek assistance from the PCHC, because they believed it could solve some aspects involving SCD. If the patient's needs evolve in such a way that PHC is not effective, they can be rerouted to other levels of service.

In the professionals' perception, help was sought from the PCHC in cases of mild pain episodes and fever. In cases of severe pain, the recommended care setting was the hospital. The PCHC is considered by the professionals to be a "scheduling center" in terms of meeting the needs of SCD patients: "The mother comes when the girl has milder episodes, when they are severe she takes her to the hospital. She goes there when there is a fever or when they need to vaccinate, or get medications. Here is the place where they schedule appointments, in other words, this is a 'scheduling center'" (I-1, I-4).

In the perception of the professionals, the blood center's staff is better able to care for acute events: "It is a demand, an appointment that they come to us for. But I believe that the blood center, they do the follow up, and we (PHC) deal with the crises. Depending on the crisis, we send them to the blood center. They have a hematologist there, and they really value having a specialist." (I-7).

In simulating care for SCD patients that may come to the PCHC for spontaneous needs, it was observed that initial reception should be by a mid-level professional who identifies the patient as a person with SCD. Next, they should direct the patient to the nurse to conduct the screening, noting the presence of warning signs, and prioritizing service. Afterwards, the patient should be forwarded to the team physician. However, there is the perception that during pain crises, SCD patients should be sent to the hospital, revealing the professionals' lack of knowledge about the possibility of solving these cases in PHC, as described below: "Patients experiencing any pain crisis must be seen in the hospital, not here [PCHC]" (I-5).

#### **Subcategory 2: the reality of assisting sickle cell disease patients in primary health care**

The professionals stressed that PHC staff are not prepared to assist SCD patients, which appears to be related to a lack of knowledge regarding existing protocols. This leaves the

professionals disoriented, not knowing what to do: "PHC is not prepared enough. What do the nurses have to do? What do the physicians have to do? What does the dentist have to do? How do I know what to do in each of these situations? How does the monitoring of medication work? I think these roles should have been defined" (I-1, I-8).

The professionals showed a lack of collaborating referrals between the blood center, the hospital, and PHC: "Sometimes I want to monitor patients when I refer them, but I cannot. I do not know about the hospitalizations and specialist consultations. This complicates the work, since there is no feedback" (I-6). This statement highlights the truncated coordination for care of SCD patients, because there is no monitoring throughout the health care network. There is no communication and interaction, which complicates monitoring of SCD patients in PHC. The healthcare team is often not aware of hospitalizations and consequently cannot follow the case. The professionals complain that admission to hospital is not immediately communicated to them by the family or by the secondary and tertiary levels, hindering the follow-up of the patients.

The professionals reported that they do not take responsibility for caring for these patients, because there is a specialized service that does this. Scheduling of health services in the PCHC is done considering the other diseases that do not have a specialized support service. In this way, the team does not conduct activities to connect with and track patients according to the peculiarities of SCD: "I think it is because the blood center provides such a good service that we trust them a lot and think that we do not need to do anything else" (I-6).

Another explanation for not taking responsibility for the care of SCD patients may be the excessive load faced by the PCHC team: "We [PHC professionals] cannot handle everything. There is so much! There are many patients with diseases that need assistance" (I-13). This statement can indicate lack of planning in scheduling the team's activities. The professionals work to solve problems and cannot plan to meet the demands in their service area. Including SCD in the healthcare team's routine becomes a challenge in the professionals' perception, given the challenging factors in this process.

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## **Discussion**

In this study, the physicians and nurses perceived limitations in the access to the PCHC by SCD patients. Patient contact with the PCHC and its professionals is minimal, limited to scheduling appointments. It was confirmed that help is sought by SCD patients from the PCHC in the case of mild pain episodes and for vaccines. Assistance to persons with SCD is not part of the healthcare team's work routine.

The families do not recognize the PCHC as a location for and gateway to care and the assistance system. This is mainly the result of insufficient knowledge on the part of professionals<sup>3</sup> which affects assistance.<sup>2</sup>

The reasons why people with SCD and their families do not seek help from the PCHC may also be related to difficulties in accessing the PCHC, so they resort to secondary care because they have already scheduled specialist consultations or received care from the hospital in urgent and emergency situations. Furthermore, these patients may not be aware that

PHC activities are aimed at prevention, promotion of health, and continuous care, and may even have sought the service previously and not obtained an effective solution to their problem at that time.<sup>1-3,6</sup>

There are countless barriers to including SCD patients in PHC services. A study conducted in London indicated practical difficulties in accessing health services and lack of confidence in the capacity of these professionals to provide specific information on SCD.<sup>6</sup> Continuous education of PHC professionals in the workplace<sup>7</sup> is essential to promote behavior changes in order to improve assistance provided to these individuals.

One factor indicated by the professionals is their own healthcare team's lack of interest in caring for SCD patients. One explanation is the low prevalence of SCD compared to other chronic diseases such as hypertension and diabetes, and because the disease is not contagious like tuberculosis or hanseniasis. Furthermore, because there are no Ministry of Health programs that encourage the inclusion of SCD in the PHC line of care, and therefore, no funds can be transferred for this purpose, and managers indicated that there would be no interest in providing this care. Therefore, the focus of the professionals' efforts would reside in more common diseases for which funds are available, or for which there is monitoring by the managers. However, although the prevalence of SCD is lower than that of other chronic diseases, it is notable that the northern region of Minas Gerais is the area with the second-highest incidence of the disease. In addition, SCD causes a significant impact on families as a result of more intense social and clinical repercussions compared with other chronic diseases, and this needs to be recognized by health professionals.<sup>1,3</sup> Studies show that many PHC professionals do not know that SCD is part of the line of care provided by PHC.<sup>8,9</sup>

The finding that bonds are not established between SCD patients and the PCHC is of concern. This bond is something that promotes interaction and closeness between the professionals and users, and is also a significant tool for stimulating citizen awareness and self-care.<sup>10</sup> Strong ties should be established through dialog, respect, and confidence, causing these individuals to reflect on care and be equally responsible in this process. The strengthening of this bond between the professional, the person with SCD and their family is critical to reducing the morbidity and mortality of the disease. Closer ties will allow the monitoring of persons with SCD throughout their lives. Even when the family seeks help from the PCHC, the team is passive, responding only to spontaneous demand. This feature denotes the traditional hegemonic medical model based on healing practices.<sup>11</sup>

Creating bonds between patients and the PCHC is urgent due to the historical and social issues related to the disease in Brazil. SCD has historically been neglected in Brazil and around the world because it is predominantly a Black disease. In addition to this historical neglect, it is notable that this disease affects a population that is socially vulnerable and suffers from economic difficulties, illiteracy, and little access to healthcare services, culminating in early death.<sup>12</sup> Consequently, equitable assistance is necessary to establish strategies to create joint responsibility between families and the health service.<sup>13</sup>

A systematic review identified that interventions by PHC professionals aimed at people with chronic conditions are emerging as innovative care, especially for children with low socioeconomic levels. However, there are no interventions targeting specific genetic diseases such as SCD and cystic fibrosis.<sup>14</sup>

Studies have indicated the need for PHC to better assume its role as the gateway to the health care network, as well as to create connections with patients with certain diseases such as mental disorders,<sup>10,13</sup> tuberculosis,<sup>15</sup> hanseniasis,<sup>16</sup> and SCD.<sup>1-3,8</sup> Partial inclusion, or even the exclusion of these diseases from the PHC care routine results from the fact that treatment of these diseases has historically taken place in secondary care represented by specialized centers. Even after the decentralization of care for hanseniasis, tuberculosis, and mental health to PHC, professionals still hold the old view that monitoring and control continue to be the responsibility of specialized centers, and not of PHC.<sup>10,15,16</sup> The situation is very similar to that of SCD. The professionals believe that the blood center should take responsibility for care, and therefore, they are not concerned with providing specific care to persons with SCD.

These professionals are unaware of the levels of complexity of health care in SCD. They do not see themselves as a gateway to the system for these patients. The PCHC can be decisive in many situations related to the disease such as mild pain episodes, fever, growth and development consultations, monitoring of prophylactic penicillin and folic acid supplementation, administration of vaccines, prevention and treatment of leg ulcers, initial treatment of priapism, dental evaluation, guidance related to the environment, water intake, physical activity, health education, monitoring of school and work, family planning, genetic counseling, monitoring of specialist consultations, and hospitalizations.<sup>3</sup>

The blood center appears in the professionals' statements to be a place for monitoring and care for acute crises. In Minas Gerais, the blood center is a specialized secondary health service responsible for specialist consultations. Specifically in the municipality under study, the blood center provides care for cases that should be the responsibility of the hospitals and urgent care units. The blood center's activities are more prominent since they rely on specialists whose clinical proximity to people with SCD is more clearly perceived by the families and by the professionals in PHC.

The professionals underestimate the potential of PHC in caring for persons with SCD, since there are no specialists in this service, only professionals with experience in family health, or in some PCHCs, pediatricians. Persons with SCD do not need to be seen by a hematologist at every appointment. For a positive impact, SCD requires multidisciplinary care. Many health activities can and should be performed by PHC professionals. The healthcare team can solve problems, providing basic services to SCD patients according to the complexity of the clinical situation.

The professionals reported that they are overloaded with their routine activities at the PCHC, and are unable to plan and care for SCD patients. A study on FHS professionals also identified overload as an impediment to appropriate approaches to social and medical issues.<sup>17</sup> Overload takes place due to productivity demands, the number of families in the vicinity,

and the scarcity of time available to conduct the various activities.<sup>18</sup>

Finally, collaborative referrals stand out as an impediment to PHC professionals providing medical assistance to persons with SCD. When the patient is assisted in a secondary or tertiary service, it is expected that the patient's PHC team will receive a collaborative referral, allowing the PHC professionals to continue the process of care for that patient.<sup>19</sup> However, collaborative referrals are not yet a reality in many regions of the country.<sup>11,19</sup>

The limitations of the present study are related to the population investigated, restricting the validity of the empirical data generated; however, they can be used in circumstances that are similar to that of this municipal. Another limitation is the fact that this study investigated how access to services and routine health care are perceived by the PHC physicians and nurses, not by the people who have the disease, which could be the focus of complementary studies.

In this study, ignorance was noted on the part of the professionals with regard to the details of monitoring persons with SCD, a fact that indicates the need for training of these professionals. There are limitations in accessing the PCHC, and according to the perception of these professionals, health care for persons with SCD in PHC is affected. Adoption of protocols defining the role of each team member is essential because PCHC professionals do not know how to approach SCD patients. It is recommended that secondary and tertiary care professionals should be trained so that in each consultation or hospitalization, they guide patients about the importance of monitoring from the PCHC, helping to create a bond between patients and the PCHC.

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## Conflicts of interest

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