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Access and care of individuals with sickle cell anemia in a primary care service

Acesso e assistência à pessoa com anemia falciforme na Atenção Primária

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Sickle cell anemia; Quality of health care; Primary care nursing; Public health nursing; Community health nursing

Descritores
Anemia falciforme; Qualidade da assistência à saúde; Enfermagem de atenção primária; Enfermagem em saúde pública; Enfermagem em saúde comunitária

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Abstract

Objective: To determine health community agents' opinions on access and care delivery to individuals with sickle cell anemia.
Methods: This was a qualitative study conducted among 14 health community agents from a municipality with a high prevalence of sickle cell disease. Data were submitted to analysis of thematic content.
Results: Access to the basic health unit of individuals with sickle cell disease occurred only in situations of acute episodes. We observed a barrier between patients and basic health units. Care for patients with sickle cell disease was not prioritized for those with alert signs, nor was there specific follow-up in child rearing, vaccines, or medicines. Home visits were conducted without a systematic plan.
Conclusion: According to the perspective of health community agents, the care of individuals with sickle cell disease was inadequate and individuals' access to care was limited.

Resumo

Objetivo: Conhecer a opinião dos agentes comunitários de saúde sobre o acesso e a assistência à pessoa com anemia falciforme.
Métodos: Pesquisa qualitativa realizada por meio de grupo focal, com 14 agentes comunitários de saúde em município de elevada prevalência da doença. Os dados foram submetidos à análise temática de conteúdo.
Resultados: O acesso da pessoa com doença falciforme à unidade de saúde ocorre apenas em situações de episódios agudos. Verificou-se a existência de barreira entre a pessoa doente e a unidade de saúde. Na assistência não há priorização do atendimento em casos de sinais de alerta, não há seguimento específico de puericultura, as vacinas especiais e a medicação não são acompanhadas, as visitas domiciliares são assistemáticas.
Conclusão: Na perspectiva dos agentes comunitários de saúde a situação da assistência à pessoa com anemia falciforme se mostrou precária e o acesso limitado.

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Introduction

Hemoglobin disorders constitute a group of hereditary conditions that involve genes responsible for the synthesis of globin. It is estimated that 7% of the world population has a hemoglobin disorder, of which sickle cell disease is the most common. This disorder is the most common hereditary condition in both Brazil and the world. The prevalence of sickle cell trait is estimated to be between 2% and 8%. In Brazil, the number of individuals with sickle cell anemia is about 25,000 to 30,000.[1] Because of the prevalence of this disorder and its clinical importance, it is considered a public health problem in several countries, including Brazil. In addition, it is a chronic disease characterized by clinical variability across patients and within individual patients; episodes of well-being overlap with situations that require urgent or emergency care. Sickle cell disease is more predominant in black populations,[2] who, because of social and economic issues, need more equity in health care.

To reduce morbidity and mortality, several care levels are involved in the care of patients with sickle cell disease. Primary health care in Brazil emphasizes a Family Health Strategy, which focuses mainly on health promotion and prevention of injuries and diseases. Ideally, Family Health teams are the main entrance through which patients access the health care network, and this service must be prepared to monitor patients with sickle cell disease during their lifetime. Studies have reported gaps in the knowledge[3,4] and daily practice of primary health professionals with regard to sickle cell disease.[5] Nonetheless, few studies have addressed access to care and quality of care among patients with sickle cell diseases in basic health units.

A population-based cohort study showed that although early diagnosis for sickle disease was implemented through neonatal screening, the mortality rate from sickle cell disease in children is still high. The study also emphasized lack of knowledge among the health teams who are delivering care to patients with sickle cell disease and their families when they are seeking health services.[6]

The Family Health Strategy has a fundamental role in the care of patients with sickle cell disease. The creation of a bond among the patient, his/her family, and the primary health team is crucial to facilitate understanding of the disease, anticipate risk situations, and avoid complications that require hospital admission.[4] Other important factors are patients' nutritional follow-up, growth, and development; follow-up of adherence to prophylactic antibiotic therapy; immunization schedules; the influence of the patient's environment and other factors that can trigger acute episodes.[5]

The Family Health Strategy consists of a multidisciplinary team that includes technicians and auxiliary professionals who are fundamental to creating and strengthening the bond with patients with sickle cell disease and community health agents. The duty of community agents is to deliver services at home or in the community for an individual or a group. Because health community agents work within the community, they represent the link between the health team and the population that needs assistance.[7]

The routine of a community health agent is directly related to the nursing team, which supervises activities to identify health markers and patients who need differential care by other professionals, conduct follow-up for specific health problems during home visits, and recognize areas requiring uniformity for the team.[7] The nurses' role is emphasized in this context because nurses are among the professionals responsible for maintaining continuing education of community agents.

Considering the important role of health community agents in the Family Health Strategy and the fact that sickle cell disease affects the family and constitutes a public health problem, this study aimed to determine health community agents' opinions on access and care delivery for individuals with sickle cell anemia.

Methods

This qualitative study was carried out in the municipality of Janaúba, north of Minas Gerais, in

the southeast region of Brazil. This city has roughly 72,000 inhabitants and constitutes the region in our state with the second-highest population of patients with sickle disease.

Fourteen patients with sickle cell disease were selected from the records of the municipality's Neonatal Screening Program, made available by the Center for Actions and Research in Diagnostic Support. Subsequently, we investigated the relationship between each patient and the family health unit in which he/she was registered, according to the area defined by our search. We invited only health community agents from Family Health Strategy teams whose coverage area included patients with sickle cell disease. Participants who met the following criteria were included: (1) those working in the Family Health Strategy during the study period (professionals on vacation or those with any special leave permission were excluded); (2) those who had patients with sickle cell disease in their micro-area of covering; and (3) those who agreed to participate in the study.

Data were collected throughout using a focus group technique in order to investigate the subject in more depth.[8] This technique provides time for reflection and discussion about care delivery to individuals with sickle cell disease. A moderator/coordinator and two observers conducted the focal group. Focal group sessions used a plan that included the following topics: access of patients with sickle cell disease to the basic health unit and reality of care provided to these patients. Professionals' testimonials were recorded by using a digital recorder and were then transcribed in full. Observers' opinion was also considered in the data analysis. Focal group meetings lasted for no more than 1 hour and 30 minutes.

Data collected from participants and observers' speeches were submitted to content analysis in the modality of thematic analysis. Data were organized by interpretative categories.[9] The following steps were taken during the analysis: pre-analysis, exploration of the material, treatment of results, and interpretation.

Development of this study followed national and international ethical and legal aspects of research on human subjects.

Results

Based on analysis of participants' discourses, it was possible to identify the point of view of primary health community agents regarding situations in which health care was delivered to individuals with sickle cell disease. Data were organized into three thematic categories (Figure 1).

The first category entailed the access of patients with sickle cell disease to services available at the basic health unit. This theme concerned reasons that led the individual with sickle cell disease to seek a basic health unit. The seeking of the basic health unit service was minimal, and some professionals considered it nonexistent. The reasons for patients seeking the basic health unit were related to scheduling laboratory test, scheduling of specialized consultation, consultations to follow up individual growth and development, and intercurrent situations, such as pain and fever episodes. In cases of clinical intercurrence, the seeking of care was associated with the fact that the health unit was the closest health care site to the patients' house.

The second theme in the first category is related to the barrier that prevented patients with sickle cell disease from seeking the primary care service, leading them directly to secondary care units (i.e., blood centers). This barrier occurs because some primary care professionals do not have the knowledge, skills, and behavior to deliver care to patients with sickle cell disease. The family's preference for follow-up from secondary care providers rather than the primary care service is emphasized. The family attends follow-up visits only in the blood center, and they consider this follow-up sufficient to address their health care needs.

In the second thematic category, we observed aspects of care to individuals with sickle cell disease in the basic health unit. We noted in the first theme that prioritized care in the setting of alert signs is still not a reality for patients with sickle cell disease.

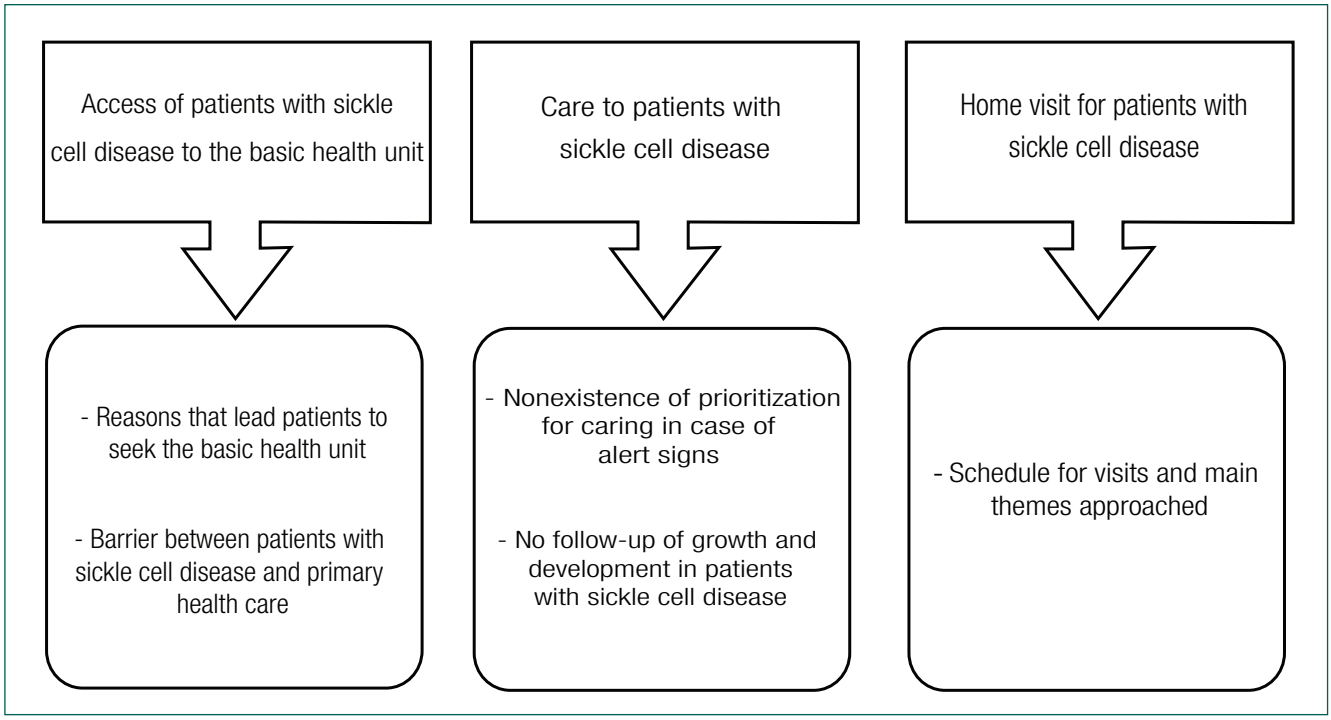

Figure 1. Thematic categories of the study

Several times patients had to wait for assistance as long as other patients did. If the child has fever or feels very ill, he/she has the right to priority. The professionals' lack of knowledge regarding prioritization of care and awareness of alert sings for potentially severe events was evident. In primary care health units, the response to spontaneous demands is carried out without any standardization. There are no criteria for immediate assistance.

The second theme showed that consultations to monitor the growth and development of children with sickle cell disease are conducted according to the routine schedule used for all children. Health professionals are not conducting the interval follow-up visits recommended for children with sickle cell disease. The professionals' lack of knowledge on the specific schedule recommended for these children was evident. Thus, the follow-up of growth and development is compromised.

The third thematic category stated that health community agents were not conducting home visits in a systematized way. The points emphasized by agents as important during visits were infectious disease, medication, pain, consultations, exams, and the child's schooling situation. Professionals cited medication monitoring as the action most frequently performed during home visits. However, agents did not believe that follow-up of medicines was relevant in all visits; they considered such follow-up important only when changes in medication were needed. The actions of health community agents during visits should function as if they become part of family relationships. When treatment is denied, the home visit is a fundamental instrument for better family adherence to the treatment.

The professionals' lack of knowledge about medicines needed for children with sickle cell disease and the special vaccine schedule needed could have negative implications for a satisfactory follow-up in the correct use of medicines and vaccines taken by the child with sickle cell disease. Heath community agents reported follow-up vaccines based only on schedule recommended to all children.

Discussion

Limitations of this study are related to the qualitative method used, which does not allow us to extrapolate the results or establish a relationship of cause and effect.

The contribution of these results is related to the delivery of health care to individuals with sickle cell disease as based on the opinions of health community agents of primary care services. A worrying finding was that professionals did not know the specific care needed during follow-up of patients with sickle cell disease. Therefore, quality of care seems to be compromised.

Access of individuals with sickle cell disease to health services must be through the Family Health Strategy, which is considered the main entrance for the health system. Family Health Strategy teams coordinate care and also refer patients to other levels of care, which ideally must be organized in care integrated networks. In our study, patients sought out the primary care health team only for lab exams, consultation, and situations of clinical intercurrence, such as pain and fever episodes. Families of patients with sickle cell disease do not consider other services provided by primary care teams to be important; these include vaccination, bandages, nursing consultation, distribution of medicines, education groups, actions for health promotion and prevention, and scheduling of consultations.[5] Results also showed that the health team did not feel responsible for coordinating care delivery to patients with sickle cell disease and felt that the patient's family was responsible for seeking the best care.

The role of Family Health Strategy[10] goes beyond the disease; it must propose longitudinal care that addresses the patients' needs and health problems. A study conducted in Juiz de Fora – MG, southeast region of Brazil,[11] among professionals from the Family Health Strategy reported that access to this service is needed to rebuild the conventional care model, which is currently characterized by medical consultation to specialists.

Access is understood as the ability to generate services and address demands of health to a specific group. Accessibility can be considered as service features and resources that facilitate patients' use of health care services or make that use difficult. In this way, several factors influence access, such as geographic, organizational, sociocultural, and economic factors.[12]

Individuals with sickle cell disease have difficulty accessing primary care because of some special issues, such as having a genetic disease,[13] and because this population is predominantly black.[14,15] Genetic diseases, in general, do not have defined guidelines in primary care; therefore, loss to adequate follow-up of families occurs. In addition, the focus has been on specialized care, and there are few guidelines on how to structure primary care in the setting of genetic diseases.[13] Sickle cell disease differs from other genetic diseases because it is included in the primary care guidelines proposed by the state of Minas Gerais and by the federal government. However, there are no care protocols similar to those for other chronic diseases, such as hypertension and diabetes mellitus. This gap can present access difficulties because professionals do not know their role in the delivery of care for patients with sickle cell disease. Social vulnerability is emphasized as a concern regarding the black population's access to health services, which is often difficult.[14,15]

The care for individuals with sickle cell disease with regard to access and use of primary care services prompted two questions: How do users access the system, and how effective are the care and services delivered? Access involves the location of the unit, the amount of time (hours and days) available for population care, the ability to obtain consultations in a specific unit and for specialized areas, and the prioritization of care in cases of alert signs. Effectiveness is directly related to the ability of health services to address the needs of users. It is ideal for patients with sickle cell disease to attend a dental follow-up visit every six months, have a physical exam, have easy access to medicines, be followed up for folic acid and prophylactic antibiotics for up to five years, have access to vaccines, attend visits for regular follow-up of growth and development, and receive health education for themselves and their families.

We found that access of patients with sickle cell disease to primary care is reduced because they sought secondary care directly (in many cases, at blood centers). Seeking secondary care is based on historical factors because the treatment of sickle cell disease is perceived as complex and an exclusive

competence of blood centers. Therefore, professionals at other levels of care do not know or even ignore patient with the disease, and they end up convincing the patient to recognize the blood center as the only place at which to take care of their health. Today, for several families, this is still a reality.

Patients with sickle cell disease experiencing alert signs must be given priority in the health services of the Family Health Strategy, but the health community agents in this study did not mention this. We verified the professionals' lack of knowledge on priority of care in cases of alert signs (fever, pain, sudden increase of pallor, severe jaundice, abdominal distension, increase in size of spleen or liver, coughing or respiratory difficulty, priapism, neurologic changes, impossibility of fluid intake, dehydration, vomiting, and hematuria). Another study among families of children with sickle cell disease found that care in the presence of alert signs is never or rarely prioritized.[5]

Professionals of Health Family Strategy have been dissatisfied with spontaneous demand and mentioned that it was excessive and posed difficulties in establishing a more humanized embracement. Embracement of spontaneous demand consists of conservative care with the aim to know the user's reason for seeking the health unit.[11] Generally in the front line to embrace patients are the nursing technicians, health community agents, and nurses, who usually do not know about prioritization of care for patients with sickle cell disease in the case of danger sings.

The main focus of child rearing consultations in primary care is follow-up of child's growth and development, promotion of breastfeeding and healthy feeding of the child, actions to improve immunization, preventing accidents, and delivering care for the prevalent diseases in childhood.[16] In addition, the follow-up of nutritional disorders is especially important for children with sickle cell disease. The schedule of consultations for these children is, by the nature of the disease, differentiated: monthly up to one year of age, quarterly up to five years of age, and every six months up to ten years of age. In our study, consultations for children with sickle cell disease had a follow-up schedule similar to that used for other children being not observed the specific ages as indicated in the specific calendar. This occurs because of the low knowledge of professionals concerning growth and development of children with sickle cell disease. A previous study reported that 88.5% of health community agents and nursing technicians did not know about the specific schedule of consultations for these patients.[4]

The assessment of growth and development surely detects health status of children with sickle cell disease. During follow-up of a child, it is possible to recognize problems that may interfere in this process, thereby minimizing the occurrence or severity of clinical manifestations of the disease.[16] In this sense, child rearing consultations for sickle cell disease are mainly designed to prevent acute events and sequelae of chronic conditions that could compromise several organs and tissues. Authors believe that children with sickle disease whose follow-up matches the schedule for such children will present fewer acute events than those whose schedule follows that used routinely for all other children. The child rearing visits involve a more intimate contact between family and health professional.[17] Hence, professionals must take advantage of these meetings to engage in individual activities of health education; look for alert signs; palpate the spleen; and address the patients' environment (for example, verify whether it is too cold or very hot**,** factors that are quite harmful to a child with sickle cell disease), use of medication and special vaccines, school frequency, liquid ingestion, and exercise. At these visits it is also important to encourage mothers to disclose their doubts and fears in order to promote a bond and greater adherence toward care as a result of "having a child with sickle cell disease".

In the follow-up of patients with sickle cell disease, regular home visits are fundamental. In our study home visits did not occur in a systematized way. The visit constitutes a therapeutic action at the homes of bedridden patients that helps professionals understand the family's real-life condition, actively search for absent patients, check suppressed demand, act for health promotion and prevention, and establish health education activities for the patients and the families.[18]

Home visits must be developed using a planned and systematized approach. A study carried out in Nova Iguaçu, Rio de Janeiro, southeast region of Brazil, found[19] that health community agents are responsible for defining visit criteria, using their own judgment, which usually is defined by more suitable places to reach in their covering area. They organize visits by establishing priorities based on their own experiences. Visits developed in a non-systematic way generate inequities because families who live in more distant locations or who have more complex chronic problems, from the community agents' point of view, might not receive priority in visiting.

We verified some items that must be observed by the professional during visits to patients with sickle cell disease: medicines, frequency of school attendance, and pain episodes. However, according to the professional's perception, it is not necessary to follow up on medicines taken at all visits. The prescription of prophylaxis with penicillin is, at this time, the role of blood centers, but the incentive to adhere to follow up with the medicine must be provided by the Family Health Strategy.[5] A study carried out in Belo Horizonte, Minas Gerais, southeast region of Brazil,[20] assessed adherence to prophylactic antibiotic therapy by three methods and found gaps in continuing administration and low adherence as reported by the children's mothers. Explanations for the lack of adherence focused on family beliefs and religion and parents' concern about the consequences of long-term antibiotic administration. Besides prophylactic antibiotic therapy, the use of folic acid should also be monitored during visits in order to compensate for the enhanced erythropoiesis. Thus, follow-up of medicines must be conducted in all home visits in order to guarantee adequate adherence.

Professionals' lack of knowledge toward sickle cell disease was mainly related to medicines and special vaccines. A research conducted in the north region of Minas Gerais[3,4] reported a low level of knowledge among both professionals who pursued an undergraduate degree and those who did not have a college degree from the Health Family Strategy regarding several aspects of care delivered for patients with sickle cell disease. The knowledge mentioned would be translated, indirectly, in the quality of health care that professionals are delivering to patients under their responsibility. A study with 63 families of children with sickle cell disease reported that vaccine schedule routine was considered to be at an acceptable level but not the special vaccines schedule, which was inadequate. The deficiency in special vaccine coverage was also mentioned in a report from Espírito Santo, southeast region of Brazil, in which 50% of children with sickle cell disease had an incomplete immunization schedule.[21]

Because few data have been reported on sickle cell disease in primary health care, further studies are warranted, particularly those showing more conclusive results related to the training of professionals delivering primary health care in order to change the reality seen in our report.

Conclusion

Health care delivery for patients with sickle cell disease, based on health community agents' opinion, was inadequate. Professionals did not know the particularities of follow-up needed for patients with this disease, and these patients have limited access to the basic health unit. In addition, they did not recognize primary care as the setting that can provide several aspects of health care. We suggest educational strategies with families that address the importance of the basic health unit and the role of each care level in helping patients with sickle cell disease. Training of non-graduated professionals working in primary care is imperative so that they can take the responsibility for care of those with sickle cell disease.

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Collaborations

Xavier Gomes LM; Pereira IA; Torres HC; Caldeira AP and Viana MB declare that contributed to the project design, analysis and interpretation of data, drafting the manuscript, critical revision of the important intellectual content and final approval of the version to be published.

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