

## SICKLE CELL ANEMIA: PERCEPTION OF HEALTH PROFESSIONALS AND MANAGERS ABOUT THE STRUCTURING OF THE CARE NETWORK

Anemia falciforme: percepção dos profissionais de saúde e gestores acerca da estruturação da rede de atenção

Anemia falciforme: percepción de profesionales de la salud y gestores sobre la estructuración de la red de atención

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### ABSTRACT

**Objective:** To investigate the perception of health professionals and managers about the structuring of the health care networks for people with sickle cell anemia. **Method:** Exploratory, descriptive and cross-sectional study. The approach used was the triangulation of methods. It was performed with 15 health professionals and managers. Data were collected from March to June 2016 through semi-structured interviews. We performed descriptive statistics with the quantitative data, since the qualitative ones were interpreted through reading and categorization process. **Results:** Lack of understanding on the part of the participants about the care network for people with sickle cell anemia, as well as ignorance about the policies and other aspects, which was directly influencing the quality and efficiency of the assistance offered. **Conclusion:** It is necessary that managers provide opportunities for qualifications, and professionals are able to offer an effective assistance to the person with sickle cell anemia.

**DESCRIPTORS:** Anemia, Sickle cell; Health services; Assistance; Integrality in health; Quality of life.

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## RESUMO

**Objetivo:** Investigar a percepção dos profissionais de saúde e gestores acerca da estruturação das redes de atenção à saúde às pessoas com anemia falciforme. **Método:** Estudo exploratório, descritivo e transversal. A abordagem utilizada foi à triangulação de métodos. Foi realizado com 15 profissionais de saúde e gestores. Os dados foram coletados no período de março a junho de 2016 por meio de entrevistas semiestruturadas. Foi realizada a estatística descritiva com os dados quantitativos, já os qualitativos foram interpretados por meio de leitura e processo de categorização. **Resultados:** Falta de compreensão dos participantes sobre a rede de atenção às pessoas com anemia falciforme, bem como o desconhecimento sobre as políticas e demais aspectos, influenciando diretamente na qualidade e eficiência da assistência prestada. **Conclusão:** É necessário que os gestores proporcionem oportunidades de qualificações e os profissionais se capacitem para prestarem uma assistência eficaz a pessoa com anemia falciforme.

**DESCRIPTORIOS:** Doença falciforme; Serviços de saúde; Assistência; Integralidade em saúde; Qualidade de vida.

## RESUMEN

**Objetivo:** Investigar la percepción de profesionales de la salud y gestores sobre la estructuración de las redes de atención de salud a las personas con anemia falciforme. **Método:** Estudio exploratorio, descriptivo y transversal. El planteamiento empleado fue la triangulación de métodos. Se realizó con 15 profesionales de la salud y gestores. Los datos se recopilaron de marzo a junio de 2016 mediante entrevistas semiestructuradas. Se realizó estadística descriptiva con los datos cuantitativos, pues los cualitativos se interpretaron mediante lectura y proceso de categorización. **Resultados:** La falta de entendimiento de los participantes sobre la red de atención a las personas con anemia falciforme, así como la ignorancia sobre las políticas y otros aspectos, influyendo directamente en la calidad y eficiencia de la asistencia ofrecida. **Conclusión:** Se hace necesario que los gestores proporcionen oportunidades para cualificaciones, y los profesionales sean capaces de ofrecer asistencia efectiva a la persona con anemia falciforme.

**DESCRIPTORIOS:** Anemia de células falciformes; Servicios de salud; Asistencia; Integralidad en salud; calidad de vida.

## INTRODUCTION

Chronic diseases are becoming relevant in the Brazilian health scenario, as they are also being recognized as a cause of suffering for people. Among the chronic diseases of great relevance are sickle cell diseases (SCD). FD are hereditary hemoglobinopathies, in which the predominant phenotype is Hb S, being the most common types: Hb SS, S-beta Thalassemia and heterozygous pairs Hb SC and Hb SD.<sup>1</sup>

Sickle cell anemia (AF) or (Hb SS) is a type of hemoglobinopathy characterized by being very common in black people and having variable symptoms, and may occur asymptomatic periods interspersed with periods of crisis. Thus, the participation and integration of different levels of health care is of utmost importance to improve the quality of life of people with PA and reduce morbidity and mortality.<sup>2,3</sup>

Regionalization is a guideline of the Unified Health System and a structuring axis of the Management Pact and should guide the decentralization of health actions and services and the organization of the Health Care Network (RAS). The RAS

are organizational combinations of health actions and services, of different technological densities that, integrated through technical, logistic and management support systems, seek to guarantee the integrality of care, according to the provisions of Ordinance No. 4,279 of 12/30 /2010.<sup>4</sup>

Despite the wide range of studies on FD itself, little is known about the structuring of care networks that provide care to patients with this type of health condition, having as one of the main actors of this network the health professionals and managers. Therefore, it is essential to carry out further studies on this theme, so that the links between health care networks that provide care services to these people with AF are revealed, so that new and broad knowledge on the subject is formed. From this perspective, this research aims to investigate the perception of health professionals and managers about the structuring of health care networks for people with sickle cell anemia.

## METHODOLOGY

This is a descriptive and cross-sectional exploratory study with a method triangulation approach.<sup>5</sup> The present study was conducted at the three levels of care for people with PA: primary health care (Family Health Strategy-FHS), in secondary care (emergency hospitals in the cities of the interior of Piauí) and in tertiary care (Center of Hematology and Hemotherapy of Piauí). The municipalities that were part of the study were: Paquetá, Picos, Itainópolis, São João da Varjota and Oeiras, both from the State of Piauí.

The study selected health professionals and managers from the chosen municipalities who voluntarily agreed to participate in the research and cooperated at all stages. The technique used to determine the number of study participants was the saturation criterion proposed by Bardin, which is used to close the final sample size of a study. According to Bardin, when there is a repetition of the speeches, where no new data can appear, the inclusion of new participants can be suspended<sup>6</sup>. Soon the research was developed with 15 participants. Data were collected from March to June 2016.

For data collection, semi-structured interviews were used through a script composed of two parts: the first with sociodemographic questions and the second with open questions related to the structuring of the health care network for people with AF. The interviews were recorded after the consent of the participants and transcribed in full, preserving their speech.

Quantitative data were analyzed using the Statistical Package for Social Sciences - SPSS version 20.0, and descriptive analysis was performed with absolute and relative frequency of the variables. Qualitative data were interpreted through reading and categorization process, based on Bardin's Content Analysis Theory, which consists of three steps: pre-analysis; material exploration and treatment of results and interpretation.<sup>6</sup>

In this study, the speeches were categorized by similarity into thematic units. Data were divided into five categories, namely: "knowledge of professionals about the health care network"; "functioning of care for people with PA"; "monitoring

of people with PA”, “functioning of the referral and counter-referral system” And “structuring the health care network for people with PA”. After categorization and analysis, the data were compared based on the studied and referenced literature.

The study was submitted and approved in November 2015 by the Research Ethics Committee of the Faculty of Medical Sciences of the State University of Piauí (CEP / FACIME / UESPI) under CAAE 51139415.6.0000.5209. All participants were asked to sign the Informed Consent Form (FICF) in accordance with National Health Council Resolution No. 466/2012 governing research among humans, in order to preserve anonymity, it was decided to identify participants with letters and numbers, such as “E01” and so on.<sup>7</sup>

## RESULTS

The sociodemographic profile of the interviewed professionals is described in table 1, and from its analysis it was possible to characterize the study population.

**Table 1 -** Sociodemographic profile of the study participants. Picos, PI, Brazil, 2016

Variables	n	%	Statistics
<b>Gender</b>			
Male	05	33,3	
Female	10	66,7	
<b>Age range</b>			
20 to 30 years old	04	26,7	<b>Avg.:</b> 37,13 years
30 to 40 years old	06	40	<b>Median:</b> 37 years
Above 40 years old	05	33,3	
<b>Color</b>			
White	05	33,3	
Brown	07	46,7	
Black	03	20	
<b>Marital status</b>			
Single	04	26,7	
Married	10	66,7	
Divorced	01	6,7	
<b>Degree of education</b>			
Graduation	02	13,3	
Specialization	09	60	
Master's degree	04	26,7	
<b>Graduation course</b>			
Nursing	08	53,3	
Nutrition	01	6,7	
Pharmacy	02	13,3	
Medicine	02	13,3	
Languages	02	13,3	
<b>Children</b>			
Yes	12	80	
No	03	20	

Variables	n	%	Statistics
<b>Monthly income</b>			
2 to 3 Salaries	02	13,3	
4 to 5 Salaries	04	26,7	
6 to 7 Salaries	04	26,7	
Above 8 Salaries	03	20	
Not defined	02	13,3	

According to the analysis of table 1, we can observe the predominance in the female sample (66.7%), as well as in the study with 83 professionals in the city of Santa Cruz do Sul-RS, which also had a predominance female in the sample (95.1%). This fact, which is observed in other studies, is justified by the expansion and elevation of levels of education and education, which led women to the paid labor market.<sup>8-11</sup>

Regarding the age group, it was observed that the majority of respondents were aged between 30 and 40 years (40%), with an average age of 37.13 years, as well as the study conducted in the Federal District - DF, Brazil. with another population of nurses, who presented similar results, with an average age of 38.5 years. The study conducted in Ribeirão Preto in the interior of São Paulo showed an average age of 46 years.<sup>10,11</sup>

Regarding color, (46.7%) self-declared brown, while the study on the nursing profile in Brazil shows that (31.3%) of nurses declare to be brown.<sup>12</sup> When analyzing the items marital status and existence of children it was found that 10 (66.7%) of the participants were married, and 12 (80%) of them have children. Regarding these data, a survey showed a similar result in their study, as of the interviewed professionals (52.8%) were married and (68.7%) reported having one to two children.<sup>13,8</sup>

Regarding education, it was found that in general most of the professionals had postgraduate education, where (60%) had *latu sensu* and (26.7%) *stricto sensu*. Other authors also found a similar conclusion regarding this aspect of the interviewed professionals.<sup>8,14</sup>

Regarding the training course of the interviewed professionals, there was a predominance of the Nursing course (53.3%), similar to a study conducted in the city of Montes Claros-MG, with 95 professionals, with a percentage of (47.4%). (%) of professional nurses.<sup>15</sup>

Regarding monthly income, it was observed that the prevalence of income was between four and five, and six and seven salaries, both with a percentage of (26.7%). Contrary to the results of this study, a percentage of (75%) professionals reported having an income of up to two minimum wages.<sup>8</sup>

The following are the results obtained from the analysis of the statements of the interviewed professionals and managers, which will be significant to achieve the objectives of this study. The following are the thematic categories elaborated using the content analysis technique. The categories concern the exploration of the participants' testimonies about the main aspects of ARS people with PA.

## Category 1: Participants' Knowledge of the Health Care Network (CPRAS)

It comprises thematic analysis units that demonstrate the participants' level of knowledge about the RAS. This category includes the following subcategories: has knowledge (TC), has no knowledge (NTC) and partially knows (PC). This category resulted in fifteen thematic units.

When asked about the subject, most of them demonstrated to know what the RAS are about, with a predominance of the "CT" subcategory, with eight thematic units.

*The health care network is the way in which the client will go so that his treatment is guaranteed, his health care in that specific problem of his. (E08)*

*Integration of service levels from primary to tertiary level. (E09)*

However, a worrying situation was found, since most participants did not know or partially knew the care network for people with PA, as shown in the statements below.

*Primary, primary, and health promotion. (E13)*

*Provide a good service to patients looking for the most diverse health care services and programs. (E15)*

By observing the speeches above, it is noticed the participants' lack of understanding about what is, in fact, the care network for people with PA, a factor that directly influences the quality of service provided by these professionals and managers. A survey of 14 health professionals from the city of Janaúba, state of Minas Gerais, also found a weakness of the participants' knowledge, forming a barrier between professional and patient, making the person with PD not look for the basic health unit, detaching directly to secondary care.<sup>3</sup>

The results obtained in this category can be related to the third guideline of the Comprehensive Care Policy for People with Sickle Cell Disease, which guides the establishment of a training policy for all actors involved in care, as well as the promotion of permanent education. Given this, health professionals and managers, especially those of Primary Care, as the user's preferred gateway to the system, should be properly trained in FD.

## Category 2: Working with people with AF

It comprises the thematic analysis units related to how people with AF are treated, about how this flow happens within the network, according to the interviewees. This category comprised the following subcategories: scheduled care (AG), spontaneous demand (DE), patient referred to other services (PEOS), urgent care only (ASU) and unknown (NS), resulting in ten thematic units.

When asked about how patients were treated, most participants reported that this assistance was scheduled. However, some testimonials stood out in which primary care health professionals described only referring patients to other levels of care and specialized centers of both the public and private network, without consulting or providing information to the client.

*Would refer to the private network to a hematologist. (E08)*

*If a direct patient is to be diagnosed it would be referred to secondary care. (E11)*

*Forward to HEMOPI Teresina. (E12)*

*They are forwarded to another call center. (E15)*

We can see that the health team does not feel responsible for coordinating the healthcare of people with PA. However, the person with PA should be accompanied by the family health team throughout his or her life, since the bond formed between primary care professionals, patients and family members is of paramount importance for the knowledge of the disease, developing actions of health promotion, thus identifying the risks and avoiding complications, generating a better prognosis for the person with AF.<sup>16,17</sup>

Given this, it is noted the importance of assistance in primary care, both in the first care and subsequent monitoring of people with PA simultaneously with the care provided in the referral centers.

## Category 3: Accompanying AF people

It comprises thematic analysis units related to the monitoring of people with PA according to the interviewees. This category comprised the following subcategories: multiprofessional consultations (CM), home visit and consultation (VDC), patient referred to other services (PEOS), no follow-up (NEA) and no know (NS), resulting in fourteen thematic units.

When asked about the theme, there were different reports regarding the form of follow-up, however there was a predominance of the multiprofessional consultation modality, as can be observed in the following statements.

*It goes through medical consultation, nursing, nutrition, physiotherapist if necessary, psychologist. Collects exams and receives medication in addition to the pharmacist's care. (E06)*

*Medical consultation, nursing, nutrition, physiotherapy, psychologist. (E07)*



The second guideline of the National Policy on Integral Care for People with Sickle Cell Disease addresses the issue of comprehensiveness, which should be promoted through the care of a multidisciplinary team and the establishment of interfaces between the different technical areas of the Ministry of Health, aiming at the articulation of other actions that exceed the competence of Hemorrede.<sup>18</sup>

In addition, some respondents also cited the occurrence of home visits in addition to multiprofessional consultations. In other testimonies, participants demonstrated not knowing how to specify and even mention that there is no follow-up as shown in the speeches below.

*I do not know.* (E01)

*Consultation and home visit.* (E02)

*Does not exist.* (E15)

A study conducted in 2015 showed that (95%) of nurses who perform their function in primary care do not follow up with people with PA because they do not have any training. Another study showed that the lack of knowledge of professionals is from the neonatal screening used to detect PA. Given this, it is observed that the lack of knowledge of professionals about policies and other aspects related to care for people with PA makes it impossible to perform a continuous reception and quality intervention. Therefore, there is a need for training of Family Health Strategy professionals in FY.<sup>19-21</sup>

#### **Category 4: Reference and Counter Reference System Operation**

Thematic analysis units related to the patient information system within the SAR include people with PA, from the interviewees' point of view. This category comprised the following subcategories: Run / Run Partially (FFP), No Counter Reference (NECR), No System (NES) and No Know (NS), resulting in fourteen thematic units.

When asked about the functioning of the information system in the care network for people with AF, most statements showed that the information flow does not work as it should, whereas the counter-reference does not exist, i.e there is no return of information. Some have even reported that this information system does not exist at all, as can be seen in the statements below.

*Does not exist.* (E05)

*There is no counter reference.* (E08)

*In almost a totality there is no counter-reference.* (E10)

*There is a referral to refer to another location, and there is no counter reference.* (E15)

A survey conducted in the municipality of Divinópolis in Minas Gerais with health professionals from an FHS showed a similar result to this research. In the study cited, the interviewees demonstrated to know the referral and counter-referral system, but stated that it does not work effectively.<sup>22</sup> This system was created to improve patient care, but the shortcomings that are evident are clear. Steps should be taken to make such a system effective.<sup>23</sup>

#### **Category 5: Structuring the health care network for people with AF**

It comprises the thematic analysis units that demonstrate the report of health professionals and managers regarding the structuring of the SAR with people with PA. This category comprises the following subcategories: network works regularly (RFR), network does not work (RNF), does not know (NS) and network under construction (RFC). This category resulted in fifteen thematic units.

When questioned about the structure and functioning of the care network, people with sickle cell anemia participants expressed their knowledge with little support, showing mainly not knowing how the network works in their field or how this network should actually be structured, as can be seen in the speeches below.

*I do not know it due to my short stay.* (E01)

*I have no knowledge.* (E05)

*I would go to the private network to a hematologist.* (E08)

*It is directed to private care, because we do not have a care network structured by the SUS.* (E10)

*Here in the municipality this network of attention to people with sickle cell anemia is still under construction.* (E11)

*Does not work.* (E13)

Through the analysis of the testimonies, it is possible to notice a great lack of knowledge of health professionals and managers about the policies and ordinances that guide the care of people with PA, a factor that directly influences the quality and efficiency of the care provided.

Thus, there is a need for reorganization, structuring and qualification of the care network, as well as the implementation of a Comprehensive Care Program for People with Sickle Cell

Disease, in all states, to extend the life expectancy of people with AF with quality as well as adequate care at all levels of care to provide better quality of life for people with clinical manifestations of the disease.<sup>24</sup>

## CONCLUSION

The findings show a worrying picture regarding the care provided to people who experience this chronic situation, since the participants' knowledge about the theme was very limited.

The analysis of the statements about the care and follow-up of people with PA revealed that a substantial portion of the participants do not know, in fact, how to proceed with the peculiarities of follow-up or what conduct to take with clients who live this reality.

Given this, it is understood that there is a need for professionals to reflect on their role for this population and to be continually seeking training so that they feel safe to provide integral and effective assistance to people with PA and their families. In addition, managers should encourage and provide more opportunities for qualification and continuing education for themselves, and for health professionals working in the ARH, with AF.

It is concluded, therefore, that this study was of great relevance for reflection, besides serving as a basis for further studies and discussion on the subject. On the other hand, this research is configured as an important instrument for improving the health professional's knowledge about the assistance to be provided to people with PA.

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