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Lived experiences of mothers caring for children with autism spectrum disorders: Caring model testing

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Introduction: Mothers as primary caregivers of children with autism spectrum disorders need professional support. Also, helping these mothers requires understanding of their lived experiences. Unfortunately, it is usually forgotten in the health care programs in Iran. However, the qualitative studies are important to understand lived experiences and mixed method approach is suggested to confirm the qualitative data.

Objectives: This study aims to uncover the lived experiences of mothers caring for children with autism spectrum disorders by testing the caring model.

Materials & Methods: The exploratory mixed method study was based on taxonomy model. Qualitative phase was conducted by phenomenological of hermeneutic on 18 cases of Iranian mothers of children with autism spectrum disorders in Mashhad. In this study, purposeful sampling was applied and semi-structured interviews for data collection were used. Data analysis was done with the interpretation methods of Diekelmann, Allen and Tanner. In quantitative phase, qualitative data were used in constructing the questioner of caring model. After determining reliability and validity, the questioner during a cross-sectional design on 150 samples of mothers were tested. Statistical Package for the Social Sciences (SPSS) version 18 was used for the analysis.

Results: First, 31 common meaning, 11 sub-themes, and four major themes: 1) spiritual journey, 2) mother or teacher, 3) taking care of special child, and 4) the child showed priority of life were emerged by interpretation of hermeneutic. Then, three essential structures as 1) wondering between what is and what will be 2) reflection on the failure in her struggle, and 3) helping her child is becoming all of the mother's life were formed. At the end the constitutive pattern was discovered: "taking care by mothers is being a mother" The themes were confirmed by testing model of caring by survey.

Conclusion: This research concluded that caring for the autistic children was a difficult responsibility. It led the meaning of mothers' lives to change. Mothers in this study believed taking care of autistic children to be a duty related to their job as mothers. They accept this job as a labor of love to make it possible to care for their children with all the challenges involved in this long journey.

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