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## Perceived challenges of mothers having a child with thalassemia major: A phenomenological study

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Thalassemia is a genetic blood disorder that requires a life-long treatment of blood transfusion and chelating drugs. It poses a range of stressors and challenges for patients, their families, and health care team. Mothers are the primary caregivers and therefore, understanding their perceptions of having a child with thalassemia is very important. This study aimed to explore challenges of having a child with thalassemia major as perceived by Jordanian mothers. A descriptive phenomenological approach was used. Twenty three Jordanian mothers were selected purposefully from two major thalassemia treatment clinics in Jordan to participate in this study. Semi-structured, face-to-face interviews were used to obtain the participants' perspectives. Interview sessions were transcribed verbatim, and translated from Arabic to English. Data were analyzed using Colaizzi's process of descriptive phenomenology. The study revealed that thalassemia has a significant impact on mothers' lives. Many forms of challenges associated with rearing children with thalassemia were illustrated using four major themes: "Psychosocial problems", "Financial problems", "Inadequate information", and "Disease consequences". Participants expressed their worries and fear resulting from the complications of the disease and its treatment. They voiced their needs for more information about the disease and managing the side effects of treatment. Therefore, nurses are advised to address the needs of mothers caring for children with thalassemia and to provide psychosocial support and sufficient information about the child's disease and its treatment.

### Biography

Ghada Mohammad Abu Shosha has completed her PhD in Pediatric Nursing from Jordan University in 2011. She is now an Assistant Professor of Nursing in the Faculty of Nursing at Zarqa University, Jordan. She had an expanded clinical experience in the area of pediatric intensive care unit and child health. She has published many articles in hematology and oncology disorders in children, focusing on children perspectives toward health care services and treatment facilities.

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