Objective: to describe the accessibility to the treatment of Pará patients diagnosed with leukemia to support nursing interventions. Method: exploratory and descriptive study with a quantitative approach, performed in the Chemotherapy Clinic of Ophir Loyola Hospital in the city of Belém/PA, Brazil. A form from April to July 2013 was used. For data analysis, descriptive statistics were used. The research project was approved by the Research Ethics Committee, under CAAE number 20486313.9.0000.5170. Results: profile of socially vulnerable participants, a fact that has worsened with the onset of the disease. Socioeconomic conditions have determined the possibilities of access and to health services goods or the absence influenced the evolution of the disease. Conclusion: nursing care to patients with leukemia need to be expanded, and the nurse has a responsibility to contribute to the health education of patients in services to meet the specific needs of each.

Descriptors: Primary Health Care; Nursing; Leukemia.

RESUMO

Objetivo: descrever a acessibilidade ao tratamento de pacientes paraenses diagnosticados com leucemia para subsidiar as intervenções de enfermagem. Método: estudo exploratório e descritivo, com abordagem quantitativa, realizado no Ambulatório de Quimioterapia do Hospital Ophir Loyola, no município de Belém/PA, Brasil. Foi utilizado um formulário no período de abril a julho de 2013. Para análise dos dados, empregou-se a estatística descritiva. O projeto de pesquisa foi aprovado pelo Comitê de Ética em Pesquisa, sob o CAAE nº 20486313.9.0000.5170. Resultados: perfil de participantes socialmente vulneráveis, fato que se agravou com o aparecimento da doença. As condições socioeconômicas determinaram as possibilidades de acesso aos serviços e bens de saúde ou a ausência influenciou a evolução da doença. Conclusão: os cuidados de enfermagem aos pacientes com leucemia precisam ser ampliados, e o enfermeiro tem a responsabilidade de contribuir para a educação em saúde desses pacientes nos serviços de forma a atender às especificidades de cada um. Descritores: Atenção Primária à Saúde; Enfermagem; Leucemia.
The Primary Health Care (PHC) is the “gateway” to the Unified Health System (SUS), which requires high solvability on the fundamental demands for protection and prevention of health of the population, and must have diagnostic sensitivity to give the appropriate referrals to the welfare system.1

The work of nurses must follow the transformations of a healing and hospital-centered approach to promotion and prevention to health, ensuring the participation of the multidisciplinary health team and the population in actions of the PHC, which requires knowledge of Social and Health Sciences.2 In this context, the nurse plays a fundamental role in rehabilitation, health education, promotion and prevention of health in the broadest concept and collective actions, which may aid in the distribution of demand from patients in health services, ensuring efficient accessibility and optimization of SUS resources.

In Brazil, studies on accessibility to SUS are lacking, focusing on the macro-sociological aspects and not deepen the issues about the socio-economic and organizational context of health services, as well as its effectiveness. Thus, the complexity of light and dialogic technology is not seen, in which people seek to solve their health problems.3,4

Cancer appears as a major epidemiological problem in Brazil constituting the second cause of death by a disease, which characterizes the need for early detection in public health system, decreasing the spending of public funds to diagnosis and cancer treatment.5

Among the most aggressive cancers, there is the group of malignancies affecting the bone marrow and lymphatic tissue, including a high incidence in children (leukemia). The National Cancer Institute José de Alencar Gomes da Silva estimates for 2014/2015, in Brazil, 576,000 new cases, with estimated risk of 5.20 new cases per 100,000 men and 4.25 for each 100,000 women. About leukemia, it is estimated 9370 new cases and 5,050 in men and 4,320 in women. It is important to highlight that leukemia is the fifth most common cancer in men in the North, with 530 new cases that occur in this region and 250 in the state of Pará, with crude incidence rate in the region of 3.57 for men and 2, 81 for women, considering the proportion of 100,000.6

The Hospital Cancer Record of the reference hospital to treat cancer in Pará pointed out that, among the ten most common histological types, in patients from 0 to 19 years old, there are leukemia, myeloproliferative diseases, and myeloblastic diseases, affecting 41.39 % of women and 46.82% of men. Similarly, on the location of the primary tumor, again diseases of the hematopoietic and endothelial reticulum system are the first, with 48.90% of women and 54.55% of men in the age group of 0-19 years old. This concern is also among adults since among the ten most frequent cancers, tumors of the hematopoietic system and endothelial reticulum constitute the fifth most frequent cancer in women and third in men.7

Considering the complexity of resources that society has for the diagnosis and cancer treatment and based on the epidemiological importance of leukemia in Pará, it has opted for the study of leukemia accessibility patients because the determinants of prognosis depend on the early diagnosis. Thus, the following question is raised up: what is the accessibility of patients with leukemia to perform the treatment in Pará?

**OBJECTIVE**

- To describe the accessibility to the treatment of patients diagnosed with leukemia in Pará to support nursing interventions.

**METHODOLOGY**

Descriptive exploratory study with a quantitative approach and convenience sample. Data collection took place between April to July 2013, through a form composed of sociodemographic profile and questions relating to the accessibility of patients with leukemia to Ophir Loyola Hospital Chemotherapy Clinic (HOL), located in Belém (Pará), reference to the diagnosis and treatment of cancer of the North, whose average attendance is 370 cancer patients, and 100 having a diagnosis of leukemia.

The study inclusion criteria were: patients older than 18 years old being treated for cancer chemotherapy, with orientation in time and space. The final sample comprised 50 patients, which fully met the inclusion criteria. According to their available time, there was data collection. Data analysis was carried out through descriptive statistics.

The project was approved by the Ethics Committee of the Pará State Nursing University “Barata Magalhães” (Opinion CAAE number: 20486313.9.0000.5170).
RESULTS

Of 100 patients with leukemia treated at the clinic of HOL, 50 participated in the study, 28 (56%) men and 22 (44%) women. The age range of patients interviewed were distributed as follows: 28 subjects of 18-34 years old (56%); 10 patients of 35-49 years old (20%); 9 patients of 50-59 years old (18%) and three patients over 60 years old (6%).

Concerning the education of patients, 7 (14%) were illiterate, 18 (36%) had an incomplete primary education or full, 19 (38%) had an incomplete secondary education or complete, and six (12%) had incomplete or complete higher education. As the occupation of the patients, there were students, professionals, self-employed and retired, with a prevalence of 24 professionals (48%), 13 students (26%), 10 (20%) self-employed and 3 (6%) retirees. On the family income, 44 (88%) had an average income of 1-2 times the minimum wage and six (12%) gained over three times the minimum wage. Also, 27 (54%) patients are from the interior of Pará, 22 (44%) of the metropolitan area of Belém and 1 (2%) of another State of the country. In the color/race, 28 (56%) were brown declared, 13 (26%) black and 9 (18%) white, data that corroborate the data of the 2012 census.

As for the history of cancer in the family, 44 (88%) denied it and six (12%) reported a case in the family. It was shown a higher incidence of myeloid or chronic lymphocytic, with 32 (64%) patients, followed by nine (18%) patients with myeloid leukemia or acute lymphocytic.

With regard to symptoms, the most frequent complaints of these patients, since the onset of the disease were: strain 26 (52%), fever/weight loss 32 (65.4%), headache 15 (30%) anemia/pallor 14 (27%), and other complaints 22 (44%).

The accessibility of patients occurred in the hospital, 20 patients (40%) in primary care (Family Health Program, Municipal Health Units and Basic Health Units), 17 patients (34%), and in private schools, 13 patients (26%).

Structural and logistical factors have conditioned the second demand for private services, which occurred as a result of the need for examinations out of the state, delay in delivery of test results, as well as delay of hospital vacancies, difficulty in establishing the diagnosis of leukemia, initial treatments for anemia, hepatitis, flu or virus, leishmaniasis and palliative treatments with painkillers and anti-inflammatory.

Another important challenge is the Pará State extension for a referral to specialized institutions, resulting in a maximum time of three months diagnosed with leukemia, with specialized treatments for other conditions (cardiac and psychiatric). On the other hand, when the professional suspected of leukemia from the clinical and blood test, 12 (24%) patients were referred to the Center for Hematology and Pará Hematology Foundation (HEMOPA) and Ophir Loyola Hospital (HOL).

Although the patients have been referred directly to the hospital, they touched with the delay in receiving the results of the myelogram and often resorted to a private service or were transferred to a third hospital to wait for a vacancy of a bed in HOL, with a recorded maximum time of eight months. For eight patients (16%), there was the correct diagnosis of the disease, and they performed treatments for flu, hepatitis, anemia, leishmaniasis, and virus infection. This group took the maximum time of six months for diagnostic confirmation.

Regarding the role of nursing in the process of accessibility of patients to treatment, it became clear that 14 (28%) patients reported on the work of nurses in the Family Health Program, Municipal Health Units, and Units Basic Health. The nurse conducts health education about the tests, feeding and care of personal hygiene and the follow-up to continue the treatment. While the Ophir Loyola Hospital, the clinic and outpatient nurses guide on: chemotherapy and adverse effects, nutrition, outpatient treatment, laboratory tests and personal hygiene and home.

It is noteworthy that the interaction between work and family is essential for the development of educational interventions, both the nurse, and other professionals. This subsidizes a professional support able to meet the needs of people and enables humanized care.

DISCUSSION

Data from this study corroborate the estimate of INCA (2014/2015) that points to cases of leukemia, with the predominance of the male population in the state of Pará and the country as a whole, reflecting an estimated risk of 5 new cases per 100 thousand men and 4 per 100 thousand women.

In this study, the age group of predominantly patients with leukemia was 18 to 34 years old, totaling 28 (56%), that is the productive population of the society; 18 (36%) had incomplete or complete elementary
Accessibility of people with leukemia... 

Despite the difficulties faced by patients in accessing referral hospital, most could get to HOL. As a rule, they had immediate care and has started treatment, either in hematology clinic or even in regular consultations with hematologists at the clinic, except when all beds were occupied, pending results of any examination or the patient was in advanced disease and needed to stabilize his picture receiving drugs from the first chemotherapy cycle. This agility in the hospital network has also been ensured due to the new legislation that sets a deadline of 60 days for early treatment of cancer by SUS: Law 12,732/12, enacted on 05/23/2013. 12 

Considering many patients come from the interior of the State of Pará, where health indicators are critical, and considering the displacement of current difficulties in the daily life of Pará, either land or waterway, the demand for health care of these patients is much harder. Therefore, it is often with the help of family and neighbors that these patients bear their displacement, and their caregiver, to the capital, regularly. These difficulties are present throughout the search for health care, leading some patients to leave the public system in search of solving their problems in the private sector when they can afford.

Primary care is the SUS input way, having the function to carry out the stratification of risks, distributing all health needs of a population, and forward each situation to the appropriate level of complexity. Healthcare levels are fundamental to the rational use of resources and to establish the management focus of loved governance of Health Care Networks 13 however, for this to happen, it is necessary that the professional primary care is quite cautious that in his clinic there are diagnostic sensitivity and meet health services to refer patients appropriately, because, as we have seen, the main complaints of leukemia are simple and do not characterize an emergency, at first glance, but the association of one of those complaints with other findings and good epidemiological investigation of the case avoid misdiagnosis. 

Another important discussion that the study urges us to do is on the Health Care Networks (RAS) as an integrated model, organized in points of attention to provide a continuous and comprehensive care to the population, and thus improving the quality of service making rational use of SUS resources to replace the current fragmented and hierarchical model. However, to do this, it is necessary to always rescue the principles of SUS and the Public Health Reform, in defense
of a public SUS, by understanding it as a right that cannot be at the mercy and be directed by market logic, so that do not lose the essence of this system, still under construction.

On the other hand, this reality remains somewhat distant than we found in the study. It still prevails the hegemonic model centered on the hospital as a synonym for health, an attention model to health facing attention to acute events, sported model the population (great victim), for health professionals, politicians and managers, who often given the capitalist logic of a neoliberal country, prioritizing investments in this sector just as seen in the following statement:

(...) A strategic sector for the business of producing industrial enterprises of inputs, construction contractors, advertising agencies, consulting services and training of human resources, insurance companies, banks and others. 14

They are sectors target of pressure to consumption, regardless of whether or not the needs. This logic and low investment in primary care make this sphere not socially relevant, often by precarious level it is and the lack of resolution to the problems of the population. When it comes to the state, the situation is more critical.

Another question we must consider is the fact that the gateway to the SUS, PHC, there is no operation on weekends and holidays, and all the demands of those days resort to an emergency care hospital. This context reflects, in large part, the predominance of demand from the population, the hospitals, bringing significant economic repercussions for the health system of the country.

The unfortunate impoverishment of Primary Health Care in the four corners of the state is not giving answers to the basic demands of its astringent population. Therefore, there is no diagnostic sensitivity to propose appropriate referrals within the health system. Because of this process, there is the inefficiency and lack of social reference in the PHC. The study showed the prevalence of patients who make the hospital the gateway to the SUS when it should be the PHC, reflecting a poor use of resources for public health, which end up spending more if there were protection and prevention health.

The results of this study also point to a gap in the nursing care of the patient with leukemia, as nursing has little interaction with these patients on an outpatient basis. To deepen this type of study could be useful for professionals working in outpatient clinics and hospitals, improving the quality of service and benefiting the public service, and providing concrete benefits that can contribute to the scientific development and changes in public policy health care of patients with this disease.

To try to meet the ever increasing demands in the oncology nursing education in the country, the National Cancer Institute (INCA, 2008) 15 and the Ministry of Health published the third edition of the textbook titled Nursing Actions for Cancer Control. In this book, we also find that gap related to nursing and hematological cancers, because this book discusses with the main wealth nursing actions in several types of cancer, but only tumor cancers. Although leukemia is not statistically so worrying in Brazil, it is among the top five cancers that most affect the population in the North. Therefore, the study of nursing care for patients with leukemia, here, is of fundamental relevance to public health.

CONCLUSION

Analyzing the study variables, we found that a large proportion of patients is men that are in the economically active age group, come from the state and live in a socially vulnerable situation that is aggravated by the disease. The disease not only interferes with the biological aspect. Its economic impact changes the family dynamics and changes roles within the group, because the patients reduce their work activities and their studies, or even lose their jobs. These conditions will interfere with the possibility of access to health services and hence on how the patient performs the search for health care.

The two main obstacles for patients with leukemia happen, respectively, before the diagnosis and after diagnosis. Before the diagnosis, a group of patients does not seek health services to perform the first symptoms, and the other portion is routed incorrectly in the health system after a mistaken diagnosis. The other obstacle happens after the diagnosis because the natural tendency is that patients start treatment immediately in the reference hospital, but many patients have to wait for a reference hospital bed or at another hospital while awaiting test results carried out of the State.

This problem, although for a short period, exposes patients in other hospitals that do not have the profile and the care of a cancer hospital as the emergency room, as well as delays the initiation of appropriate treatment. The services of this scope, at all levels of complexity, have an inefficiency that has its origin in primary care, where lack diagnostic sensitivity for early detection of the problem
and not appropriate referrals for the better distribution of patient requests, something that would be able to ensure efficient access to hospital service that is burdened with the SUS having huge expenses with chemotherapy and complex hospital procedures.

The result of this study gives us a responsibility to conduct further studies on accessibility, as there are few studies, but they are extremely important to evaluate the effectiveness of health services and the consolidation of SUS, especially when it comes to chronic diseases and neoplasms that grow with the demographic and epidemiological changes in Brazilian society, already shaping up as a public health problem in the coming years.

The nursing care to patients with leukemia need to be expanded further, as the nurse has a responsibility to contribute to health education, promotion and prevention to health, and distribute patients demand in the services to meet the specificities of each patient in primary health care.

REFERENCES


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