

# Focus Group with People Living with Thalassemia (Paraná, Brazil)



**1<sup>ST</sup> PAN AMERICAN CONFERENCE**  
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THALASSAEMIA  
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FEDERATION

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## AFFILIATIONS

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## Background

Thalassemia care within different healthcare systems reveals structural and service-related challenges that directly affect its quality. At Hemepar, in Curitiba (Paraná), individuals living with thalassemia shared their experiences and the limitations they face in their care.

## Objetive

The aim of this research was to give voice to the experiences and perceptions of patients with thalassemia regarding their care journey, access to treatment, social and emotional impacts, and future expectations.

## Methods

A focus group was conducted with nine patients (including minors accompanied by family members), in a roundtable format, moderated by a representative from ABRASTA (Brazilian Thalassemia Association), following a structured discussion guide.



Participants of the focus group in Curitiba (Paraná, Brazil)  
Source: Abrasta

## Results

Some participants reported delays in early diagnosis due to healthcare professionals’ lack of knowledge about the disease, as well as difficulties accessing exams, medication, and transportation—often requiring legal action or formal complaints to ensure their rights. Participants also described experiences of prejudice, bullying, and emotional challenges during childhood and adolescence. Feelings of low self-esteem and fear about the future were common. The word most frequently used to describe the disease was “overcoming.” Many reported a lack of adequate information about thalassemia in public health services.

## Discussion and Conclusion

The experiences shared reveal that the impact of thalassemia goes beyond biomedical aspects. The disease directly influences daily life, social relationships, education, and employment. Actively listening to patients highlighted the importance of supportive policies, psychological assistance, and effective communication. Despite the challenges, many remain hopeful and engaged.