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### 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

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