

MOTHERS' AWARENESS AND EXPERIENCES OF HAVING A THALASSEMIC CHILD: A QUALITATIVE APPROACH

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Abstract

The purpose of this study was to understand the mothers' level of awareness regarding Thalassemia and their experiences of having a Thalassemic child. A total of (N=64) mothers were chosen as participants. Focus Group Discussion (FGD) was carried out. The purposive sampling was used in this study. Mothers rather than their affected children were chosen as participants because we trust that mothers can demonstrate the impact of Thalassemia on both their children and the family in a better way. Criteria include (1) parent of a child affected with Thalassemia, who requires blood transfusion support (2) child who is registered in one of these centers (i) The Children's Hospital & the Institute of Child Health Multan, Pakistan (ii) Fatimid Foundation Multan, (iii) Minhaj UI Quran Foundation Multan, (iv) Amina Blood Foundation Multan. A semi-structure focus group moderator's guide corresponding to the research questions was developed. To gain in-depth understanding, questions were divided in four major domains which were (i) Belief about child disease, (ii) Awareness and knowledge about Thalassemia, (iii) Thalassemia impact on child and family, and (iv) Prevention and future concerns. Coding and categorizing was carried out using QSR NVivo-7. Transcripts were thematically coded according to the research themes that emerged from the discussions, and the themes were further sorted into subthemes. This study was approved by the Medical Ethics Committees of each participated Thalassemic Centers. The finding of this study indicates significant impact of Thalassemia on patients and their families in terms of financial state, emotional well being and social activities. Mother's education level was very low about Thalassemia. Majority of the children's parents were cousins but they were not screened for Thalassemia before marriage and despite of the birth of Thalassemic child, they were unaware about prenatal diagnosis. The study highlights the need of implementing effective public educational programs and to make pre-marital screening compulsory for general public to reduce the prevalence rate of the disease. Moreover, additional facilities for premarital screening and counseling should be made accessible and available to general public.

Keywords: Mothers, Experiences, Thalassemia Child