

An Exploration of Mothers' Experience of Children with Thalassaemia Depending on Iron Chelation Therapy in Thalassaemia Centre of Provincial General Hospital Badulla

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Thalassaemia is a genetic disorder characterized by insufficient production of haemoglobin. Regular blood transfusions are required for the survival of these children. Hence, this study aimed to explore the mothers' experiences of children with Thalassaemia depending on Iron Chelation Therapy in the Thalassaemia Centre of Provincial General Hospital Badulla (PGH-Badulla). In this phenomenological study, 12 mothers who are caring for their children (<12 years old) with Thalassaemia depending on Iron Chelation Therapy in the Thalassaemia Centre of PGH-Badulla, were purposefully selected. Face-to-face in-depth interviews were performed using a semi-structured interview guide. Data were analysed using Marshall and Rossman's thematic analysis method. Ethical approval was obtained from the Ethics Review Committee, the National Hospital Sri Lanka. Mothers' experiences were classified into four main themes namely "fear and worry", "good service for the cure", "support to save the children" and "neglect others and self-care". Mothers' worried about financial difficulties, caring tension, and uncertainty about the child's future. Hence, they expect good service for the cure of their children through effective treatments, care from the hospital staff, and avenues for more health information. Further, these mothers neglect self-care, family, and social relationships due to this sacrifice to look after their children with Thalassaemia. Caring process of children with thalassaemia has affected negatively on several aspects of mothers' life including psychological, physical, and socio-economic difficulties. Assistance from family, healthcare providers, government, and voluntary organizations is required for mothers to overcome these burdening issues.

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