

Abstract

Title : Exploring the lived experiences of the parents of girls with multiple sclerosis in Ardabil

Objective: The lifestyle of parents and the home environment plays an important role in the various aspects of the life of children with neurological disorders. On the other hand, chronic illness in children causes more mental health risks for parents compared to other family members. Therefore, exploring the experiences of parents of girls with multiple sclerosis and presenting them to health care planners and managers can have a positive effect on the health of the community, because one of the pillars of health assessment of different communities is the psychological state of that society. Therefore, the purpose of this study was to explore the lived experiences of parents of girls with multiple sclerosis.

Methodology: This research was done by phenomenology method. The statistical population was parents of the girls' with multiple sclerosis who were the member of association of multiple sclerosis in Iran. Sampling continued until data saturation, and totally the data was saturated with 12 participants. Data were gathered using deep and semi-structured interviews, and analyzed by Colaizzi's method.

Result: Of the total number of transcripts, 450 codes were extracted. After several stages of analysis and integration of similar codes, 5 main concepts and 15 sub-concepts were generated including: distress (fear, discontent, waving future and mental engagement); cripple (desecration, depreciation); adaptation barriers (economic burden, problems of the process of treatment, and management of the others); reactions to the illness (ups and downs of diagnosis, denial, bargaining, concealment, resort and prayer, interpretation of the disease); and compromise with the disease (acceptance, hypothesis of the cause of the disease, satisfaction, mobilizing family, lifestyle changes, and learning the work).

Conclusion: The experiences of parents of girls suffering from multiple sclerosis, which in this study are mentioned as distress, cripple, adaptation barriers, reactions to disease, and compromise with the illness, shows that in addition to the mental dimension, the disease also affects the parental physical dimension and can lead to experiences that are new to them and may lead to confusion.

Keywords: MS, Phenomenology, Parents, Experiences, Colaizzi Analysis, Chronic illness