

SOCIAL IMPACT OF THALASSEMIA MAJOR ON PATIENTS' FAMILIES

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ABSTRACT

The objectives of this study were to find out the social impact of Thalassemia major on patients' families; to describe the awareness among the parents regarding Thalassemia Major; the cost of treatment of Thalassemia Major and the sufferings it brings to the families; the social problems faced by patients' families. The study population consisted of the parents of Thalassemia major children, visited to the (i) Minhaj UL Quran (ii) Amina Blood Foundation (iii) Fatimid Blood Foundation Multan and (iv) Thalassemia / Hemophilia Centers of The Children's Hospital & the Institute of Child Health Multan. A sample of 500 respondents was drawn from the total population and structured interview was administrated. Data were analyzed and interpreted by using SPSS (Statistical Package for Social Sciences) 19.0 version software. A structured interview was conducted for data collection. Interview schedule was constructed after the detailed literature review and also accessing the situation of peripheries in District Multan. The interview discussed with two experts of Sociology and two senior doctors (>8 years' experience) working in the Thalassemia centers, Government and Private Health Institutions. It was revised to incorporate recommended improvements. Descriptive and inferential statistics were applied to analyze the data that includes: frequency, percent, mean, standard deviations, one way ANOVA and Pearson correlation. The study summarized that the health care providers should be encouraged to talk about Thalassemia as a public health problem in Pakistan and should enhance the public awareness to eliminate the Thalassemia in Pakistan.

Keywords: Impact, Thalassemia, Major, Patients' Families