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Nursing care in Sickle Cell Disease in the Family Health Strategy

Assistência de enfermagem na Doença Falciforme na Estratégia Saúde da Família*

Cuidados de enfermería en Enfermedad de Células Falciformes en la Estrategia Sanitaria Familia

Mayron Morais Almeida[1]; Márcia Sousa Santos[2]; Francisco Wharleson Torres da Silva[3]

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ABSTRACT

Objective: To evaluate the care provided by nurses people living with Sickle Cell Anemia. **Methods:** An exploratory and descriptive study with 28 nurses in the city of Caxias (MA). Data analysis was carried out through the Iramuteq software. The study was approved by the Institute of Education and Health Sinop EIRELI with CAAE: 47406315.9.0000.5685. **Results and Discussion:** There was a predominance of female and aged between 31 to 40 years. Most nurses in the study demonstrated a knowledge of the subject sickle cell anemia, but said they do not provide the support the carriers of the disease people or the lack of patients in UBS's coverage area, is the lack of staff training to provide a quality care the same. **Conclusion:** The study showed that nurses do not provide adequate assistance to people with sickle cell anemia.

Descriptors: Anemia Sickle Cell, Nursing Care, Family Health Strategy, Health Centers.

* Article produced by cutting the monographic work: ANEMIA FALCIFORME: cuidados realizados por enfermeiros na Estratégia Saúde da Família, 2015. Presented to the Faculty of Sciences and Technology of Maranhão - FACEMA, as a requirement to obtain a bachelor's degree in Nursing.

[1] Nurse graduated from the Faculty of Sciences and Technology of Maranhão – FACEMA. Caxias – MA. Brazil. Email: mayronmorais@outlook.com.

[2] Nurse. Master in Family Health. Professor at the Faculty of Science and Technology of Maranhão. Caxias-MA. Brazil. Email: mssenfermeira@gmail.com.

[3] Nurse graduated from the Faculty of Sciences and Technology of Maranhão - FACEMA. Caxias – MA. Brazil. Email: wharlesontorres@gmail.com.

RESUMO

Objetivo: Avaliar os cuidados realizados por enfermeiros as pessoas vivendo com Anemia Falciforme. **Métodos:** Estudo exploratório e descritivo realizado com 28 enfermeiros na cidade de Caxias (MA). A análise dos dados ocorreu por meio do *software Iramuteq*. O estudo foi aprovado pelo Instituto Superior de Educação e Saúde Sinop Eireli com CAAE: 47406315.9.0000.5685. **Resultados:** Houve predominância do sexo feminino e idade variando entre 31 a 40 anos. A maioria dos enfermeiros do estudo demonstraram ter conhecimento acerca da temática anemia falciforme, porém afirmaram que não prestam a assistência às pessoas portadoras da doença, seja pela falta de pacientes na área de abrangência da UBS, seja pela falta de preparo dos profissionais em prestar uma assistência de qualidade as mesmos. **Conclusão:** O estudo mostrou que os enfermeiros não prestam uma assistência adequada às pessoas portadoras de anemia falciforme.

Descritores: Anemia Falciforme, Cuidados de Enfermagem, Estratégia Saúde da Família, Centros de Saúde.

RESUMEN

Objetivo: Evaluar la atención proporcionada por enfermeras personas que viven con anemia de células falciformes. **Métodos:** Un estudio exploratorio y descriptivo con 28 enfermeras en la ciudad de Caxias (MA). El análisis de datos se realizó mediante el software Iramuteq. El estudio fue aprobado por el Instituto de Educación y Salud Sinop EIRELI con CAAE: 47406315.9.0000.5685. **Resultados y Discusión:** Se encontró un predominio del sexo femenino y con edades comprendidas entre 31 y 40 años. La mayoría de las enfermeras en el estudio demostraron un conocimiento de la anemia de células falciformes sujeto, pero dijeron que no proporcionan el apoyo a los portadores de las personas de la enfermedad o la falta de los pacientes en el área de cobertura de UBS, es la falta de capacitación del personal en pago calidad de la Atención de la misma. **Conclusión:** El estudio mostró que las enfermeras no proporcionan asistencia adecuada a las personas con anemia de células falciformes.

Descriptores: Anemia de Células Falciformes, Atención de Enfermería, La Estrategia de Salud, Centros de Salud.

INTRODUCTION

Sickle cell anemia is an inherited and genetic pathology caused by a mutation in hemoglobin S (HbS) linked to descendants of African, Indian and Mediterranean lands. Nowadays, a large part of the world's population is diagnosed with Sickle Disease.[1-2]

The pathology is characterized by large numbers of deformed, sickle-shaped or crescent-shaped red blood cells, because of the increase in blood protein responsible for transporting oxygen (hemoglobin S) rather than hemoglobin A. Deformed or abnormal hemoglobins (S) , Until they can carry oxygen, but when deoxygenation occurs in the tissues, the molecules that form the hemoglobin structures form in polymers, developing bundles known as tactoids.[3-4]

Reduction of morbidity and mortality in sickle cell patients should be indispensable. Considering that it is necessary to compromise the various levels of health care. Primary Health Care in Brazil has an emphasis on the Family Health Strategy, which focuses on health promotion and the prevention of diseases and diseases.[5]

The Family Health strategy has a centralized health services center at all levels of care, so in theory, they are the closest access to sickle cell patients and their families with the necessary care for people with this chronic disease.[1] Even though the evidence shows that the existing deficiencies are in the practice developed daily and in the knowledge of sickle cell care in the community health network itself.

The person with Sickle Cell Anemia must be followed up by the family health team throughout their life. Based on this assumption, it is elaborated as a guiding question for the basis of the research: Are there care provided by nurses of the Family Health Strategy to people living with Sickle Cell Anemia?

Based on this problem, the objective was to evaluate the nursing care in the Family Health Strategy carried out by nurses to people living with Sickle Cell Anemia.

METHODS

This is a field study, descriptive with a qualitative approach,[6] carried out in the city of Caxias-MA, located in the eastern state of Maranhão, Northeast Brazil. The city has approximately 160 thousand inhabitants and is covered by 32 Health Basic Units. The urban area is organized with 39 Family Health Strategy teams, distributed in 22 UBS in the three modalities, and the rural area with 19 teams, in 11 UBS, in two modalities.

The study population was composed of all the nurses from the city of Caxias-MA, who were included in the Family Health Strategy. Sampling was of the non-probabilistic type, for convenience, composed of 28 nurses working in the Family Health Strategy in the urban area of the municipality. The inclusion criteria were: senior nursing professionals (nurses) linked to the Basic Health Units of Caxias-MA in the urban area, who had more than one year of experience and who accepted to respond to the questionnaire that was proposed by the study. Exclusion criteria were: nursing professionals of technical level and average of the basic health units of Caxias-MA of the urban zone, who were less than one year old and who did not accept to participate in the study.

The collections took place in the period between August and November 2015, by the duly trained researchers, through a semi-structured interview containing open and closed questions. The interview was carried out using an instrument for data collection, an electronic MP4 device to record the nurses' responses, in a closed place of the interviewee's preference, with an average duration of 40 minutes each and attempting to preserve their privacy and comfort, with To prevent interruptions of any kind. It should be noted that the interviews were scheduled according to the nurses'

availability. Therefore, in some cases, it has been returned to the Basic Health Units as often as necessary.

For the analysis of the data and the processing of the study, Iramuteq software (Interface for Multidimensional Analyzes of Textes et de Questionnaires), developed by Pierre Ratinaud in the year 2009 in France.

It is a program that is anchored in software R and allows different forms of statistical analysis on textual corpus and tables of individuals by words. Iramuteq enables different types of analysis, from the simplest to the multivariate, such as the Hierarchical Descending Classification, and organizes the distribution of the dictionary so that it is easy to understand and clearly visible.[7]

The Iramuteq software, to perform classic lexical analyzes, identifies and reformats the text units, which are transformed from Initial Context Units (UCI) into Elementary Context Units (UCE). The number of words, the average frequency and the number of hapax (words with one frequency) are also identified. Vocabulary research is done and reduced to words, based on its roots (lemmatization), the dictionary being created from the reduced forms and identified the active and supplementary forms.[7]

In order to form the phases of the study, it was necessary to follow some steps, among them: the knowledge of all the nurses of the Family Health Strategies, where we were able to interview 28 nurses about the knowledge about care for people with Sickle Cell Anemia and The same 28 interviews were for analysis and data processing.

The corpus was constituted by existing data in the results and conclusions of the studies that were placed in a single text file, according to Iramuteq's tutorial guidelines.[7] The corpus was formed by the set of texts to be analyzed, fragmented by the software in segments of text. During the preparation of the corpus we made all necessary corrections of the reading and decoding of the fixed variables, according to the following table.

For the analysis, we defined the Descending Hierarchical Classification (CHD) method, proposed by Reinert in 1990, in which the texts are classified according to their respective vocabularies and the set of them is divided by the frequency of the reduced forms. From matrices that cross segments of texts and words (repeated X2 tests), the CHD method is applied to obtain a stable and definitive classification. We also used the similarity and cloud of words chart, which groups the words and organizes them graphically according to their frequency. It is a simpler but graphically interesting lexical analysis.[7]

The CHD analysis aims to obtain classes of text segments that, in addition to presenting similar vocabulary to each other, have vocabulary different from the text segments of other classes.

The systematization of the results and conclusions of the studies allowed the achievement of the objectives of the research on sickle cell anemia and the care of nurses in the family health strategy. The results were published and analyzed according to theoretical framework.

As it is a research with human beings the present work was submitted for evaluation by a Committee of Ethics in Research, being approved under the No. of CAAE 47406315.9.0000.5685 and opinion No. 1.254.827, as recommended in Resolution No. 466/2012 of the CNS/MS.

RESULTS AND DISCUSSION

The study included 28 nurses, predominantly female (27) and age between 31 and 40 (46.4%). With regard to schooling, nurses' graduation ranged from 2 to 22 years, with an average time between 2 and 8 years (60.7%). The majority (25; 89.30%) reported having completed one or more postgraduate courses.

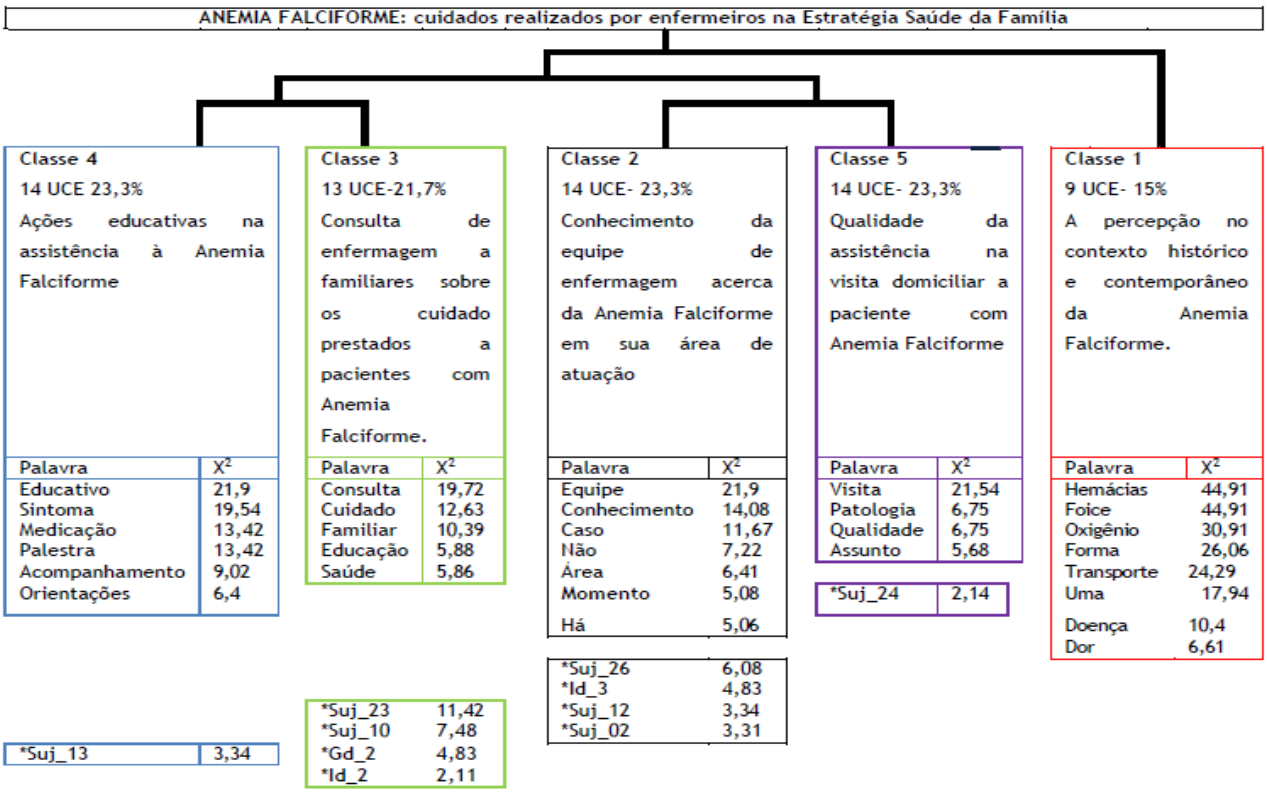
As for the description of the specializations studied, 17 (39.5%) nurses reported having specializations in Family Health, 3 (6.9%) in Maternal Child, 9 (29.9%) in Public Health, 7 (16.2%) in Family Health Strategy, 2 (4.6%) in Health Management, 1 (2.3%) in Worker's Health, 1 (2.3%) in Elderly Health, 1 (2.3%) in Urgency and Emergency, 1 (2.3%) in Mental Health and 1 (2.3%) in Intensive Care.

Table 1 – Database to decode variables. Caxias-MA, 2015

Age	Graduation	Especialization
Id_1 (20-30)	**Gd_1 (2-8)**	**Esp_1 (yes)**
Id_2 (31-40)	**Gd_2 (9-15)**	**Esp_2 (no)**
Id_3 (41-50)	**Gd_3 (16-22)**	

Source: Field survey.

Figure 1 – Dendogram of the Descending Hierarchical Classification by classes and units of elemental context with approach in the care done by nurses to people with Sickle Cell Anemia in the Family Health Strategy. Caxias-MA, 2015



Source: Direct search.

The textual corpus analyzed is composed of 26 units of initial context (UCI) or interviews of which 87 text segments or units of elementary context (UCE) were obtained. Iramuteq recognized the separation of the corpus into 60 elementary text units, with 68.97% of it being used. The hierarchical descending analysis resulted in the following distribution of thematic classes or contexts: classes 5 and 2, 3 and 4 are interrelated and linked to class 1 representing (15%) the use of the corpus. However, classes 2 and 4 are the most successful, each representing (23.3%) of the textual corpus. The classified textual segments were divided into 05 classes, according to the dendrogram represented in Figure 1.

The nurses' reports on the care practice of patients with Sickle Cell Anemia gave rise to a discourse about the phenomenon analyzed, whose statement was grouped in five thematic categories: Educational actions in the assistance to Sickle Cell Anemia; Nursing consultation to relatives about the care given to patients with Sickle Cell Anemia; Knowledge of the nursing team about Sickle Cell Anemia in their area of action; Quality of care in the home visit to patients with Sickle Cell Anemia and the perception in the historical and contemporary context of Sickle Cell Anemia.

Class 4 – Educational actions in the care of Sickle Cell Anemia

The study demonstrated that some participants in the research know the ways to provide mechanisms for health promotion and education for these patients. However some reported not offering due to lack of patients in the Basic Health Unit, as shown in the reports below:

> *We give educational lectures to these patients and their families, but we do not have patients with sickle cell anemia [...]. (Enf_01)*

> *No, because we do not have patients with anemia in our area of coverage. We only provide the necessary medication, guidelines and health education guidelines on the signs and symptoms in addition to optimizing care in health networks to patients who follow up [...]. (Enf_03)*

> *No, because we do not have patients with this problem or I was not informed by the community health agent about a case, so we did not promote explanations in the form of lectures and meetings, home*

visits .... However arising in the Basic Health Unit, we will develop activities aimed at this pathology orientations regarding the treatment of educational lectures on nutrition. (Enf_06)

From the discourses of the nurses, it should be noted that this one should elaborate educational actions directed to people with sickle cell anemia and their families, about diagnosis, pathology, clinical manifestations, healthy eating habits, vaccinations, preventive and prophylactic measures that, Prevent complications of the disease.

The importance of the educational guidelines to the person with Sickle Cell Anemia related to the oral manifestations of the pathology, with the intention of detecting some changes in the clinical condition early, alerting to the worsening and progression of the pathology, thus allowing the search for actions that may minimize or remedy such events.[8]

The Family Health Strategy performs admirable functions in assisting the person with sickle cell disease. The establishment of concrete bonds between patients and their families with the health team of the Basic Health Unit is essential to promote the acquisition of pathology, improvement in the knowledge of the main signs and symptoms, in order to prevent risks and complications that require Search by tertiary level.[9]

The importance of nutritional monitoring in growth and development, adherence to prophylactic antibiotic therapy, monitoring patient routines on the vaccination schedule, and varying guidelines with emphasis on care for the environment and other factors triggering acute episodes are highlighted.[5]

In this context, it is evident that the person with sickle cell anemia needs educational actions focused on feeding, genetic counseling, vaccination, acute signs and symptoms of pathology and medication. Therefore, the nurses of the Basic Health Units should know all the appropriate strategies for health education and promotion so that these patients can coexist with sickle cell anemia in a more harmonic way, reducing the fear and anguish that are present in the life of these people. [10]

Class 3 – Nursing consultation to relatives about the care given to patients with Sickle Cell Anemia.

The nurses in general have demonstrated knowledge about the main care that can be performed in the Basic Health Units, which they can pass on to the patients that may come to these units, as shown in the following dialogues:

Guidelines that are given to the patient and family the use of the ferrous sulfate periodic appointments to conduct examinations. (Enf_09)

So far, I have not taken care of any patient with sickle cell anemia during any graduation time. The only contact I had was during the supervised internship, and I was offered guidance to my family members. (Enf_24)

At the moment I do not accompany any patients with sickle cell anemia, but the cases that have already happened we work with family guidelines in order to identify early signs of severity [...]. (Enf_27)

The nurse has the essence of caring holistically in the community, in the family, always seeking techniques developed for promotion, recovery and rehabilitation of health, prevention of diseases. And hence the importance of the nurse to know all the steps of nursing consultation. Thus, it is imperative that nurses have genetic knowledge to guide families in the planning of Sickle Cell Anemia, but for this, it becomes necessary for nurses to understand the meaning of the person affected by Sickle Cell Anemia within the family. [11]

There is an imaginary barrier on the part of people with Sickle Cell Anemia in the search for the Basic Health Unit for nursing consultation. This obstacle is explained by the simple fact that nurses are not prepared to perform consultations aimed at relatives and / or patients with Sickle Cell Anemia. We highlight the choice of families for the reception of the secondary level of health due to the lack of nurses' capacity in their primary care consultations.[5]

The nurse during the nursing consultation and responsible for the primary care, for the comfort, reception and well-being of its patients, either offering direct and indirect care, or systematizing several sectors for the assistance or generating the autonomy of the clients by health education. It is essential for nurses to develop links with patients and their families so that they can provide essential care information. [12]

In a study,[13] it was observed that Sickle Cell Anemia is a pathology that does not have a characteristic treatment. Thus, the evolution in the quality of life of these patients is based on prevention measures. Regarding these measures we can mention the education of the patient and family members regarding aspects of the pathology, monitoring the growth and development of children, nutritional guidelines, genetic counseling, hydration, techniques for teaching how to palpate the spleen and check the temperature.

Therefore, the Family Health Strategy nurses should be able to carry out quality nursing consultations on the main guidelines for the care of patients with Sickle Cell Anemia. Therefore, they can demystify the negative ideas of users about the procedures carried out in the Basic Health Units. Because in the study it was evident that the nurses do not perform nursing consultations with their relatives, in order to guide the same about the care.

Class 2 – Knowledge of the nursing team about Sickle Cell Anemia in their area of practice

The analysis of the speeches showed that most of the subjects in the study are unaware of the existence of patients in the area covered by their respective Basic Health Units, probably due to the lack of communication between the community health agents or the lack of adherence / interest of the patients. Patients and relatives to the primary care that immediately sought the secondary care (blood centers), as shown by the deponents' speech:

Not until now I have not done a direct follow-up of people with sickle cell anemia since I do not have public (Enf_06).

Not because there are no patients in the basic health unit with anemia under follow-up [...]. (Enf_16)

Currently not because I do not have a patient in the area of my family health strategy [...] (Enf_18).

Not because we do not have public and the traces for sickle cell anemia have turned negative. (Enf_22)

No, because in my area of coverage I did not report any cases of sickle-cell anemia by my community health agents, so I do not advise on the importance of medical follow-up, much less on the family and the patient. (Enf_25)

Thus, as the Ministry of Health warns, within the scope of the Family Health Strategy, it is expected that nursing professionals should be inserted in the community, in order to fulfill the principles of the National Primary Care Policy, which highlights the creation Of links and the continuation of care as essential conditions for the promotion of integral and quality care.[13 14]

In view of these findings, it is pointed out that such pathology requires early follow-up, since it is essential that nursing professionals be aware of the existence of the disease and be able to identify it before major consequences. Such anemia causes direct and indirect impacts on the patient's family and health professionals, who, because of lack of knowledge, are not prepared to holistically receive people with sickle cell anemia.[15]

The nurses of the Basic Health Units are responsible for performing essential functions in the quality of life and longevity of people with Sickle Cell Anemia. It is perceived that knowledge alone is not enough to deal with the problem, since an adequate infrastructure is essential, so that it can implement services so that it can carry out an early diagnosis, treatment and follow-up of the cases.[16]

Thus, it is revealed in the present study the need of nurses to acquire knowledge about their area of coverage, so that they can offer better care to these patients. However, we observed in studies that most nurses are unaware of their area and mainly the forms of care, since sickle cell anemia is a very complex pathology and lacks all the professionals of the Basic Health Units involved.

Class 5 – Quality of care in the home visit to patients with Sickle Cell Anemia.

The study showed that the research nurses do not carry out home visits, because they report that in their areas of coverage there were no cases of patients with sickle cell anemia. However some said that they visit other patients with other pathologies, in order to offer quality care:

I do not go on a home visit, but if a case is detected I will visit with the aim of promoting quality care for these patients [...]. (Enf_03)

Clarifying about the possibility of the couple having another child with the same condition, we do not have patients with this pathology, but we visit other patients [...]. (Enf_09)

We do not carry out home visits because I do not have patients with sickle cell anemia in the area. We only make the visits scheduled by the community health agent in order to promote a quality assistance to the target public [..]. (Enf_14)

We did not visit these clients, but we did a home visit with other patients with chronic diseases. (Enf_23)

According to some authors,[16-17] the nurse develops the practice of the home visit, however it has been shown that he has done in greater proportions the assistance activities within the Basic Health Units. In this way, he has abandoned the use of the environment of the visit Household to make the bonds between the families and leaving them without a quality assistance. However, in this environment, the nurse practitioner works with the objective of attending to all the difficulties that may arise related to the health of his patients, taking into account home infrastructure, family relationships, problems that may affect the community, diagnosis of pathologies, Among other problems, always with an approach in the assistance of its clients.

The home visit is a care practice developed by the nurse within the Basic Health Unit, with the objective of directly and indirectly investigating the health needs of its clients, besides using it as care practices such as dressings, collection of exams , Vital signs assessment and health promotion and education.[18]

On the basis of these findings, community health agents do not organize home visits in an organized way to patients with Sickle Cell Anemia. The same ones highlighted some themes in the visits as: infectious pathologies, medication, algia, next consultations, examinations and situation of the child in the school. The actions of the community health agents in the visit imply in penetrating the family affinities. It is therefore clear that the monitoring by community agents of people with sickle cell anemia is of paramount importance.[5]

Certain components should be emphasized by nurses in visits to people with sickle cell anemia, as well as medication, school attendance, and vaso-occlusive crises. In the view of the professional, it is not important to monitor the medication at all visits. Prescription of antibiotic prophylaxis is, as a function of blood banks, support for adherence and follow-up needs to be done by the Family Health Strategy.[5]

Another factor that makes home visits essential points in the care of these patients is the monitoring of oxygen levels that, when in low concentrations lead to a change in the conformation of the erythrocytes triggering thromboembolic events and forming ulcers mainly in the lower limbs. It is only by knowing patients with sickle cell anemia that the nurse can individually plan the care to be rendered. [19]

Therefore, it is evident that home visits are essences to patients with Sickle Cell Anemia, because through it the nurse can supply all the needs of their clients, with the objective of seeking improvements in care, and consequently bring quality of life to these patients. However, it is still imperative that nurses seek current evidence every day to offer the best mechanisms of a visit, as it is highlighted in the results that nurses do not perform home visits.

Class I – The perception in the historical and contemporary context of Sickle Cell Anemia.

It was observed that nurses have historical and contemporary knowledge about Sickle Cell Anemia, because at some point in their academic formation, they had some contact with the subject. Therefore, most of the research subjects reported on concepts, epidemiological data, physiopathology and some signs and symptoms as evidenced by the following statements:

Sickle cell anemia is a disease that, like the other anemias, causes red blood cells to fall, the sickle-shaped name is due to the shape of the red blood cells that take on the shape of a scythe [...]. (Enf_04)

Sickle cell anemia originates in Africa arrived in Brazil through the immigration of African blacks [...]. (Enf_07)

Sickle cell anemia is a deficiency in the red blood cells where they are sickle shaped, which means that cells carry little oxygen and a predominant hereditary disease in blacks [...]. (Enf_16)

It is an inherited disease that occurs due to a change in the shape of hemoglobin and this different shape can obstruct small vessels causing pain [...]. (Enf_21)

It is an inherited disease that has in the red series cells with altered format that shows abnormality of the same it has no cure, however it is treatable. (Enf_26)

Sickle cell anemia has become a public health problem in many countries and even in Brazil. Moreover, it is a chronic pathology characterized by clinical variations of the disease among patients, with moments of comfort interspersed with circumstances that demand urgent or emergency care. It is a predominant pathology in blacks who, due to social and economic issues, needs health attention in a more egalitarian way. [20]

Sickle cell anemia is considered a chronic, incurable disease with treatment, however, it is responsible for promoting a lot of suffering for its patients. In this sense, early diagnosis becomes essential for the advancement of the patient's life expectancy, which in Brazil is 30 years. Therapy and follow-up of health professionals help assist the patient in various aspects of his or her life.[1]

Sickle cell disease was first described in 1910 at the University of the West Indies in Central America, in which elliptic cells were analyzed in elongated form. In another study, Sickle Cell Anemia is a hereditary pathology linked only to one gene, widely disseminated in Brazil, predominant in blacks of African descent, but with manifestations in whites and browns. [21]

Sickle cell anemia is a chronic genetic disease that is diagnosed through birth-specific tests. Mainly characterized by episodes of vaso-occlusive crises, because the red blood cells have a sickle shape. Therefore knowledge about the pathophysiology of the disease and the emotional, psychological and social aspects of the patient is essential. [22]

Sickle cell anemia is a disease with clinical management characterized by acute episodes, which can have several complications, affecting all systems and decreasing life expectancy. In addition to other manifestations such as: episodes of pain attacks, infections and pulmonary infarctions, delayed growth and sexual maturation, stroke, leg ulcers. However, the patient faces all the complications of the disease, but always requires a satisfactory and weighted clinical follow-up. [23]

Patients with sickle cell anemia should have specific care within the first two months of life. Educational actions should be directed initially to family members, from the first contact, they need to be guided as to

the need to maintain proper nutrition and hydration and signs and symptoms. Nurses should advise family members about the prevention of infections, vaccinations and use of antibiotics and encourage them to recognize the main complications of the disease.[1]

A study[15] shows that about 95% of the nurses who perform their function in Primary Care do not follow up patients with Sickle Cell Anemia because they do not have any type of training. The lack of technical and theoretical knowledge in whatever space of performance leaves the service without quality.

Faced with such findings, some authors[24] show that the follow-up done by the team of health professionals is a proven tactic to improve the care provided to this group, which suffers from environmental factors and chronic diseases. Therefore, in order to carry out quality care, it is necessary that all professionals in the Family Health Strategy involved in this context have some type of training or know the best evidence regarding the treatment.

The follow-up of people with Sickle Cell Anemia at the primary level is diminished by the fact that users directly seek the secondary level. This preference for the secondary level is, according to history, due to the fact that the treatment of the pathology is understood as complicated and of exclusive capacity of the blood centers. Thus, the health professionals of the other levels of care ignored people with pathology because they did not know it.[5]

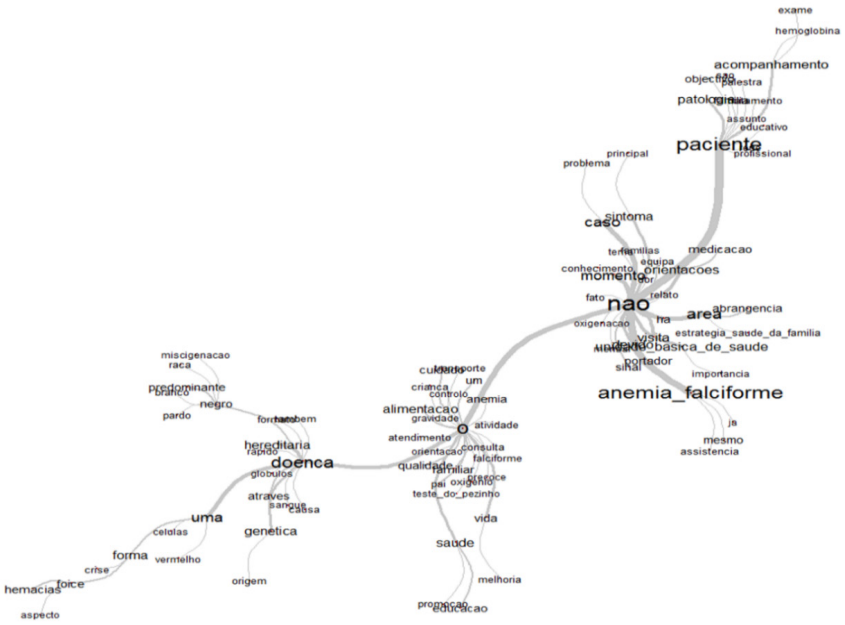
Thus, it is observed that nursing in Basic Health Units plays a fundamental role in orienting the family to the disease and offering support to the particular part of the diagnosis, such as: guilt, anger, fear, depression, emotions of lesser reproductive value than Help the lives of family members, particularly the mother of the child with Sickle Cell Anemia.

This phenomenon occurs due to the lack of habilitation of the nurses of the Basic Health Units, the support of guidelines, neonatal screening, the use of antibiotics, immunizations, genetic counseling and educational actions directed at patients and their families. Relevance in public health. Many deaths would be avoided by educating and improving the social, economic and cultural conditions of families who have people with Sickle Cell Anemia. [25]

It is evidenced that the lack of knowledge, on the part of the Basic Care professionals, about treatment information, about the care and failures in the systematization of the service that makes it impossible for a continuous reception reveals that patients and their families prefer the choice of secondary care or taking Decisions for self-care.

The analysis of similarity is based on graph theory, allowing to identify the co-occurrences between words and its result indicates indications of the connection between words, helping in the identification of the structure of a textual corpus, characterizing the common parts and the specificities in The descriptive variables identified in the analysis. [26]

Figure 2 – Results of similitude analysis. Caxias-MA, 2015



Source: Direct search.

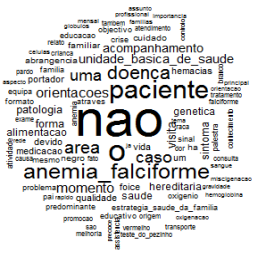
According to Figure 3, the tree is displayed in the interface of the similitude analysis results with the identification of simultaneous occurrences between words and suggestions of the connectivity between the terms: sickle, sickle-cell anemia, and not all patient assisting in the presentation of the Composition of the representational field of care performed by nurses in the Family Health Strategy for people with Sickle Cell Anemia.

According to the co-occurrence tree, the results indicated that the care performed by nurses to people with sickle cell anemia is divided as follows: 1 - genetic and hereditary disease, 2 - the main guidelines for improving quality of life and 3 - no follow up in patients with sickle cell anemia in Family Health Strategies.

Through the word cloud method, the Iramuteq software organizes them graphically according to their frequency, allowing rapid identification of keywords in the corpus. Therefore, the ones that managed to obtain the highest frequencies were: non, patient, Sickle cell anemia, area, the, case, guidelines, follow-up and Basic Health Unit.

Therefore, it is clear that through the word cloud method, which exposes the grouped words and organized graphically according to their frequency, it is noticed that there are no guidelines in the follow-up of the patient with Sickle Cell Anemia in the Basic Health Unit.

Figure 3 – Word cloud analysis results. Caxias, 2015



Source: Direct search.

CONCLUSION

The Family Health Strategy functions as a mechanized company to offer assistance operated by multiprofessional teams established in Basic Health Units. Multiprofessional teams need knowledge of all their area of coverage, so that it can act with quality in the accompaniment of all families. It is well known that the actions of recovery, promotion, prevention and health education, should be offered to all without distinction of patients.

Nurses play important roles, as far as care is concerned, for being an indispensable member of the team. In this way he develops activities aimed at planning, coordinating, assisting and evaluating all the physical and human resources of the Family Health Strategy.

At present, basic care is the gateway for all users, so the nurse must know all the aspects that can be evaluated in relation to the care given to the person with Sickle Anemia, so that the patients and their families will not be entered at the secondary level . It is therefore clear that Sickle Cell Anemia has been made a public health problem because of its complexity.

The research allowed the expansion of knowledge about the dimensions of sickle cell anemia in the Basic Health Unit. The analysis made of the speeches made possible an understanding of the reality of the patients with the pathology, inserted in the Family Health Strategies. Through these reflections, the study led us to understand that the care taken by nurses in the Family Health Strategy to people with sickle cell anemia are deficient.

The data suggest that the research nurses have characteristics that lead us to understand that they do not care for patients with Sickle Cell Anemia, do not develop health promotion and education, do not perform a home visit, because they report they do not have confirmed cases in their area of coverage. Therefore, it is necessary that the study participants seek to broaden and qualify their knowledge regarding the care of people with Sickle Cell Anemia.

Given all this, it is interesting that the nurses understand the whole physiopathological process and the main factors that will trigger the disease. Because we perceive that the main form of care for these patients is knowledge, because through this science nurses can guarantee the main actions, to avoid the main symptoms, since early detection of complications, may enable an adequate treatment and an improvement in quality Of life.

Therefore, qualified professionals should feel more securely protected to perform or provide holistic and qualified care to people with Sickle Cell Anemia and their families, providing more effective care and seeking to establish early diagnosis and appropriate case management, with Based on real knowledge, contributing effectively to avoid future complications and deaths.

In this sense, the study provided support for the understanding of quality care for patients with Sickle Cell Anemia, as well as an approach on the knowledge of pathology, so that other healthcare professionals can understand the importance of caring for people living With Sickle Cell Anemia in Basic Health Units.

Therefore, it is expected that the results of this study can guarantee discussions about the subject matter, besides offering theoretical and practical bases for the professionals of the study. It is emphasized the need to carry out other studies, with different groups, in order to guarantee positive changes in the Family Health Strategies related to the care provided to people with Sickle Cell Anemia.

REFERENCES

1. Ministério da Saúde (BR), Secretaria de Atenção à Saúde, Doença falciforme: condutas básicas para tratamento Ministério da Saúde. Brasília: Ministério da Saúde, 2012. Disponível em: http://bvsms.

saude.gov.br/bvs/publicacoes/doenca_falciforme_condutas_basicas.pdf. Acesso em: 06 set 2016.

2. Vieira GB, PTC Gonçalves, Meirelles JR, Sória DAC. A Sistematização da Assistência de Enfermagem no Cuidado ao Paciente Portador de Anemia Falciforme com Úlcera de Perna. R. pes.: cuid. fundam. Online. [Internet]. 2013. dez., [citado em 6 set. 2016]; 5(5):142-47. Disponível em: http://www.seer.unirio.br/index.php/cuidadofundamental/article/view/1676/pdf_1014
3. Bosco PS, Santiago LC, Carneiro BM. Educação e o meio ambiente como fatores essenciais no cuidado de enfermagem aos clientes portadores de anemia falciforme. R. pesq.: cuid. fundam. Online. [Internet]. 2012. jan./mar., [citado em 6 set. 2016]; 4(1):2654-58. Disponível em: http://www.seer.unirio.br/index.php/cuidadofundamental/article/download/1551/pdf_474.
4. Guimaraes, TMR, Miranda WL, Tavares MMF. O cotidiano das famílias de crianças e adolescentes portadores de anemia falciforme. Rev Bras Hematol Hemoter. [Internet]. 2009 Fev/Mar [citado em 5 nov. 2015]; São Paulo, 31(1):9-14. Disponível em: http://dx.doi.org/10.1590/S1516-84842009005000002.
5. Gomes LMX, Torres HC, Caldeira AP, Viana MB. Acesso e assistência à pessoa com anemia falciforme na Atenção Primária. Acta Paul Enferm. [Internet]. 2014 [citado em 29 maio 2015]; Minas Gerais, 27(4): 348-55. Disponível em: http://www.scielo.br/pdf/ape/v27n4/1982-0194-ape-027-004-0348.pdf.
6. LEOPARDI, M. T. Metodologia da pesquisa na saúde. 2 ed. rev. e atual. Florianópolis: Artmed, 2002.
7. Camargo BV, Justo, AM. IRAMUTEQ: um software gratuito para análise de dados textuais. Temas psicol. [Internet]. Ribeirão Preto, 2013 dez [citado em 31 maio 2015]; 21 (2):513-8. Disponível em: http://pepsic.bvsalud.org/scielo.php?script=sci_arttext&pid=S1413-389X2013000200016&lng=pt&nrm=iso.
8. Meneses RCT, Zeni PF, Oliveira CCC, Cláudia MMCM. Promoção de saúde em população quilombola nordestina - análise de intervenção educativa em anemia falciforme. Esc Anna Nery. [Internet]. Rio de Janeiro, 2015 Mar [citado em 1 nov 2015]; 19(1):132-9. Disponível em: http://www.scielo.br/pdf/ean/v19n1/1414-8145-ean-19-01-0132.pdf.
9. Gomes LMX, Vierira MM, Reis TC, Barbosa TLA, Caldeira AP. Conhecimento dos profissionais de nível médio sobre doença falciforme: estudo descritivo. Online braz j nurs. [Internet]. Niterói (RJ), 2013 set [citado em 29 maio 2015]; 12(2):482-90. Disponível em: http://dx.doi.org/10.5935/1676-4285.20134034.
10. Bosco PS, Santiago LC, Carneiro BM. Educação e o meio ambiente como fatores essenciais no cuidado de enfermagem aos clientes portadores de anemia falciforme. R pesq cuid fundam online. [Internet]. 2012 jan/mar [citado em 99 ago 2016]; 4(1):2654-58. Disponível em: http://www.seer.unirio.br/index.php/cuidadofundamental/article/download/1551/pdf_474.
11. Rodrigues CCM, Araujo IEM, Melo LL. A família da criança com doença falciforme e a equipe enfermagem: revisão crítica. Rev Bras Hematol Hemoter. São Paulo, [Internet], 2010 jul [citado em 29 maio 2015]; 32(3): 257-64. Disponível em: http://www.scielo.br/pdf/rbhh/v32n3/aop79010.pdf.
12. Rocha SMM, Almeida MCP. O processo de trabalho da enfermagem em saúde coletiva e a interdisciplinaridade. Rev Latino-Am. Enfermagem [Internet], 2000 dez [citado em 1 nov 2015]; Ribeirão Preto, 8(6): 96-101. Disponível em: http://www.scielo.br/pdf/rlae/v8n6/12354.pdf.
13. Braga JAP. Medidas gerais no tratamento das doenças falciformes. Rev bras hematol hemoter. [Internet]. São José do Rio Preto. 2007 set [citado em 31 maio 2016]; 29 (3): 233-8. Disponível em: http://www.scielo.br/pdf/rbhh/v29n3/v29n3a09.pdf.
14. Ministério da Saúde (BR), Secretaria de Atenção à Saúde. Departamento de Atenção Especializada. Doença falciforme: saiba o que é e onde encontrar tratamento. Secretaria de Atenção à Saúde. Brasília: Ministério da Saúde, 2012.
15. Diniz D, Guedes C. Anemia Falciforme: Um Problema Nosso. Uma abordagem bioética sobre a nova genética. Cad Saúde Pública [Internet]. Rio de Janeiro, 2003 dez [citado em 31 maio 2015]; 19 (6): 761-70. Disponível em: http://www.scielo.br/pdf/csp/v19n6/a20v19n6.pdf.
16. Araújo A. Complicações e expectativa de vida na doença falciforme: o maior desafio. Rev bras hematol hemoter. [Internet]. São Paulo, 2010 [citado em 31 maio 2015]; 32 (5): 347-59. Disponível em: http://www.scielo.br/pdf/rbhh/v32n5/a04v32n5.pdf.
17. Marin MJS, Gomes R, Siqueira Junior AC, Nunes CRR, Cardoso CP, Otani MP, Moravcik MY. O sentido da visita domiciliária realizada por estudantes de medicina e enfermagem: um estudo qualitativo com usuários de unidades de saúde da família. Ciênc Saúde Coletiva. [Internet]. Rio de Janeiro, 2011 nov 2010 [citado em 1 nov 2015]; 16(11): 4357-65. Disponível em: http://www.scielo.br/pdf/csc/v16n11/a08v16n11.pdf.
18. Aciolil S, Kebian LVA, Faria MG, Ferraccioli P, Correa VAF. Práticas de cuidado: o papel do enfermeiro na atenção básica. Rev de enferm UERJ. [Internet]. Rio de Janeiro. 2014 Set/Out [citado em 31 maio 2015]; 22(5): 637-42. Disponível em: http://dx.doi.org/10.12957/reuerj.2014.12338.
19. Vieira GB, Gonçalves PTC, Meirelles JR, Sória DAC. A Sistematização da Assistência de Enfermagem no Cuidado ao Paciente Portador de Anemia Falciforme com Úlcera de Perna. R pesq cuid fundam online. [Internet]. 2013. dez. [citado em 09 ago 2016]; 5(5):142-7. Disponível em: http://www.seer.unirio.br/index.php/cuidadofundamental/article/download/1676/pdf_1014.
20. Luna ACA, Rodrigues MJ, Menezes VA, Marques KMG, Santos FA. Caries prevalence and socioeconomic factors in children with sickle cell anemia. Braz Oral Res. [Internet]. São Paulo, 2012 Fev [citado em 31 maio 2015]; 26(1): 43-9. Disponível em: http://www.scielo.br/pdf/bor/v26n1/a08.pdf.
21. Lobo C, Marra VN, Silva RMG. Crises dolorosas na doença falciforme. Rev Bras Hematol e Hemoter. [Internet]. São José do Rio Preto, 2007 Set [citado em 1 nov 2015]; 29(3): 247-58. Disponível em: http://www.scielo.br/pdf/rbhh/v29n3/v29n3a11.pdf.
22. Barakat LP, Patterson CA, Daniel LC, Dampier C. Quality of life among adolescents with sickle cell disease: mediation of pain by internalizing symptoms and parenting stress. Health and Quality Life of Outcomes [Internet]. 2015 Ago [citado em 31 maio 2015]; 6(60):1-9. Disponível em: http://www.hqlo.com/content/6/1/60.
23. Wang CW. The patophisiology, prevention, and treatment of stroke in sickle cell disease. Curr Opin Hematol. [Internet]. 2007 maio [citado em 31 maio 2015]; 14(13):191-7. Disponível em: http://www.ncbi.nlm.nih.gov/pubmed/17414206.
24. Souza KCM, Damião JJ, Siqueira KS, Lílian CSS, Santos MR. Acompanhamento nutricional de criança portadora de anemia falciforme na Rede de Atenção Básica à Saúde. Rev Paul de Pediatr. [Internet]. São Paulo, 2008 Dez [citado em 2 Nov 2015]; 26(4): 400-4. Disponível em: http://www.scielo.br/pdf/rpp/v26n4/a15v26n4.pdf.
25. Fernandes APPC, Januário JN, Cangussu CB, Macedo DL, Viana MB. Mortalidade de crianças com doença falciforme: um estudo de base populacional. J Pediatr. [Internet]. Porto Alegre, 2010 [citado em 1 Nov 2015]; 86(4): 279–84. Disponível em: http://www.scielo.br/pdf/jped/v86n4/a06v86n4.pdf.
26. Marchand P, Ratinaud P. L'analyse de similitude appliqueé aux corpus textueles: les primaires socialistes pour l'election présidentielle française. In Actes des 11eme Journées internationales d'Analyse statistique des Données Textuelles. JADT; Liège, Belgique [Internet]. 2012 set/out [citado em 1 Nov 2015]; 687-99. Disponível em: http://lexicometrica.univ-paris3.fr/jadt/jadt2012/Communications/Marchand,%20Pascal%20et%20al.%20-%20L'analyse%20de%20similitude%20appliquee%20aux%20corpus%20textuels.pdf.

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Author responsible for correspondence:
Márcia Sousa Santos
Faculdade de Ciências e Tecnologia do Maranhão – FACEMA
Departamento de Enfermagem
Rua Aarão Réis, 1000, Centro
Caxias/MA, Brazil
ZIP-code: 65606-020