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17TH INTERNATIONAL CONFERENCE FOR
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WITH CML



EVALUATION OF NEEDS IN PATIENTS DIAGNOSED WITH CML IN COLOMBIA

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Advocacy Session #3
Best practice in patient advocacy
#CMLHZ19

Background

In Colombia there are no records of recent research studies with CML patients, who know their experience with the health system.

The interest and purpose of the Funcolombiana to develop this research study is the description of the health itineraries, as well as the main barriers to access the health system, since the onset of the symptoms of the disease.

Likewise, to describe the needs for access to health services, according to the health affiliation regime, in order to identify possible inequalities in access to services, for the LMC patients.



Implementation

- ❖ A transversal descriptive study was carried out, using the information gathering techniques, the structured interview and the focal group. The study was carried out with Colombian patients, diagnosed with CML, linked to the Colombian Leukemia and Lymphoma Foundation.
- ❖ Inclusion criteria for the study were: Patients in active treatment with some tyrosine kinase inhibitor (Imatinib, Nilotinib, Dasatinib, Ponatinib, Bosutinib), patients in the subsidized or contributory health regime and patients diagnosed more than one (1) year ago.
- ❖ The analysis was performed taking two timelines with the facts of the study: The first one from the onset of the symptoms of the disease, until the beginning of the treatment. And a second timeline with the facts related to access to treatment, monitoring and control of the disease.
- ❖ **Challenges and successes in implementing the project:** The publication of the results: Newspapers, congresses, journals.

Result and Impact

165 patients were recruited for the study:
56% females - 44% males

Receiving treatment in **14** Cities around the country

Health Care affiliation:

68% Contributory regime

32% Subsidized regime

Time with the diagnosis:

1 – 5 years: 29%

6 – 10 years: 39%

More than 10 years: 32%

Current therapy

Imatinib - 30%

Nilotinib - 38%

Dasatinib - 28%

Bosutinib - 2%

Ponatinib - 2%

Result and Impact

25% were misdiagnosed

Suggesting poor knowledge of the pathology and difficulties for making a diagnosis.

The most frequent misdiagnosis were:

- ❖ Bacterial infection
- ❖ Stress

62% suspended the medication for non-medical reasons:

- ❖ 79% contributive regimen
- ❖ 91% subsidized regimen

***Main reason: Delay in the delivery of the medicine.**

103 (62%) lost response to the medication and 18% attributed it to the lack of medication.

For the question about access to the medication at the time of the survey: 30% received the medication immediately. **38%** in the first two weeks after the formulation and authorization. **12%** three to four weeks. **3%** more than one month. **18%** had not received it.

Result and Impact

Access to Hematology

52% were referred to hematologist immediately, or within 15 days. (56% contributory – 42% subsidized).

28% between 3 and 4 weeks (21% contributory- 42% subsidized).

20% more than 2 months reaching even 6 months the wait. (23% contributory - 16% subsidized).



Result and Impact

About access to medication:

27% of patients considered the delay in delivery of medicines, as the main problem for patients with CML in Colombia (19% contributory – 44% subsidized).

10% expressed as main difficulty the delay in allocation of medical appointments.

5% express as difficulty, the EPS (Health Services Provider) administrative procedures.

10% referred other difficulties.

43% No difficulty.

The present study shows a greater vulnerability for patients affiliated to the subsidized regime, mainly in terms of access to the specialist for the confirmation of their diagnosis, as well as timely access to medicines, evidencing inequity in care according to the regimen of affiliation.

Conclusion and recommendation

- ❖ Although patients with LMC in Colombia do not show explicit denials of procedures or medicines, if they refer to frequent delays in authorizations, as well as in the provision of medicines, which occur more in the subsidized regimen, which affects the timeliness in their treatment and therefore the proper control of their disease. A clear example of these unjustified delays in which there has been no denial is that 24.2% of patients who reported NOT having received all the boxes of medication for their treatment, corresponding to a period of 8 months.
- ❖ **I believe that other advocates can take advantage of their databases and promote this type of research studies, as well as being useful to create awareness campaigns and proposals to the government, to improve the conditions of patient care.**

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