

THERAPEUTICAL ITINERARY OF QUILOMBOLA CHILDREN WITH FALCIFORM DISEASE

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ABSTRACT

Objective: To describe the therapeutic itinerary of *quilombola* children with sickle cell disease. **Method:** This is a descriptive-exploratory study with a qualitative approach, conducted in the *quilombola* community of Praia Grande, in the Maré Island, Bahia, with mothers of *quilombola* children with sickle cell disease, from July to September, 2018. As a collection instrument, we used the semi-structured interview and ecomap. The data analysis was based on the interactive content analysis model of Miles and Huberman. **Results:** They evidenced the pilgrimage of the mothers in search of care for the children; the lack of structure of the care network, as well as the repercussion of this disease in the lives of mothers, children and families. **Final considerations:** The therapeutic itinerary of *quilombola* children with sickle cell disease permeates by a reality of iniquity and inadequacy of the health care network of the child and a lack of preparation on the health professionals for the care. There is evidence of the need for network articulation and professional training, given the magnitude of sickle cell disease.

Keywords: Child health. Sickle Cell. Health Services. African Continental Ancestry Group.

INTRODUCTION

Sickle cell disease (SCD) is a genetic and hereditary disease most prevalent in Brazil and the world. It results from a mutation in the red blood cells, more specifically in the gene that produces hemoglobin A, originating another mutant, called hemoglobin S, of a recessive character⁽¹⁾.

Considered a global public health problem, it reaches more than 300,000 children per year⁽²⁾. It is estimated that, in Africa, about 500,000 children are born each year with SCD⁽¹⁾. In Brazil, the data estimate that about 3,500 children with SCD are born, one in 1000 live births. Bahia is the state with the highest incidence of live births diagnosed with SCD, one in every 650 births⁽³⁾. It should be emphasized that this incidence is responsible for a high mortality in children aged 0 to 5 years, especially in those who do not receive

periodic care with health team⁽¹⁾.

This disease mainly affects the poorest population in low-and middle-income countries, especially the countries of the African continent, and is considered to have the highest incidence in the black population⁽²⁾, which is more socially vulnerable, communities that are inhabited, secularly, by descendants of individuals of Afro-Brazilian origin.

Thus, unveiling the context of health care for *quilombola* children with SCD, aiming to promote equity in health, is one of the great challenges faced by professionals who work for the health of children in Brazil, since primary health care services are failing in the care process and submit these children to a process of pilgrimage, by health institutions, which begins in primary care, which is not effective in providing care and has continuity in other localities, where access to health services is difficult. These facts show the health inequities

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experienced by the *quilombolas* when they need assistance⁽⁴⁻⁵⁾.

The paths taken by people seeking health care and/or treatment for the disease constitute the Therapeutic Itinerary (TI). It is believed that studies about TI in different situations of childhood illness make it possible to know the service network and the difficulties encountered in offering and planning these services, perhaps subsidizing interventions and changes in the articulation of the service network⁽⁶⁾. Since the basic guidelines of the integral care line for the person with SCD establishes Basic Care as the gateway to the search for care/health care and should direct each person to the appropriate care in the service network, according to the needs of the children with SCD⁽¹⁾.

Scientific production on the subject is limited and studies show that attention to children's health is still incipient in *quilombola* communities. The population does not usufruct integral health care, which reveals an urgent need to adopt actions and measures to improve the health and environmental conditions of *quilombola* families, as well as guarantee access to health, which includes access, basic care and the adequate functioning of medium and high complexity services, so as to ensure the resoluteness and integrality of the health system^(4-5,7).

Thus, the importance and necessity of studying sickle cell disease in *quilombola* children is highlighted, considering the social network in which the disease is submerged and seeking to emerge the voice of the protagonists of this reality. This way, the objective of this study is to describe the therapeutic itinerary of *quilombola* children with sickle cell disease.

METHODOLOGY

This is a descriptive-exploratory study with a qualitative approach, carried out from July to August of 2018, in the *quilombola* communities of Maré Island, Salvador-Bahia, with a total of 11 communities, comprising approximately 7,000 Afro-descendants with low purchasing power.

The approach to the communities began in 2008, through teaching-research-extension activities of the Group of Studies and Research

on Child and Adolescent Health at the Nursing School of the Federal University of Bahia. The group of researchers has experience in the teaching and research work with traditional and vulnerable communities and, before beginning the data collection, they have attended and lived with the study scenario. The invitation to the survey participants was made during group visits or extension activities in the community. After accepting the participants, the date, place and time of the interviews were scheduled.

Thus, the sample of this study was selected by the record of children with SCD available at the municipal health department. The participants of this study are two mothers of *quilombola* children with SCD, covering all participants, who met the following selection criteria: being natives and recognizing themselves as *quilombola*; primary family caregiver aged 18 years or older; have sought for care in the child's health service and have cognitive and verbal ability to respond to the instruments of the study.

As a data collection instrument, a semi-structured interview script and the ecomap were used, and the latter was aimed at identifying the relationships established with the health system, as well as the linking network of this family, a network that is capable of to influence the care of the child with SCD.

The interview was guided by two guiding questions: Tell me how you discovered your child's sickle cell disease? How is SCD child care in the community, and what health services do you use to help your child? As well as additional information regarding the elaboration of the ecomap to approach and knowledge of family experiences such as: family formation, social bonds, religious bonds and health services used.

After each interview, feedback was given to each participant, with the presentation and interpretation of the ecomap, in order to guarantee the initial impressions of the data collected. After the conclusion of the study, the researchers presented the results for validation of the researched group.

The content analysis proposed by Miles and Huberman⁽⁸⁾ guided the evaluation and interpretation of the data in a dynamic and cyclical process, of comings and goings that

made it possible to glimpse the categories, which constitute the units of analysis.

In compliance with Resolution 466/12 of the National Health Council, this study was submitted and approved by the Ethics and Research Committee with Human Beings of the Federal University of the Recôncavo of Bahia, under Opinion No. 2,771,928. It was authorized by the leaders of the *quilombola* communities with an agreement term. In the invitation addressed to mothers of *quilombola* children, they were informed about the theme, purpose of the study, risks and benefits, as well as the application of a free and informed consent form, read and signed by the participants, and to ensure confidentiality and anonymity of the information, the participants were coded by the letter “E” followed by the sequence number in which they were carried out.

RESULTS

The study participants were female, with ages ranging from 34 to 48 years. All are mothers; incomplete elementary school; monthly income of a minimum wage plus the benefit of *bolsa família*; As for religion, one was catholic, and the other evangelical. As for race/color, one declared himself black and the other brown.

Regarding the children's gender, the parents reported that they were males and that the diagnosis of sickle cell disease occurred soon after neonatal screening. Regarding the age group of the children, one is nine years old and the other is six years old.

To better describe the network of therapeutic support to the *quilombola* child with SCD, the ecomap was used, which graphically represented the linking of the families to the health institutions and the popular support network.

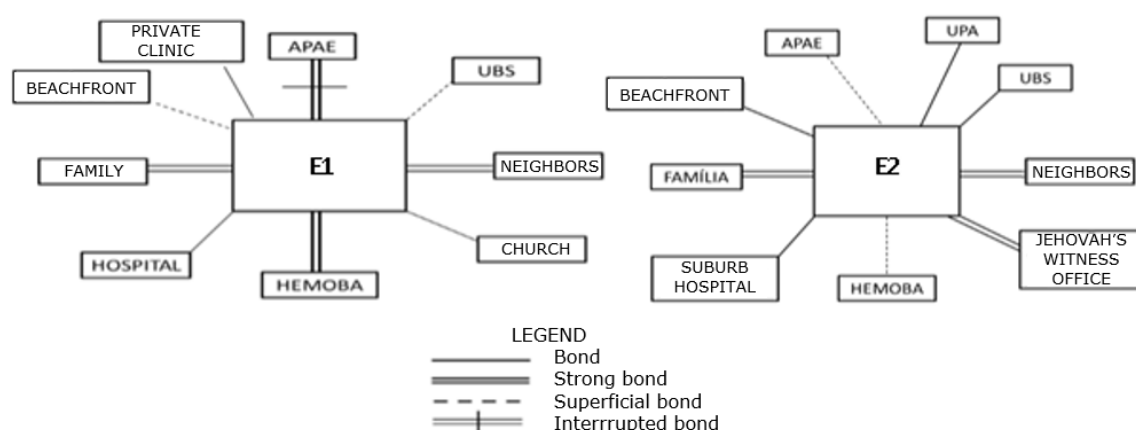


Figure 1: Ecomap of the participants' connections with the health care network of *quilombola* children with sickle cell disease. Salvador, 2018. Source: Authors' elaboration.

The mother E1 says that, after confirming the diagnosis of SCD, the child was assisted by the Association of Parents and Friends of the Exceptional (APAE). During the initial treatment, she remained firm and assiduous, however, this bond was interrupted, since from a certain age, the follow-up offered by this organ was no longer available, and this woman was oriented to find a more specialized service that could serve the specificities of the child's pathology. Whereas, E2 reveals that her son, after the diagnosis of SCD, did not have any follow-up at the APAE, making it even more

difficult to assist, which made her seek other support services for child care.

Both reported a superficial link with the Family Health Unit of the *quilombola* community, which, according to the parents, did not feel welcome, besides stating that the professionals had no scientific knowledge to follow their child's illness. The E2 mother reports having a very strong bond with the Emergency Care Unit (UPA) and the hospital due to her son's constant sickle cell crisis. Thus, through the ecomap, it is possible to visualize the TI and the frailty of the *quilombola* child care network with SCD.

The search for health care for *quilombola* children with sickle cell disease

The trajectory of *quilombola* children with sickle cell disease is complex, occurs in a longitudinal way and favors the abandonment of care due to i) financial difficulties, ii) access to health services and, especially, iii) as a result of the disarticulation of the health care network for this population:

He found out in the foot test [...] I took him to APAE [...] he went once a month to for exams, to talk with the psychologist and social worker, all that [...] but when he gets older they no longer do the follow-up at the APAE [...] they told us to go to the hemocenter [...] but I didn't, because the difficulty to get there [...] sometimes I take the clinic [...] but it seldomly because they do not attend to his illness and advise to look for another service [...] if there was care service here on the island it was much better [...] because there at the APAE the service was to collect blood and measure to see the growth [...] I think this could be done here at the clinic [...] the expense was too much [...] I had to pay for a boat [...] after paying a transport to take me to the APAE [...] my boys could not ride a bus, he would vomit because he has trouble breathing and shortness of breath and still has pain crises constantly [...] these days he was hospitalized there at the Hospital in the capital [...] to speak the truth, this month I took him to private care [...] I go to the doctor twice a year to find out how he is doing. (E1)

The diagnosis was through the foot test [...] but I've been going a long way to find care [...] I'm doing exams on him see if he can be followed-up [...] while I'm trying to make an appointment with some pediatrician [...] in the clinic here they do not attend to his case [...] they only give the medicine for pain, fever [...] I do not consult the nurse anymore [...] they say: you're going to have to see a specialized care [...] because here is a basic health unit [...] when it's at dawn and he's in pain, I take him to the UPA, on the land or Reference Hospital [...] since nobody here attends him [...] these days he was hospitalized because he was feeling pain [...] it is difficult because at night there is no care [...] if there is any problem he has to cross by private boat [...] there were times in which people died on the way [...]. (E2)

The fragility of the health system for the follow-up of the child with SCD is identified in

the reports of the mothers, since what is recommended by the Ministry of Health in the line of care for the SCD is not carried out by the managers and health professionals, making it difficult to treatment and favoring the lethality of the disease.

Feelings experienced with sickle cell disease

The speeches reveal the feelings of sadness, anguish and the suffering experienced by the mother, child and family. At times they turn to God and in others they feel helpless and want death:

[...] I cried a lot, I was sad [...] will my child die? I had that feeling, but then I said: it is an illness and is in the God's hand [...] he feels pain [...]. (E1)

[...] there are days that I cry with him [...] he screams all night [...] I cry, my brother goes crazy, they like each other [...] oh my God, it's much pain! [...] he cries a lot, there are days he does not sleep ... there are days when he says 'mother I want to die so I won't feel this pain' [...] he feels so much pain in his leg, in the belly, he gets dehydrated [...]. (E2)

Living with the chronicity of SCD in a child without adequate health support, potentiates the suffering, since no appropriate conditions of treatment are offered to reduce the complications and damages of the disease. When a network of care is structured to the person with SCD, it ensures a better health and life condition for the person affected, however these benefits are not available to everyone.

DISCUSSION

Knowing the TI of *quilombola* children with SCD enabled us to immerse in a universe permeated with inequity, social vulnerability and inadequacy of child health care, as well as the verification of how this social stratum is marginalized and forgotten. Going thru this way to unveil the reality of the health care of the child with SCD, made it possible to verify the deficiency of the functioning of a health network for the child, as recommended by the Unified Health System.

In Brazil, SCD is a public health problem with high rates of morbidity and mortality. Its clinical manifestations bring losses to the health and well-being of the patient, negatively impacting on their expectation and quality of life⁽⁹⁾.

When faced with the diagnosis of SCD in their children, parents feel distressed, going through a phase of denial, suffering and doubts until they accept the diagnosis⁽¹⁰⁾. Therefore, the need to educate the patient and the family regarding the knowledge about the disease emerges.

Co-responsibility for care and treatment for the rest of life emerges as challenges to be overcome⁽¹¹⁾. Thus, we affirmed that the study participants demonstrated a lack of knowledge about the health care network of children with SCD, ministerial policies, and the repercussions of the disease on the child's life.

People diagnosed with SCD should be integrated into the health care network, ensure full care through multidisciplinary team care, and access to information, genetic counseling, and essential drug assurance. Thus, it is important to train the actors involved, as well as stimulate research with the objective of improving the quality of life of these individuals⁽¹²⁾.

This study revealed the lack of preparation of primary health care professionals in *quilombola* child care with SCD, since the family health strategy team should be the center of the SCD children as established in the care line⁽¹⁾, however the professional qualification to act in front of the SCD, is not yet a reality in the research scenario of this study, pointing to the need of adequacy of care to children with SCD.

The onset of TI in children with SCD usually occurs with the discovery of the diagnosis, detected through neonatal screening (foot test). In the country, since 2001, the National Neonatal Screening Program (PNTN) was established to perform the early diagnosis of SCD. However, it is noted that not all children can access and be inserted into health care networks. Thus, although comprehensive and effective, neonatal screening has not been sufficient to significantly reduce the mortality of children with SCD, for this would require a greater attention and

involvement among health professionals and families⁽¹³⁾.

The performance of the family health team in primary care is a valuable strategy for strengthening and qualifying care in *quilombola* communities. However, it is important to highlight that actions should be planned in order to meet the specificities of these populations⁽¹⁴⁾.

The study shows that the frequency of consultations for children with SCD, for example, will depend on the clinical severity and the family profile. It is recommended that, up to one year of age, professional visits should be more frequent for better understanding of the disease and guidance of the parents⁽¹⁵⁾. However, in the *quilombola* community studied, there was a distancing regarding the professionals' performance in the care given to children with SCD.

Another study⁽¹⁶⁾ shows that the follow-up of patients with SCD, in a family health unit, presents a low coverage, in addition to being incipient the education and health for such, situations that meet the findings of the research in question. It also revealed the deficiency in secondary care, which is related to the access of this population to the hemocenters, since the service is not able to meet the demand of the population that presents SCD⁽¹⁷⁾.

When the child with SCD has an articulated assistance between the primary (Basic Health Units - UBS) and secondary (Hemocenters and other units) networks, with trained professionals to identify the potential signs of gravity, it can favor the reduction of hospital admissions⁽¹⁸⁾.

The non-articulation of the network shows the fragility in the organization of the health system and does not guarantee the necessary treatment in a universal way. Assistance to the *quilombola* child with SCD is inappropriate and the pilgrimage begins in the community itself, from the search for the primary care service, which proves ineffective in providing assistance to children and continues in other localities, where access to services been revealed as difficult. This fact evidences the iniquities in health experienced by *quilombolas* when they need health care⁽⁴⁻⁵⁾.

There is an insufficiency of the health services to guarantee an equitable and integral service to the health of the *quilombola* users.

There is a fragility of the links between the ESF team and the community, there is a reversal of the assistance logic, with a greater demand for secondary and tertiary care. The need for health services to understand the specificities, demands and sociocultural characteristics of *quilombola* communities was perceived, so that services are offered that correspond to the real needs and desires of this population⁽¹⁹⁾.

It was evidenced that the deterioration of the *quilombola* child care network with SCD started with primary care, which has repercussions for the other contexts, reaching the secondary and tertiary level, since there is no articulation and intersectoral communication for reference and counter-referral of user. This also revealed the lack of resoluteness and hosting of health services at the three levels of care.

Another study⁽¹¹⁾ also pointed out the need to train the multiprofessional team and to include the information of the disease in the files of the primary care system, expanding and qualifying the access of the services for this care. In addition to including the disease in the parameters of regulation and classification of risk, instituting, within the SUS, the line of integral care to the person with SCD⁽¹¹⁾.

It is also important to emphasize the need to prioritize therapy for the prevention and early diagnosis of complications, actions that may help reduce the number of hospitalizations and reduce the possible sequelae of the disease.

Study⁽²⁰⁾ showed that increasing the education of families and health professionals regarding adherence to treatment, as well as overcoming barriers to medical care, especially those related to parents' mistrust, are necessary to achieve this goal.

It is suggested that managers and health professionals seek, with the National Policy of Integral Health of the Black Population, to relate the Social Determinants of Health, the history, culture and needs of the black population, especially *quilombolas*, in order to build bonds and accountability between health services and the population, in order to enhance health practices with regard to equity and integral actions in health care networks^(4-5,7).

It is worth emphasizing that, in revealing the therapeutic itinerary of this population, it was possible to go beyond the path of seeking care, because it was allowed that the mothers shared their experiences and expressed the feelings and difficulties faced when they needed access to health services.

It was affirmed that the provision of evidence-based care can prevent morbidity and mortality in children with sickle cell disease⁽²⁰⁾.

FINAL CONSIDERATIONS

When investigating the therapeutic itinerary of *quilombola* children with SCD, it is evident that the mothers wandered through services in search of care for the children, who were weakened by the deficits of structure in the care network, highlighting the reality of iniquity and inadequacy of the care network to the child's health. For mothers and children this itinerary is still permeated by the impact of the diagnosis and the condition of chronicity.

It was also verified the distance between the users and the Family Health Unit, which reveals the gap that exists between health professionals and the assistance to children with SCD, since these are not accompanied in the program of growth and development in the family health strategy, due to the unpreparedness of health professionals for caring.

As a limitation of the study, the reduced number of participants was denoted, however, this number was the totality of the children affected by the SCD. This number was able to reveal the context of care, as well as the therapeutic itinerary in the search for assistance to *quilombola* children with SCD.

It is expected that this study has disquieted researchers, health professionals, managers, the black population, especially the *quilombola* communities, to claim the implementation of Health Public Programs and Policies in *quilombola* communities, in order to reduce the inequity of this vulnerability scenario, reduce infant morbimortality and strengthen the principles established by the Unified Health System.

ITINERÁRIO TERAPÊUTICO DE CRIANÇAS QUILOMBOLAS COM DOENÇA FALCIFORME

RESUMO

Objetivo. Descrever o itinerário terapêutico de crianças quilombolas com doença falciforme. **Método.** Trata-se de um estudo descritivo-exploratório com abordagem qualitativa, realizado na comunidade quilombola de Praia Grande, na Ilha de Maré – BA, com mães de crianças quilombolas com doença falciforme, no período de julho a setembro de 2018. Como instrumento de coleta de informações, foram utilizados a entrevista semi-estruturada e ecomapa. A análise dos dados foi baseada no modelo interativo de análise de conteúdo de Miles e Hubermans. **Resultados.** Evidenciaram peregrinação das mães em busca de atendimento das crianças; a ausência de estrutura da rede assistencial, bem como a repercussão dessa doença na vida de mães, crianças e famílias. **Considerações Finais.** O itinerário terapêutico das crianças quilombolas com doença falciforme permeia por uma realidade de iniquidade e inadequação da rede de atenção à saúde da criança e um despreparo por parte dos profissionais de saúde para o cuidado. Evidencia-se a necessidade de articulação da rede e da capacitação profissional, tendo em vista a magnitude da doença falciforme.

Palavras-chave: Saúde da criança. Doença falciforme. Serviço de saúde. Grupo com ancestrais do continente africano.

ITINERARIO TERAPÉUTICO DE NIÑOS QUILOMBOLAS CON ENFERMEDAD FALCIFORME

RESUMEN

Objetivo. Describir el itinerario terapéutico de niños quilombolas con enfermedad falciforme. **Método.** Se trata de un estudio descriptivo-exploratorio con abordaje cualitativo, realizado en la comunidad quilombola de Praia Grande, en la Ilha de Maré – BA-Brasil, con madres de niños quilombolas con enfermedad falciforme, en el período de julio a septiembre de 2018. Como instrumento de recolección de informaciones, fueron utilizados entrevista semiestructurada y ecomapa. El análisis de los datos fue basado en el modelo interactivo de análisis de contenido de Miles y Hubermans. **Resultados.** Evidenciaron peregrinación de las madres en busca de atención a los niños; la ausencia de estructura de la red asistencial, así como el efecto de esta enfermedad en la vida de madres, niños y familias. **Consideraciones Finales.** El itinerario terapéutico de los niños quilombolas con enfermedad falciforme pasa por una realidad de iniquidad e inadecuación de la red de atención a la salud del niño y una falta de preparación por parte de los profesionales de salud para el cuidado. Se señala la necesidad de articulación de la red y de la capacitación profesional, teniendo en cuenta la magnitud de la enfermedad falciforme.

Palabras clave: Salud del niño. Enfermedad falciforme. Servicio de salud. Grupo con ancestrales del continente africano.

REFERENCES

1. Brasil. Ministério da Saúde. Doença falciforme: Diretrizes básicas da linha de cuidado. Brasília: Ministério da Saúde, 2015. Disponível em: http://bvsms.saude.gov.br/bvs/publicacoes/doenca_falciforme_diretrizes_basicas_linha_cuidado.pdf.
2. World Health Organization (WHO). Regional office for Africa: Sickle Cell Disease. Available from: <http://www.afro.who.int/health-topics/sickle-cell-disease>.
3. Brasil. Ministério da Saúde. Doença falciforme: o que se deve saber sobre herança genética. Secretaria de Atenção à Saúde, Departamento de Atenção Hospitalar e de Urgência – Brasília: Ministério da Saúde, 2014. Disponível em: http://bvsms.saude.gov.br/bvs/publicacoes/doenca_falciforme_deve_saber_sobre_heranca.pdf.
4. Marques AS, Caldeira AP, Souza LR, Zucchi P, Cardoso. Atenção Primária e saúde materno-infantil: a percepção de cuidadores em uma comunidade rural quilombola. Ciênc. saúde coletiva. 2014; 19(2): 365-371. doi: <http://dx.doi.org/10.1590/1413-81232014192.02992013>.
5. Siqueira SMC, Jesus VS, Camargo CL. The therapeutic itinerary in urgent/emergency pediatric situations in a maroon community. Ciênc. Saúde Coletiva. 2016; 21(1): 179-189. doi: <http://dx.doi.org/10.1590/1413-81232015211.20472014>.
6. Moraes AC, Cohim ACOS, Almeida CR, Lima KDF. Therapeutic itinerary of children's mothers after the kangaroo method. Ciênc. Cuid. Saude. 2017; 16(2):1-6. doi: <http://dx.doi.org/10.4025/cienccuidsaude.v16i2.35994>.
7. Pinho L, Dias LR, Cruz LMA, Veloso NA. Health conditions of quilombola community in the north of Minas Gerais. Rev Fund Care Online. 2015; 7(1):1847-1855. doi: <http://dx.doi.org/10.9789/2175-5361.2015.v7i1.1847-1855>.
8. Miles MB, Huberman M. Drawing valid meaning from qualitative data: toward a shared craft. Educational researcher, 1984.
9. Ramos JT, Paes GR, Jesus FA, Oliveira DS, Fernandes ESF, Carvalho BT, et al. Mortalidade Infantil Por Doença Falciforme na Bahia: Um Estudo Epidemiológico. Rev. Saúde Col. 2017; 7(3): 36-39. doi: <http://dx.doi.org/10.13102/rscdauefs.v0i0.1658>.
10. Gesteira EC, Bousso RS, Rodarte AC. Uma reflexão sobre o manejo familiar da criança com doença falciforme. R. Enferm. Cent. O. Min. 2016; 6(3):2454-2462. doi: <http://dx.doi.org/10.19175/recom.v6i3.758>.
11. Fernandes AP, Avendanha FA, Viana MB. Hospitalizations of children with sickle cell disease in the Brazilian Unified Health System in the state of Minas Gerais. J. Pediatr. 2017; 93(3): 287-293. doi: <http://dx.doi.org/10.1016/j.jped.2016.07.005>.
12. Moraes LX, Bushatsky M, Barros MBSC, Barros BR, Bezerra MGA. Sickle cell disease: perspectives on the assistance provided in primary attention. Rev Fund Care Online. 2017; 9(3):768-775. doi: <http://dx.doi.org/10.9789/2175-5361.2017.v9i3.768-775>.
13. Sabarense AP, Lima GL, Silva LML, Viana MB. Characterization of mortality in children with sickle cell disease diagnosed through the Newborn Screening Program. J. Pediatr. 2015; 91(3): 242-247. doi: <http://dx.doi.org/10.1016/j.jped.2014.08.006>.
14. Silva EKP, Medeiros DS, Martins PC, Sousa LA, Lima GP, Regô MAS, et al. Insegurança alimentar em comunidades rurais no Nordeste brasileiro: faz diferença ser quilombola?. Cad. Saúde Pública. 2017; 33(4):e00005716. doi: <http://dx.doi.org/10.1590/0102-311x00005716>.
15. Vasconcelos DMVP. Assistência prestada a crianças com Doença Falciforme na rede de atenção à saúde de Belo Horizonte, com ênfase nos eventos clínicos e na adesão aos protocolos assistenciais. 2015. [Dissertação]. Belo Horizonte (MG). Programa de Pós-Graduação em Ciências da Saúde. Universidade Federal de Minas Gerais, Faculdade de Medicina. 2015. Disponível em: https://www.nupad.medicina.ufmg.br/wp-content/uploads/2016/12/Dissertacao_DeniseVasconcelos.pdf.
16. Rodríguez-Moldes B, Carbajo AJ, Sánchez B, Fernández M, Garí M, Fernández MC, et al. Seguimiento en Atención Primaria de los

recién nacidos con enfermedad falciforme detectados en el cribado neonatal de la Comunidad de Madrid. *An Pediatr (Barc)*. 2015; 82(4): 222-227. doi: <https://doi.org/10.1016/j.anpedi.2014.04.007>.

17. França SABA. Fatores que interferem no acesso de pessoas com doença falciforme ao hemocentro. 2015. [Dissertação]. Salvador (BA). Programa de Pósgraduação do Instituto de Saúde Coletiva da Universidade Federal da Bahia. 2015. Disponível em: <https://repositorio.ufba.br/ri/handle/ri/18325>.

18. Fernandes AP, Avendanha FA, Viana MB. Hospitalizations of children with sickle cell disease in the Brazilian Unified Health System

in the state of Minas Gerais. *J Pediatr*. 2017; 93(3):287-293. doi: <http://dx.doi.org/10.1016/j.jped.2016.07.005>.

19. Pereira LL, Santos LMP. Programa Mais Médicos e Atenção à Saúde em uma comunidade quilombola no Pará. *Argum*. 2018; 10(2):203-219. doi: <https://doi.org/10.18315/argumentum.v10i2.18737>.

20. Shook LM, Ware RE. Effective screening leads to better outcomes in sickle cell disease. *Arch Dis Child*. 2018; 103(7): 628-630. doi: <http://dx.doi.org/10.1136/archdischild-2017-314175>.

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Submitted: 31/10/2019

Accepted: 15/05/2019