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Challenges and Advances in Providing Care for Children With Sickle Cell Disease: Health Professionals' Perceptions

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Abstract

This research aimed to investigate the challenges and advances perceived by managers and health professionals in providing care to children with sickle cell disease within health care networks. This is a qualitative study, conducted in referral health services for the care of children with sickle cell disease in the northern macro-region of the state of Ceará, Brazil. Twenty health professionals participated. Data were collected from October to December 2024 through semi-structured interviews. Data analysis was performed using content analysis and Merhy's theoretical framework on work processes in health. The participants in the study were medical professionals, nurses, pharmacists, psychologists, and social workers. After the analysis, it was possible to obtain two categories: Delivering care to children with sickle cell disease within the health care network: identified challenges and Care for children with Sickle Cell Anemia in the specialized service: advances in care. In conclusion, a gap persists between the recommended guidelines and their effective implementation for achieving comprehensive health care. This scenario reinforces the need for investments in continuing education and in strengthening primary care as the coordinator of the care network.

INTRODUCTION

Sickle cell disease (SCD) is a group of blood disorders marked by hemoglobin S. It is a global public health problem. The disease results from a gene mutation for hemoglobin A (HbA), creating hemoglobin S (HbS), inherited in an autosomal recessive pattern (1). Other mutant hemoglobins, such as C, D, and E, join hemoglobin S to form the sickle cell disorder group. These variants are linked to different disease phenotypes (2).

Globally, SCD incidence rose 13.7% from 2000 to 2021. It reached 515,000 births per year. In the same period, SCD prevalence rose 41.4%, from 5.46 to 7.74 million. The mortality rate climbed nearly elevenfold (3). Early diagnosis is essential for timely intervention and effective care. This helps improve quality of life and reduce patient morbidity and mortality, as SCD can affect many organs (4–6). Newborns should be screened with heel-prick testing in the first week of life.

Many studies address SCD itself, but little is known about how health care networks organize care for these patients. Health professionals and managers play a central role in this process (7). New research is needed on the roles of managers and professionals in SCD care networks, especially for children, the focus of our study. Children with SCD still experience significant morbidity and mortality (8–10).

Sharing ideas on this topic may help health professionals and managers. It could improve their understanding of how care for children with SCD is provided. Such exchanges may support the planning of actions to reduce morbidity, mortality, and improve the quality of life of these patients.

From this perspective, this study aimed to investigate the challenges and advances perceived by health managers and professionals in delivering care to children with sickle cell disease within Health Care Networks.

MATERIALS AND METHODS

This descriptive, qualitative study was conducted with 20 professionals (16 care providers and 4 managers) in Sobral, Ceará, Brazil. Services in the study included primary care (family health center), secondary care (regional blood center), and tertiary care (two hospitals).

Data were collected from October to December 2024. Researchers adopted a questionnaire and recorded semistructured interviews. All participants gave informed consent. Audio was transcribed to .docx files with TurboScribe. Data were analyzed with Bardin's Content Analysis (11). No AI technology was used.

The ethical implications of the research are in accordance with the Declaration of Helsinki. All participants provided written informed consent prior to participation. To ensure confidentiality and anonymity, participants were identified using alphanumeric codes. This research did not receive any funding. This study did not utilize Large-Scale Language Models (LLMs). Human responsibility was given to the final version of the text, and the authors agreed that this edition reflects original work.

RESULTS

Twenty health professionals participated. They included doctors, nurses, pharmacists, psychologists, and social workers. The group averaged 33 years of age and 6 years of experience. All had postgraduate degrees, but only two specialized in hematology. Only staff at the blood center reported training in SCD care.

Delivering care to children with sickle cell disease within the health care network: identified challenges

This category highlighted the challenges professionals face in caring for children with SCD in the network. The statements below illustrate these issues:

When a case comes up, we start reaching out to **someone, some specialty or service**, trying to figure out **where we're supposed to refer them, what we're supposed to do**, so the patient doesn't get left hanging and bounced around without knowing where to go. (P1–APS)

[...] When a case like that comes in, **the first thing that comes to mind is Hemoce**. We immediately think about the network and about not leaving the child only in primary care. (G–APS)

I'm not familiar with the pathway these patients follow in the care network. (P3–APS)

As for access for these children, since I see that there isn't an established care pathway, I think they get care the same way other children do – when a need comes up, when they have a clinical issue – but not with ongoing care focused on the condition itself, **because there isn't an established pathway**. (P4–APS)

I'm not aware of any children with SCD in this territory. When the child mentioned came to the service, **it was just for a routine visit, and the mother didn't mention** that the child had any other disease-related conditions [...] (P2–APS)

Pediatric emergency professionals reported difficulties in managing these children. They emphasized the limited number of hematologists and the lack of institutional protocols.

[...] The thing is, because this is an emergency service, **we don't really stop to focus on the specific needs of a child with sickle cell anemia**. So, to be honest, I think it ends up being fairly general care, like it is for everybody else. Sometimes the only difference is that the child needs a transfusion, so we follow the transfusion protocol. (P1–AH)

It would be important for the regional hospital to have an outpatient hematology clinic because of the demand. **It's very hard to have a hematologist here, especially a pediatric one**. So, we end up relying on interconsultations, which sometimes take a while, and in some cases, we need things to move fast. (P3–AH)

As for caring for children with sickle cell anemia, **there is no institutionalized protocol here**. However, there's a caveat, because children with hematologic disorders are not actually referred to the regional hospital. (G2–AH)

[...] Another issue is that, in acute events, **they still don't have a flow everyone knows –** a clearly designed pathway with access for everybody. (P5–AH)

Another theme was the reported scarcity of training to provide care for these children.

There has **never been any training on this – not at any point**. (P3–APS)

It would help to have guidance on the specific needs of children with SCD. Teams need to know what to look for and how to assess and reassess these children. **Most importantly, they need to explain crisis severity for more sensitive care**. The team should be sensitized to these children. (G1–AH)

In his (the caregiver's) daily work, he will feel the difficulty in obtaining information from the professional at his unit of origin, the PSF unit, the small hospital if there is one in his city, or the medium-sized hospital, because the **professionals still do not have this guidance to identify a crisis in a patient with sickle cell anemia** (G1–AE).

General practitioners still lack skills and knowledge after university. They often need practice to diagnose, **manage, and care for patients properly**. (P5–AH)

Care for children with SCD in the specialized service: advances in care

In contrast, care at the regional blood center was seen as progress for the longitudinal care offered to children with SCD.

Hemoce in Sobral has been taking in this care for people with SCD, **improving territorial accessibility because it's closer** [...] (G1–AE)

When we work with a **multidisciplinary team**, things don't get so tied up. Everyone can contribute. **We listen. Even in the waiting room**, we identify some demands, sometimes in a more relaxed way. (P3–AE)

The child will be followed for life in our service, and we work so that coming to the blood center is **well accepted and not associated with something bad—quite the opposite, that it is seen as something that helps them** and gives them a good quality of life. (P4–AE)

Another important aspect concerns the adoption of protocols established by the Ministry of Health (MoH), used not only for pharmacologic interventions but also for referral to required tests, with due attention to the recommended time frames, as shown below:

We follow protocols defined by the Ministry of Health. They are followed by medical, nursing, and other professionals, covering everything from the consultation itself to routine testing and how often follow-up visits should be scheduled. (P2–AE)

We have a protocol for people with SCD, and another protocol for when transcranial Doppler is indicated, because stroke is a condition that can lead not only to death but also to years of life lost. This is one of the protocols Hemoce has been careful to follow in order to maintain care. (P1–AE)

We have Ministry of Health guidelines for managing these patients. I've even produced a guidance document that I share with professionals across the network who seek our advice on how to manage children seen in other services, especially in hospital care. (P5–AE)

In addition, there is clear attention to involving family members, who are always present in the care provided to children with SCD in response to their health needs. This involvement fosters empowerment, not only regarding clinical management but also regarding their rights as citizens when accessing health care, as reflected in the statements below:

Family members are absolutely essential because the child has no autonomy, so until they reach a level of maturity that allows self-care, our focus ends up being the caregiver. The caregiver is the one who takes on that responsibility. We talk about the importance of coming to every appointment, taking the medication every day, and understanding that these medications will help prevent complications, hospitalizations, and blood transfusions. (P2–AE)

And I spend a lot of time explaining to people what **the right to health** actually means. There's even a very simple guidance document – the SUS users' rights booklet – which I really like. I always tell people that medical transport is a right. If that service isn't available in your municipality, the municipality is

required to provide medical transport. When patients have that information, **they feel empowered**. (P1–AE)

Another important factor is follow-up by the multidisciplinary team through a digital tool (WhatsApp) used as a means of communication, which helps speed up some work processes and allows timely care in response to needs as they arise.

One thing that has improved these patients' adherence is communication through WhatsApp. We now have a group with all the patients with sickle cell anemia, and when we notice it's time to pick up medication or have tests done, we reach out and let them know. (P3–AE)

DISCUSSION

This study points to several challenges in producing care for children with SCD, such as difficulty identifying signs and symptoms and with follow-up for integrating the actions available in primary health care. Some managerial and health care practices could be democratic and participatory and aligned with SUS governing principles (1); however, we observe that care organization has been assumed by specialized care. Even after ten years of formal guidelines, a gap remains between recommendations and actual practice, and people with this condition continue to be rendered invisible, as shown here and in other studies (12–14).

Regarding referral, as the statements show, professionals either do not know how to do it or do not feel confident doing it. Yet recommendations are clear: recognize the needs of people with SCD, receive them, listen to them, provide care, and follow the care pathway according to each person's needs, ensuring comprehensive care continuity and promoting dialogue across the different points of the health care network so that people are cared for and respected in their difficulties (15).

Another challenge highlighted by professionals was difficulty with clinical management when these children experience complications, owing to the limited number of specialists, such as hematologists, the lack of institutional protocols, and, in some cases, professionals' limited knowledge about how to provide care that meets the specific needs of SCD.

The knowledge gaps identified here are consistent with other studies showing weaknesses in this care process, which directly affect the management of ill children – for example, through lack of information about the disease, limited recognition of factors that complicate day-to-day management, and low problem-solving capacity (16–18).

Also, within the challenges identified, this study found inadequate preparation and a scarcity of training and educational activities aimed at improving the care provided to children with SCD. Other studies likewise underscore the need to train professionals so they can better care for patients with sickle cell disease (19–20). This setting is troubling because when professionals are unprepared, the care provided fails to meet these patients' health needs. That, in turn, may lead to more serious clinical complications

that affect physical and mental health (21) of children and caregivers alike, especially when they have to move from one nonresolutive service to another.

Moreover, low knowledge levels point to this action type's lack or fragility. Comprehensive care for people with SCD requires recognizing the complex condition and training for teams at all care levels. In this context, continuing education emerges as a strategic tool, fostering learning, knowledge exchange, and coordination of practices. This approach is aligned with the National Continuing Health Education Policy.

To achieve this, one might think beyond the National Policy for Comprehensive Care for People with SCD and Other Hemoglobinopathies and beyond care guidelines alone, also considering the National Humanization Policy, which proposes necessary changes by bringing workers and services together through shared knowledge, transforming health practices, encouraging critical analysis of the work process, strengthening interaction among stakeholders and promoting interprofessional work (22). The role of universities must not be overlooked either, since they are key to improving the training of health professionals by including this topic in curricula in ways that foster reflection and action (19).

In the interviews, we also observed issues related to access to a more structured, specialized health service located in another municipality, far from families' hometowns. These findings are consistent with another study showing that families often need to seek care at a blood center in a different location because local health services provide insufficient support; some families had to travel to another city for follow-up, which makes care more difficult because of distance (23). Access, follow-up, and care are acquired rights, and they should be ensured throughout the health care network and, ideally, close to the user's home territory, with support and a guaranteed referral system (1).

In the second category of this study, the focus shifts to advances that affect the development of practices for producing care for children with SCD, such as the adoption and use of established protocols by some professionals, the early identification of clinical complications, and guidance for managing these children.

The publication of resolutions, guidelines, ordinances, and clinical protocols marked a period of intense struggle led by social movements working alongside institutional stakeholders, reinforcing a context favorable to health policies to support planned actions. In other words, on should understand that including SCD in public programs and policies has, at least in part, enabled people living with this disease to receive care through a comprehensive and multiprofessional approach to health in order to overcome a history of invisibility and sometimes exclusion (24).

In this context, we observed that some professionals use, albeit only partially, both relational and hard technologies through the application of protocols and by involving the child and family in care. This practice fosters empowerment, autonomy in self-care, and awareness of the disease, thereby strengthening the defense of the right to health.

Having family support in care is one of the foundations for developing collaborative interprofessional practices, in which professionals can share knowledge and strategies for shared care with the user, the family, and the community, thus promoting autonomy and empowerment (22). In addition, anticipatory guidance involves preparatory and preventive strategies directed toward an open future, instilling affective states of readiness that can improve child survival in cases of SCD (25).

Another notable point in this study concerns progress in follow-up by the multidisciplinary team with patients and their caregivers through digital tools (WhatsApp) used as a means of communication, helping improve treatment adherence. In this regard, the use of digital resources – especially telehealth – expanded during the pandemic period and helped support the care process. Evidence points to a marked increase in this practice, favoring care continuity (26–29).

CONCLUSION

This study illustrates the perceptions of health managers and professionals, showing on the one hand the emerging challenges and, on the other, the advances perceived in the production of care for children with SCD within Health Care Networks.

Based on these perceptions, it became clear that the care provided to people with SCD within services that are part of the health care network is better organized in specialized care. At the Regional Blood Center, care begins with registration and continues through follow-up based on established protocols, with the use of digital tools that improve adherence, involving not only the children but also their family members in treatment, in addition to providing support to other services within the network.

There was also a shortage of hematologists, particularly in the pediatric emergency care service, and a recognized need for investment in continuing health education, including the implementation of clinical protocols, especially in primary care and hospital care.

Because of these limitations, the production of care for children with SCD still has opportunities for improvement that need to be recognized. Clear organizational structures and better resource management are therefore recommended, along with support measures to overcome these challenges and improve the comprehensive care offered to these children.

DECLARATIONS

Declaration of conflicting interests

Raila Souto Pinto Menezes, Lívia Lopes Custódio, and Ilvana Lima Verde Gomes an declare that they have no Competing Interests and Funding.

Compliance with Ethics Guidelines

This study involved human participants. The ethical implications of the research are in accordance with the 1975 Declaration of Helsinki, revised in 2000. All procedures also followed the ethical standards outlined in Resolution No. 466/2012 of the Brazilian National Health Council. Ethical approval was obtained from the Research Ethics Committee of the State University of Ceará (protocol no. 7.043.320) and the Institute of Health and Hospital Management (ISGH) (protocol no. 7.151.062). Free and informed consent was obtained from all participants involved in the study. To ensure confidentiality and anonymity, participants were identified using alphanumeric codes.

Authorship confirmation statement

Substantial contributions to the design of the study: Menezes RSP, Gomes ILV. Data collection: Menezes RSP. Data analysis and interpretation: Menezes RSP, Custodio LL. Discussion of results: Menezes RSP, Custodio LL. Writing and/or critical review of the content: Menezes RSP, Custodio LL. Final review and approval of the final version: Menezes RSP, Custodio LL, Gomes ILV. Agreement to be responsible for all aspects of the work, ensuring that issues related to the accuracy or integrity of any part of the work are properly investigated and resolved: Menezes RSP, Custodio LL, Gomes ILV.

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Data availability

The data collected for this research have been analyzed and are available upon reasonable request to the corresponding author.

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