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The impact of illness perception and socio-clinico-demographic factors on perceived quality of life in children and adolescents with thalassemia intermedia

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Zeze Th Atwa¹, Wafaa Y Abdel Wahed²

1. Pediatric Department, Faculty of Medicine, Fayoum University Hospital, Fayoum University, Fayoum, Egypt.
2. Public Health and Community Medicine Department, Faculty of Medicine, Fayoum University, Fayoum, Egypt

Background/objectives: β -Thalassemia intermedia (β -TI) accounts for up to one-fourth of β -thalassemia patients. Evaluating and improving quality of life (QOL) should be a goal in β -TI follow-up and management strategies. Patients' perceptions of their illness and its treatment may impact their QOL. This study aimed to evaluate QOL and the factors that affect it in children with β -TI and to determine the impact of the patients' and their mothers' perceptions of the illness on patients' QOL.

Design/methods: This was a case-control study. A total of 143 children and adolescents (71 β -TI patients and 72 healthy controls) were enrolled. QOL, as perceived by the children and their mothers, was assessed using the Pediatric Quality of Life Inventory (PedsQL) 4.0 Generic Core Scale. Perceptions of the illness by the mothers and children were assessed using the Brief Illness Perceptions Questionnaire (Brief IPQ). The patients' clinical and sociodemographic data were extracted from their medical records. **Results:** The controls had higher QOL scores in nearly all domains ($P < 0.01$). The patients and mothers who had higher illness perception scores had better QOL scores ($P < 0.01$). Patient age and serum ferritin levels correlated negatively with QOL, while mean hemoglobin levels correlated positively. The use of hydroxyurea in treatment and high illness perception were independent predictors of better QOL. **Conclusion:** QOL is significantly affected in β -TI patients; maintaining a suitable hemoglobin level and standard levels of body iron are associated with better QOL. Patients' and their mothers' perceptions of the illness play an important role in QOL.

Keywords: illness perception; quality of life; thalassemia intermedia