

Cascade Screening for Beta-Thalassemia in Pakistan: Relatives' Experiences of a Decision Support Intervention in Routine Practice

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Abstract : Low uptake of cascade screening for β -Thalassaemia Major (β -TM) in the 'Punjab Thalassaemia Prevention Project' (PTPP) in Pakistan led to the development of a 'decision support intervention for relatives' (DeSIRE). This paper presents the experiences of relatives of children with β -TM of the DeSIRE following its use by PTPP field officers in routine clinical practice. Fifty-four semi-structured qualitative interviews were conducted (April to June 2021) with relatives in seven cities in the Punjab province (Lahore, Sheikhupura, Nankana Sahab, Kasur, Gujranwala, Multan, and Faisalabad). Thematic analysis shows that participants were satisfied with the content of the DeSIRE and its delivery by the field officers in a family meeting. They understood the main purpose of the DeSIRE was to improve their knowledge of β -TM and its inheritance, to enable them to make decisions about thalassemia carrier testing, particularly before marriage. While participants raised concerns about the stigma of testing positive, they believed the DeSIRE was an appropriate intervention, which supported relatives to make informed decisions. Our findings show the DeSIRE is appropriate for use by healthcare professionals in routine practice in a low-middle income country and has the potential to facilitate shared decision-making about cascade screening for thalassemia. Further research is needed to prove the efficacy of the DeSIRE.

Keywords : thalassemia, Pakistan, cascade screening, decision support

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