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Title

Lived experience of individuals with thalassemia in Eastern India

Priority 1 (Research Category)

Allergy/Immunology

Presenters

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Abstract

Introduction: Thalassemia, an inherited hemoglobinopathy, is the most common blood disorder in West Bengal, Eastern India. However, poor treatment compliance among thalassemia patients remains a challenge, leading to less successful outcomes and negative perceptions of the disease. The study aimed to explore the lived experiences of thalassemia patients in Eastern India and examined how social relationships impacted treatment adherence.

Methods: The authors employed a qualitative research design to study thalassemic patients receiving outpatient treatment at a suburban hospital clinic in Kolkata, India. Eleven adult Bengali-speaking patients were randomly selected to participate in in-person interviews, where they shared their lived experiences with the disease. Interview responses were transcribed and translated verbatim from Bengali to English. The authors, both individually and collectively, utilized an immersion-crystallization approach to analyze the content of the interviews.

Results: Among the 11 respondents, 54.6% were males and 45.4% were females. Data analysis revealed five themes for positive experiences: regular treatment seeking, strong family and community support, positive family attitudes, trust in healthcare providers, and a positive outlook. Negative experiences included stigma, relationship challenges, childhood trauma, parental stress, and inadequate healthcare facilities.

Conclusion: The findings indicate that negative life experiences impact thalassemia patients individually and socially, while strong family and community support positively influence treatment and wellbeing. In the future, we aim to conduct a similar study in the United States to examine how the experiences of thalassemia patients, particularly refugees and immigrants from various countries, differ and how these experiences affect their treatment-seeking behavior and adherence.

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