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SOCIAL IMPLICATIONS IN THE LIVES OF PEOPLE WITH SICKLE CELL ANEMIA

Implicações sociais na vida da pessoa com anemia falciforme

Implicaciones sociales en la vida de las personas con anemia falsa

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ABSTRACT

Objective: To analyze the social implications of sickle cell anemia in the life of the person with the disease. **Method:** Descriptive, exploratory, quantitative study conducted with 80 people with sickle cell anemia. Data were collected from January to July 2016 at the Center of Hematology and Hemotherapy of Piauí, through a questionnaire to obtain socioeconomic, demographic and clinical data. The data were tabulated in the *Microsoft Excel 2010* program and arranged in tables and graphs. **Results:** Pain crises were the most frequent complications (70%), (77.5%) reported not having received orientation about the disease and (62.5%) did not live in the city where the treatment was performed. **Conclusion:** Sickle cell anemia has negative implications for a person's life, such as failure or dropout. Thus, health professionals should develop strategies for coping with the disease, thus increasing the quality of life of this public.

DESCRIPTORS: Sickle cell disease; Health services; Assistance; Health integrality; Quality of life.

RESUMO

Objetivo: Analisar as implicações sociais advindas da anemia falciforme na vida da pessoa com a doença. **Método:** Estudo descritivo, exploratório, quantitativo, realizado com 80 pessoas com anemia falciforme. Os dados foram coletados no período de janeiro a julho de 2016 no Centro de Hematologia e Hemoterapia do Piauí, por meio de um questionário para a obtenção de dados socioeconômicos,

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demográficos e clínicos. Os dados foram tabulados no programa *Microsoft Excel* 2010 e dispostos em forma de tabelas e gráficos. **Resultados:** As crises dolorosas foram às complicações mais frequentes (70%), (77,5%) relataram não ter recebido orientação sobre a doença e (62,5%) não residiam na cidade onde realizava o tratamento. **Conclusão:** A anemia falciforme acarreta implicações negativas na vida da pessoa, como por exemplo, a reprovação/evasão escolar. Desse modo, os profissionais de saúde devem elaborar estratégias de enfrentamento da doença, assim, aumentando a qualidade de vida desse público.

DESCRITORES: Doença falciforme; Doença crônica; Serviços de saúde; Assistência; Qualidade de vida.

RESUMEN

Objetivo: Analizar las implicaciones sociales de la anemia falciforme en la vida de la persona con la enfermedad. **Método:** Estudio descriptivo, exploratorio, cuantitativo realizado con 80 personas con anemia falciforme. Los datos se recopilaron de enero a julio de 2016 en el Centro de Hematología y Hemoterapia de Piauí, a través de un cuestionario para obtener datos socioeconómicos, demográficos y clínicos. Los datos se tabularon en el programa *Microsoft Excel 2010* y se organizaron en tablas y gráficos. **Resultados:** Las crisis de dolor fueron las complicaciones más frecuentes (70%), (77.5%) informaron no haber recibido orientación sobre la enfermedad y (62.5%) no vivían en la ciudad donde se realizó el tratamiento. **Conclusión:** La anemia falciforme tiene implicaciones negativas para la vida de una persona, como el fracaso o el abandono. Por lo tanto, los profesionales de la salud deben desarrollar estrategias para hacer frente a la enfermedad, aumentando así la calidad de vida de este público.

DESCRIPTORES: Anemia drepanocítica; Servicios de salud; Asistencia; Integridad en la salud; calidad de vida.

INTRODUCTION

Sickle Cell Diseases (SCD) include a group of hereditary hemolytic anemias, which have in common the alteration of the normal hemoglobin A gene (HbA), determining the presence of hemoglobin S in the hematia (HbS), and the name Sickle Cell Anemia (SCA) is reserved for the homozygous form of the disease (HbSS).[1]

As for the ethnic prevalence, in Brazil, it is higher among black people. However, it is distributed heterogeneously and may affect white individuals due to the high degree of miscegenation in the country. The World Health Organization (WHO) estimates that, annually, 1,900 children with sickle cell anemia are born in Brazil. The number of sickle cell disease in the country is estimated to be between 25,000 to 30,000 and the prevalence of the sickle cell trait (HbS) is higher in the North and Northeast regions (6% to 10%).[2,3]

The most frequent clinical reported manifestations of the disease include painful crisis, infection, acute thoracic syndrome, stroke, splenic sequestration crisis and ischemic ulcer, and occur from the first year of life extending throughout life.[4] One of the main characteristics of the pathology is its clinical variability, because while some patients have a severe clinical picture and are subject to numerous complications and frequent hospitalizations, others have a milder evolution, in some cases almost asymptomatic.[4,3]

However, both hereditary and acquired factors contribute to this clinical variability. Among the most important acquired factors is the socioeconomic level, with the consequent variations in the quality of food, infection prevention and adequate health care.[5]

It is noteworthy that the lack of knowledge about the disease and its complications by society leads to disorders in the life of sickle patients. For this reason, understanding about the disease and its complications is essential for all actors involved in the stages of SCA, from health professionals to the client and their caregiver. And so, break the social stigma imposed on that public.[6,5]

Thus, the results may serve as a subsidy for nurses and other professionals to provide holistic and global care focused on health guidelines and the empowerment of SCA patients. The present study sought to analyze the social implications arising from sickle cell anemia in the life of the person with the disease.

METHOD

This is a descriptive, exploratory study, with quantitative approach, conducted at the Center of Hematology and Hemotherapy of Piauí (HEMOPI), located in Teresina, capital of Piauí, Brazil. Data were collected from January to July 2016, by the author of the study, at the population service center.

The choice of HEMOPI was made because it is a vast field conducive to the study, being the HEMOPI of Teresina-PI the reference in the treatment of hemoglobinopathies, and the only center that has the weekly and specialized care of hematologists to meet the demands of people with sickle cell anemia in any age group in the state.

The sample consisted of 80 people with sickle cell anemia treated at the respective health service. The sampling was non-probabilistic, voluntary, and therefore, people were randomly chosen and those who consented to participate signed the Free and Informed Consent Term (ICF) containing the objectives and methods of the research.

The inclusion criteria to participate in the study were: having a confirmed diagnosis of sickle cell anemia; being registered and accompanied by HEMOPI; family members or companions of children older than five (who lived and had first degree relatives of children under 18 years with SCA, so that they could answer the survey questionnaire and sign the consent form). The exclusion criteria were: children and adolescents of school age who were not attending school.

The data collection instrument was through a questionnaire with closed and open questions, to obtain socioeconomic, racial, demographic and clinical data. The data underwent a re-categorization so that the open questions became closed to facilitate the analysis process.

The data obtained were tabulated in the *Microsoft Excel* 2010 program and arranged in the form of tables and graphs, in percentage. The descriptive statistical analysis was based on the percentage of the responses of the variables.

Authorization to conduct the study was granted by means of a letter presented to the CEPA (Research Ethics Committee)

president of HEMOPI. 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) with approval No. 1,341,990 and was conducted according to the ethical standards required by Resolution No. 466/2012 of the National Health Council that governs research among human beings.

RESULTS AND DISCUSSION

80 people with SCA were interviewed, predominantly female, aged 29 to 35, race/color brown and incomplete elementary school education, as shown in Table 1.

Table 1 - Absolute and relative distribution of the study population, according to socioeconomic, racial and demographic data. Picos, PI, Brazil, 2016.

VARIABLES	n	%
Age group		
5 to 10 years old	20	25.0
11 to 16 years old	13	16.2
17 to 22 years old	14	17.5
23 to 28 years old	10	12.5
29 to 35 years old	23	28.6
Sex		
Male	34	42.5
Female	46	57.5
Race		
White	02	2.5
Brown	49	61.3
Black	29	36.2
Education		
Literate	3	3.8
Incomplete Elementary Education	43	53.8
Complete Elementary Education	1	1.3
Incomplete High School	16	20.0
Complete High School	11	13.8
Incomplete Higher Education	3	3.8
Complete Higher Education	3	3.8
School Year Failure		
Yes	21	26.3
No	59	73.8
Marital status		
Married	6	7.5
Single	68	85
Other	6	7.5
Place of residence		
Urban Area	49	61.3
Rural Area	31	38.7
Work		
Yes	41	85.4%
No	7	14.6%
Income		
No Income	21	26.2
Up to 1 minimum wage	50	65.5
Between 2 to 3 wages	7	8.7
Between 4 to 5 wages	1	1.3
Not Defined	1	1.3
Social Benefit		
Yes	45	56.3
No	35	43.7

Reporting the clinical variables, as shown in Table 2, most of the SCA diagnoses were performed in the hospital, most of the interviewees did not receive guidance on the disease and do not live in the city where the treatment takes place. Regarding the clinical complications of SCA, pain crisis was the most prevalent.

Table 2 - Population description to clinical variables. Picos, PI, Brazil, 2016.

VARIABLES	n	%
Place of diagnosis		
FHS	5	6
Clinic	15	19
Hospital	60	75
Have you received guidance about your illness?		
Yes	18	22,5
No	62	77.5
Clinical complications of the disease		
Pain Crises	56	70
Pneumonia	17	21.3
Infection	7	8.7
Do you live in the city where you receive the treatment?		
Yes	30	37,5
No	50	62.5
Frequency of consultation with hematologist		
1st consultation	8	10.0
Weekly	1	1.2
Biweekly	2	2.5
Monthly	21	26.5
Annual	5	6.2
Other	43	53.6

With regard to age and education, it is noted that none of the participants were in the school year according to their age (Table 3).

Table 3 - Description of the population in terms of age and education. Picos, PI, Brazil, 2016.

	Education					
	Literate		Incomplete Elementary School		Complete Elementary School	
Age group	n	%	n	%	n	%
5 to 14 years old	2	6.7	27	90.0	-	-
15 to 17 years old	-	-	3	50.0	-	-
18 or older	1	2.3	13	53.8	1	2.3

	Education							
	Incomplete High School		Complete High School		Incomplete Higher Education		Complete Higher Education	
Age group	n	%	n	%	n	%	n	%
5 to 14 years old	1	3.3	-	-	-	-	-	-
15 to 17 years old	3	50.0	-	-	-	-	-	-
18 or older	12	27.3	11	25.0	3	6.8	3	6.8

Regarding school failure, the age group with the highest number was 18 or older, with at least one failed year. It is worth noting that school dropouts were not calculated (Table 4).

Table 4 - Description of the population regarding age and failure. Picos, PI, Brazil.

	School Year Failure			
	Yes		No	
Age group	n	%	n	%
5 to 14 years old	8	26.7	22	73.3
15 to 17 years old	1	16.7	5	83.3
18 or older	12	27.3	32	72.7

Referring to the socioeconomic data of patients with SCA, the results are consistent with the literature that indicates that the majority are female, low education, low income, and high unemployment rate among sick people.[1,7]

Regarding the age group of the research population, there was a predominance between five and 35 years of age, a result that corroborates with a retrospective study that analyzed the survival and mortality of people with SCD and revealed that (88.9%) were in age between five and 40. In Brazil, the mean of survival of sickle-cell patients is 33.5 years, while in the Northeast the predominant age of death among people with SCA varies between 20 and 29. Therefore, despite technological advances in health and the increase in life expectancy of people with SCA, in the country, an elderly population affected by this disease is not yet expected. In contrast, in smaller findings, the literature points to records of sickle-cell patients aged between 60 and 69 years old.[8,2]

Regarding color/race, the results of this study show a miscegenation, when we have the majority of people with SCA self-declared brown, because it is considered a disease initially related to the black population, mostly. This result is in agreement with the findings of a research conducted with a *quilombola* community in the state of Sergipe, which pointed to the prevalence of (61.8%) self-declared black people and (32.6%) brown people.[9]

With regard to monthly income, low family income is perceived. Similar data was found in a study with 60 people with sickle cell anemia, in which (31.7%) had family income of up to one minimum wage. It can be observed that the financial condition of people with SCA and their family members is not favorable, linked to this, almost half of the participants stated that they do not have any type of assistance from the Continuous Installment Benefit (BPC - Benefício de Prestação Continuada) or treatment outside their homes (TOH), a fact that reinforces the social vulnerability of these people. On the other hand, a study conducted in Rio Grande do Norte with approximately 100 people revealed that (72.2%) of the participants received some type of social benefit, however, most referred to the benefit as the only source of family income.[10,11]

With regard to education, it is noteworthy that none of the participants were in the school year according to their age and failure was more frequent in people aged 18 or older. Consistent data was found in the literature, which points out that (38.3%) of adult sickle cell patients in Brazil had low education, a situation that will possibly reflect in their lives as adults.[10]

Clinical complications usually occur frequently and can lead the child to lose 40 to 50 days of class a year, compromising their performance. Studies show that the painful crisis is the most frequent occurrence and is responsible for the absences of students in classes. Ignorance of the clinical manifestations of sickle cell anemia on the part of the school can cause a lot of inconvenience to students, teachers and colleagues.[6]

The results of this research are consistent with a survey, which revealed that most people with sickle cell anemia were lagging behind in school, that is, they were at least two years older than those recommended for the grade in which they were in. A qualitative study that interviewed 12 mothers of children and adolescents with SCA showed that absences were justified when a medical certificate was provided, however, when they occurred due to painful crises without a history of hospitalization, absences were counted.[12,13]

The above scenario shows that the school is unaware of the student's health condition. The academic performance of this audience would be sufficient to conclude the grade, however, most of the time, school failure occurs merely because of bureaucratic issues, such as absences in the school year above the required frequency obeying the guidance of the Brazilian Education Guidelines and Bases Act (LDB - Lei de Diretrizes e Bases da Educação Brasileira), without taking into account the specificities of the students and the need for flexibility.[6]

This reality allows us to affirm that people with sickle cell anemia, due to the pathology and its consequences in social life, present significant difficulties in the school environment, especially of adaptation and disadvantage for learning, thus provoking school dropout. The difficulty of the schooling process of the person with SCA is highlighted in studies that deal with the living conditions of these individuals, being the school trajectory of these students marked by episodes of evasion, abandonment and age-grade distortion.[13,14]

Low education has an influence on monthly income, due to the greater susceptibility to informal jobs. Even if a formal job is acquired, it is not all occupations to which they may be subjected to. This subsequently puts them in front of work activities incompatible with their physical condition. People with sickle cell anemia have some restrictions for certain types of work, especially those that require excessive physical exertion, but are released for numerous others, as long as this occurs in healthy environments. The work, in general, contributes decisively to their insertion in society, helping them in maintaining their health.[11,15]

Regarding the profession, a study found that (72.2%) have their family income derived from some type of social benefit, of the (38.3%) who worked, only (5.5%) were formal jobs. Proving that sickle cell anemia is a chronic disease that causes limitation from the socioeconomic point of view. These people need medical follow-up, little physical effort and the correct treatment so that they do not become vulnerable to the symptoms arising from the disease. Although many people with sickle cell anemia are employed, the unemployment rate in this case is still high, above (70%). Therefore, demystifying the incapacity for work of these people with sickle cell anemia is of fundamental importance.[16,15]

With regard to the place of residence/place of treatment, (62.5 %) stated that they do not reside near the place of treatment (HEMOPI) and need some transport to travel to the capital. Asked on how the commuting occurs, most of the interviewees reported that it depends on the transportation of intermunicipal buses or the ambulance provided by the city, because not all people with sickle cell anemia have TOH or BPC as pointed out in the research.

A similar result was found in a research in a *quilombola* community, with a sample of 100 people with sickle cell disease, (33.3%) reported a shortage of public transport to make the route to the destination of the treatment site, thus hindering access to essential services for the follow-up of treatment. The lack of recognition of the special needs arising from the disease causes the affected people to have difficulties in social relations. This fact, combined with the unfavorable financial situation, further compromises access to health services, reflecting on a fragile and deficient health of comprehensive care.[9]

Regarding the frequency of consultation of sickle cell patients with a hematologist, the guarantee of universal access to health is hampered by various social, administrative, political and economic issues. In the state in question of the study, the assistance developed by hematologists is restricted to the capital, thus, displacements are necessary for this monitoring to be carried out, and so the lack of mobility of people with SCA, resulting from financial conditions, is one of the issues that interferes in the realization of the rights conferred by the policy.

Research shows that less than half of the patients (45%) had their first consultation with the hematologist before the age of three months old. This percentage is low, considering that a cohort study with 1,396 people with sickle cell anemia revealed that the median age at the first visit was 2.1 months old, this low percentage can be attributed to the difficulty that families have to make the first appointment at the hematology clinic, and this is due, in part, to the reduced number of hematologists who attend the outpatient clinic considered a reference service for these patients.[17,18]

The first guideline of the National Policy of Comprehensive Care for People with Sickle Cell Disease defines that Public Hemorrede should coordinate the entry of patients diagnosed by neonatal screening into the SUS care network, whose preferred gateway is defined by the National Policy of Primary Care (PNAB - Política Nacional de Atenção Básica) as primary care.

However, the present study showed that most of the clients were diagnosed in the hospital network when they were admitted for occurrences of painful crises. These data show that the FHS teams, which are considered the preferred gateway to the entire health system for people with sickle cell anemia, present failures in the detection of early diagnosis, thus hurting what the health policy recommends.

The reality presented is similar to the literature, when access to health services is considered difficult by interviewees with sickle cell disease in communities. It is worth noting that Piauí is the only state in the Northeast of Brazil that does not have a specific health coordination for sickle-cell diseases, and neither is the State Program of Comprehensive Care for People with Disease and Other Hemoglobinopathies implemented, which justifies the lack of data on people diagnosed and monitored based on the policy.[11]

Therefore, patients should receive comprehensive care, primarily in the specialized public service; however, most of the time, they are presented as the responsibility of blood centers only, which makes the other services unaware or even

ignore the attention to sickle cell anemia. Thus, fragmented care is given priority over comprehensive care, linked to the basic health network.

The most frequent complications were painful seizures, pneumonia and infections due to SCA. One study points to pain crises, jaundice, priaprism, splenic sequestration and lower limb ulcers that are more prevalent in adults as the most frequent causes of hospital admissions. In relation to the cause of death, infection was the most prevalent complication among deaths, and among them, acute respiratory infection due to pneumonia.[2,8]

SCA is considered a limiting disease because it causes various complications in a person's life. Therefore, the limitations generated by the disease culminate in poor socioeconomic conditions and low quality of life, interfering even in the mental health of the person, leading to anxiety and depression.[14,16]

Personal, professional and social losses of the person with SCA are evident, and it is necessary to implement concrete public health policies aimed at this public, in addition to raising awareness of the rulers and health professionals for sickle cell disease patients, especially sickle cell anemia, faced with the burdens that this can generate in people's lives.

CONCLUSION

The low socioeconomic level presented in the research makes people with SCA more dependent on public health services, however, it was noted the difficulty to access health services, in relation to displacement and the implementation of public policies aimed at sickle cell disease.

It was found that the low level of education and high rate of academic disapproval, mostly resulted from the difficulties arising from the disease and its complications, culminating in school absences, disapproval and dropouts.

Therefore, analyzing the social implications in the lives of people with sickle cell anemia is an important tool for health professionals in developing effective strategies to cope with the disease, raising the quality of life and improving the survival of this audience. This way, it is imperative to constantly pursue the implementation of public policies, actions and quality health services in a universal and integral perspective.

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