



# Fundación Colombiana de Leucemia y Linfoma

## Evaluation of emotional, social and access needs of patients diagnosed with chronic myeloid leukemia in Colombia.

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Adherence, Persistence, & Compliance, Disease Management, Health Disparities & Equity, Survey Methods

### OBJECTIVES

- Describe the main emotional, social and health care needs of patients diagnosed with Chronic Myeloid Leukemia in Colombia.
- Identify itineraries in health, as well as the main barriers to access to the system that a patient with CML faces, since the onset of the symptoms of the disease.
- Describe the needs for access to health services, according to the health affiliation regime.

### METHODS

A transversal descriptive study was carried out, using the information gathering techniques, like the structured interview through a telephone survey and the focus group.

### RESULTS

The research included a sample of 165 patients, 56% women and 44% men, with an average age of 51 years, 46% being active.

On the itinerary of the process of diagnosis of the patient with CML, it was found that 19% of patients reported not having presented symptoms, 25% of patients received other diagnosis, the most frequent being: bacterial infection, stress and anemia.

69% of patients agreed to the diagnosis after 2 months after the presence of symptoms. In terms of access to the hematology specialist, although 52% agreed immediately or maximum in two weeks, 48% took more than three weeks and up to 6 months or more, to access the specialist. This delay was greater for the poorest and most vulnerable patients, those affiliated to the subsidized EPSs (58% versus 44% in the contributory EPSs).

Once treatment began, it was found that 102 patients reported having suspended the medication for non-medical reasons, among which the delay in the delivery of medication predominated (79% contributive regimen versus 91% subsidized regimen), 103 patients reported having lost response to the medication and 18% attributed it to the lack of medication.

About time of delivery of medication, it was found that there is a greater opportunity to deliver the medicines covered by the Health Benefits Plan, in the contributory scheme than in the subsidized one. Likewise, there is a greater opportunity for the contributory EPSs in terms of access to medicines outside the benefit plan (68,4 contributory versus 52,5 subsidized, access to their medication within 2 weeks or less).

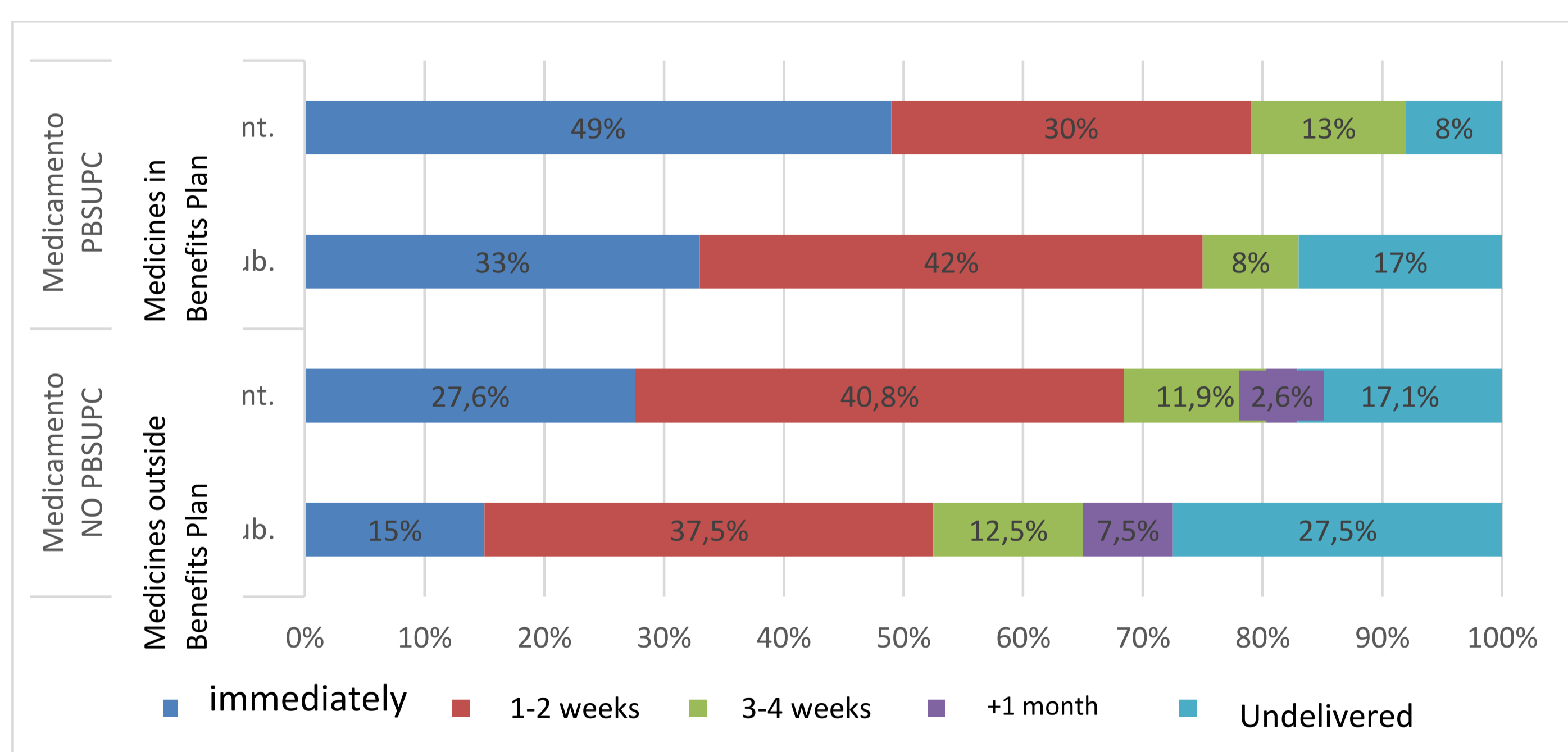


Fig 1. Time between medicine authorization and delivery by affiliation regime and type of medicine

It is concerned that 14% of the patients in the subsidized regime and 9% in the contributory regime have only received 5/8, 4/8, 3/8 and even less than 3 boxes of medication during 8 months. In addition to the delay in the delivery of medicines, other access barriers such as the change in IPS by the EPS were also evident in 46% of the patients.

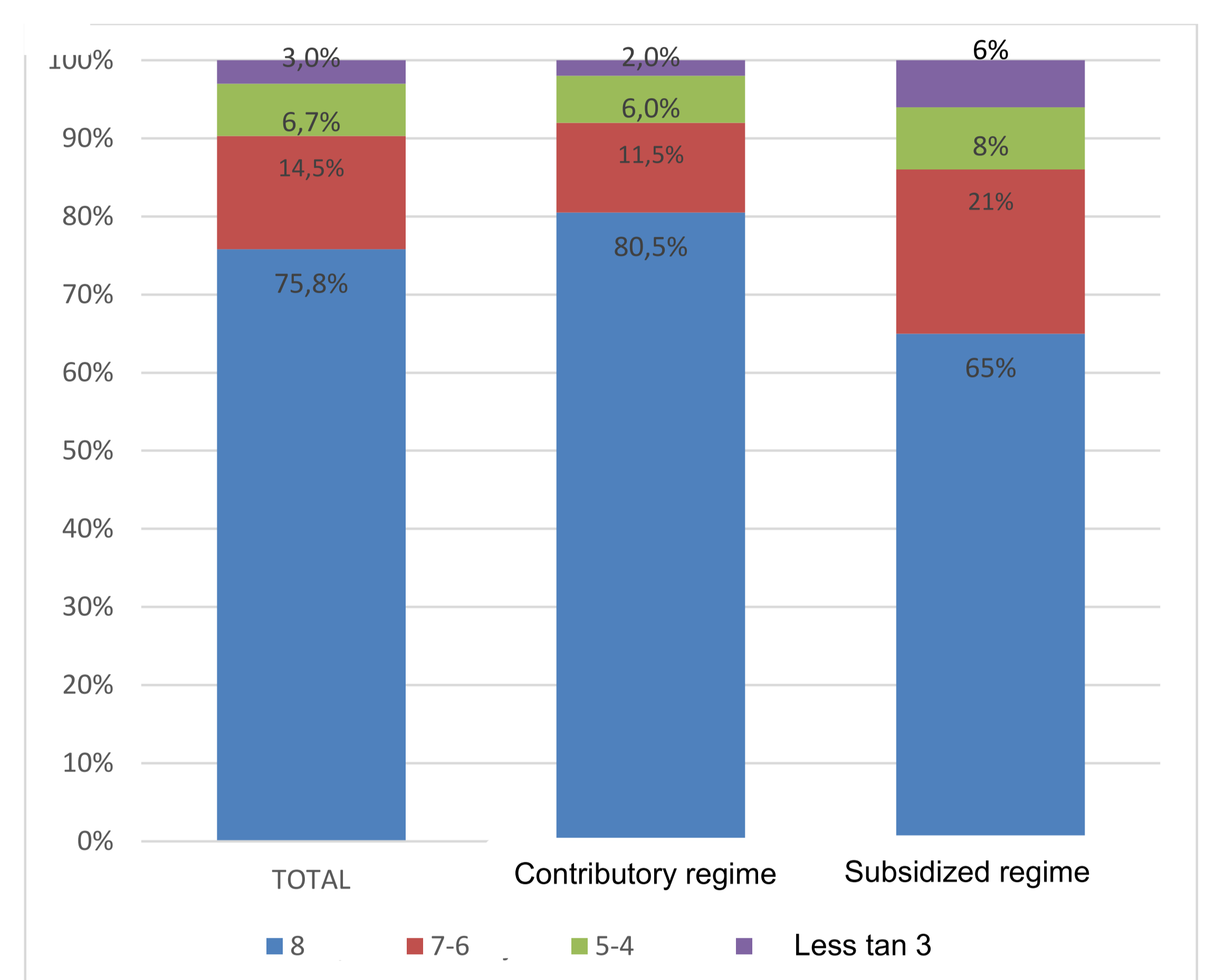


Fig 2. Number of medicine's boxes received in 2018

63% had to institute a guardianship action for the claim of their health rights, more frequent for the subsidized regime; and 27% of patients considered the delay in delivery of medicines, as the main problem for patients with CML in Colombia.

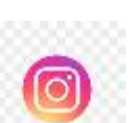
In terms of emotional needs, 59% of patients expressed a predominance of positive emotions today. 61% expressed their agreement that they feel strong and able to overcome adversity.

### CONCLUSIONS

Although patients with CML 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 EPSs, which affects the timeliness in their treatment and therefore the proper control of their disease.

The present research shows a greater vulnerability for patients affiliated to the subsidized EPSs, 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.

At an emotional and social level, it is necessary to guarantee psychological support for the patient and his family, at the moment of receiving the diagnosis. After this first phase, patients show strength and rapid adaptation to their new health condition, so that positive feelings and gratitude with life prevail.

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