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GROWING UP WITH THE FAMILIES OF B-THALASSAEMIA MAJOR USING AN ACCELERATED LONGITUDINAL DESIGN

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Introduction: It is difficult for a single investigator to study the psychosocial changes that occur over the life span of an individual affected with a chronic illness like β -thalassaemia major. Therefore, a developmental epidemiological perspective is required to understand the chain of events and problems of psychological nature.

Aim and objectives: We aimed to construct the picture of developmental epidemiology for psychosocial aspects in families of β -thalassaemia major patients attending a tertiary care hospital in north India.

Methods: The accelerated longitudinal design was used. The sample consisted of 100 children with β -thalassaemia and their 150 parents, both groups were subdivided further so that each group represented the continuum of longitudinal course.

Results: Overall 54 per cent of children had significant psychopathology. Within the parents groups, 10 per cent had adjustment disorder, 33.3 per cent depressive disorder, and 10 per cent had anxiety disorder and 11 per cent somatoform disorder. There was significant difference only in the domain of psychological health in all the three groups of parents with respect to the quality of life. Among children, quality of life improved with their progression of illness.

Conclusions: Growing up with β -thalassaemic family was analyzed. Such a design can test the hypothesized aetiological or developmental function of a targeted risk factor within a developmental path and may be used in studying the psychological impact of even other chronic illnesses over the life span of an individual for conceptual and holistic understanding.