Knowledge, attitude and practices (KAP) of the families of β-thalassaemia children in thalassaemia centers of Rawalpindi and Islamabad, Pakistan

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Abstract
The present study was designed to assess the Knowledge, Attitude and Practices (KAP) of the parents of β-thalassaemia children (410) selected from public (73.2%) and private (26.8%) thalassaemia centers of Rawalpindi-Islamabad. Qualitative and quantitative approaches were used to collect the data, which was analyzed by using SPSS. Majority of the respondents (70%) were rural young parents with no knowledge of thalassaemia before marriage. However, now 81.2% were aware about this. Majority of the respondents (89%) had the knowledge about premarital screening, 86.1% were opposed to intermarriages of carrier and 57% believed that if carrier got married then prenatal diagnosis or Chorionic villus sampling test is necessary. About 76.8% of the couples were screened and 42.2% had an experience of Chorionic villus sampling among which 20% abortions were reported. Overall 82% parents had received genetic counselling. The present study suggests that parent’s regular visits and genetic counseling at thalassaemia centers have played important role about awareness.

Keyword: KAP, β-thalassaemia, Thalassaemia children, Premarital screening

Introduction
Thalassaemia is a genetic inherited blood disorder, which can be simply defined as "the inability of the human body to produce sufficient amount of haemoglobin in red blood cell" thus resulting in severe anaemia.1 β-thalassaemia is one of the most common single-gene inherited condition in the world.2 Different studies demonstrate that almost 70,000 infants are born with β-thalassaemia worldwide each year, and 270 million people are carriers of haemoglobinopathies.3 Worldwide thalassaemia is a public health problem due to its high prevalence which is particularly common in the Mediterranean as well as in Southeast Asia, Africa and Middle East2 with reported rates ranging from 2 to 25%.4

It is an imperative cause of childhood ailment especially in South Asia.5

In Pakistan, thalassaemia is seen in almost all parts of the country and β-Thalassaemia is a major and most prevalent genetically transmitted blood disorder.6 Though there is no documentary figure available in Pakistan, however it is estimated that approximately 5000-9000 infants having β-thalassaemia are born every year. Studies on carrier rate of β-thalassaemia in general population has shown the average rate to be slightly over 5%.7,8 Study conducted at Civil Hospital, Karachi, documented that only 15% parents were aware of the nature of disease transmission and only 12% knew consanguinity as a risk factor for TM.9 Limited knowledge was also found in a research in Multan where 10(5%) respondents had a knowledge that thalassemia is an inherited disease and it comes from the parents, while majority 190(95%) were not aware.10 In a study in Karachi there was minimal ratio of awareness in common population as compared to medical students.11

The population of Rawalpindi and Islamabad is considered as heterogeneous and thalassemia centers of these cities cater patients from different regions of Pakistan particularly, Punjab, KPK, Gilgit Baktistan, AJK and Fata. The purpose of this study was to assess the gap in knowledge, attitude and practices (KAP) about β-thalassemia among the parents of β-thalassaemia children visiting thalassemia centers of Rawalpindi and Islamabad, Pakistan.

Methods and Results
This cross-sectional KAP survey was conducted with proportionate stratified random sampling technique in one each of public and private thalassaemia centers selected out of six thalassaemia centers (three public and three private) of Rawalpindi and Islamabad based on lottery method of sampling from March 2015 to August 2015. The survey was conducted at Thalassaemia Centre of SZABMU-Pakistan Institute of Medical Sciences (PIMS), Islamabad and Jamila Sultana Foundation, Rawalpindi. All parents of TM children coming to these centers were interviewed by using a questionnaire after verbal informed consent.

Parents of the patients with other blood disorders like alpha-thalassaemia, thalassaemia intermedia, aplastic

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anaemia and lymphoblastic leukaemia etc. were excluded. Data was analyzed statistically using SPSS software and results presented in the form of frequencies and percentages.

A total 410 families of β-thalassaemia patients were initially enrolled in this study among which, 300(73.2%) were from public and 110(26.8%) from private thalassaemia centres. There were 179(43.7%) fathers and 231 (56.3%) mothers who came with their children, age groups ranging from 20-60 years of age. There were 279(69%) families from the rural and 127(31%) from urban areas.

Regarding educational level of parents, 18.3% (75 out of 179) fathers and 32.9% (135 out of 231) mothers had no formal education. The distribution of disease among consanguineous marriages revealed that 268(65.4%) were cousins, 68(17.1 %) were from the same caste and 72(18.5%) were unrelated.

Parents knowledge on Beta thalassaemia is shown in detail in Table-1.

Majority of the parents, 274 (66.8%) had no knowledge of thalassaemia before the first affected child.

Similarly a wrong perception on the disorder that it was hereditary was shown by 333 (81.2%) participants. All the other questions in the questionnaire were answered in a similar manner showing a relative lack of understanding on the disorder.

Table 2 displays the attitude of the participants towards thalassaemia.

A large number of parents (259 (63.2%)) strongly agreed that there should be a legislation on pre-marital screening of the disorder to root it out.

Table-3 projects the opinion of the parents included in the study on the practices regarding the prevention of
It was encouraging to note that 77 percent of the parents 
opined that both husband and wife should be screened for 
thalassaemia.

The results of the questionnaire based study on the 
knowledge, attitude and practice towards thalassaemia 
revealed that there is a change of the parent's opinion 
towards the disorder after having a child diagnosed with 
thalassaemia.

**Discussions**

Thalassaemia is a disorder due to an autosomal 
inheritance. Its prevention depends on awareness, which 
is frequently contributed by the educational level of the 
parents. In the present study, the number of mothers with 
no formal education was higher than those of the fathers, 
with most parents having a low education level and poor 
knowledge about health management. However, 
educated parents were more proactive towards screening 
as compared to others. There is inadequate knowledge of 
accurate frequency and distribution of thalassaemia 
disorder in the developing countries.3

In the present study, it was observed that due to 
frequent visits of parents at thalassaemia centers, 
perception of families regarding thalassaemia as genetic 
and inherited disorder was found to be 81% and these 
results are in agreement with the previous studies in 
different cities of Pakistan. Majority had the knowledge
that TM in children is due to trait of thalassaemia minor in parents.\textsuperscript{9,11}

The present study also suggests that respondents have enough information regarding PMS, PND and genetic counselling. The families’ attitude toward PMS in the present study was very positive and they were in favour of PMS of each individual to prevent the general public from this disease. This is the key for eradication of thalassaemia from the society. A very optimistic attitude was noted towards termination of pregnancy in case of a defective foetus. Families had a positive attitude towards implementation of the legislation for PMS. Also a large majority of the women were in agreement for abortion being the treatment of choice for a defective foetus and most families agreed on the screening of children for thalassaemia.

In conclusion, the present study suggests that the parents’ knowledge, attitude and practices towards thalassaemia were limited before having their first affected child. However, due to regular visits and genetic counselling at thalassaemia centers they have information regarding PMS and PND, which is inadequate in the general public. In order to reduce the burden of thalassaemia in Pakistan there is need of education and awareness among carrier.

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\textbf{References}