The Experienced Problems of Mothers Having Children with Hydrocephalus: A Qualitative Study

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Abstract

Background: The children with hydrocephalus are treated acutely with a cerebrospinal fluid shunt. If hydrocephalus is untreated, it can lead to diffuse brain injury, mental and growth retardation. The development of hydrocephalus and its management present major challenges later in children and their parents’ life, requiring multidisciplinary care from pediatricians, neurosurgeons, nurses, rehabilitative therapists, and others.

Aims: This study was designed to evaluate the mothers’ problems that are experienced in the hydrocephalus treatment process.

Methods: It was used the focus group methodology and in-depth interviews for qualitative studies in the study. Interviews were performed with 15 mothers having children with hydrocephalus treated at the Neurosurgery Clinic from 2012 to 2013. Data was collected using a semi-structured questionnaire prepared by the researchers through screening. The questionnaire focused on the selection of the problems during hydrocephalus treatment process.

Results: In this study, the only nine of mothers were informed about the process of the disease. Mothers who were not informed about the disease and process stated that this disease can be treated and their children can recover. All mothers mostly experience transportation and financial problems during the treatment period starting with the diagnosis of hydrocephalus, and they have at least one complaint about their own health.

Conclusions: Mothers were more interested in problems to be experienced by themselves and their children in the near future and the physiological dimension of the disease. However, they were aware of their children’s future, home-care and special education needs.

Key words: Children, Hydrocephalus, Mothers, Problems, Turkey.