SHORT REPORT

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

Aamir Shahzad,[1] Nazia Rafiq,[2] Ikram Ullah,[3] Muhammad Javaid Asad,[4] Muhammad Sheeraz Ahmad,[5] Usman Waheed[6]

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 East[2] 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 Baltistan, AJK and Fata. The purpose of thisstudy 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

[1-3]Department of Sociology, [4,5]Department of Biochemistry, PMAS-Arid Agriculture University Rawalpindi, [6]Safe Blood Transfusion Programme, Ministry of National Health Services, Government of Pakistan.

Correspondence: Aamir Shahzad. Email: c2aamir@yahoo.com

Table-1: Knowledge regarding Thalassaemia.

Knowledge	Response	Frequency (%)
Knowledge about thalassaemia before first child	Yes	136 (33.2%)
	No	274 (66.8%)
Perception	Don't know	57 (13.9%)
	A genetic/Inherited blood disorder	333 (81.2%)
	Infectious disease	11 (2.7%)
	Any other	9 (2.2%)
Reasons and risk factors of thalassaemia	Don't know	41 (10.0%)
	Family history disorder	266 (64.9%)
	Poor health of child at time of birth	7 (1.7%)
	GOD will	89 (21.7%)
	Any other	7 (1.7%)
Treatment options for thalassaemia	Don't know	11 (2.7%)
	Blood transfusion (BT)	92 (22.4%)
	Both (BT and Bone marrow transplant)	307 (74.9%)
Role of consanguinity in thalassaemia	Don't Know/Not necessary	70 (17.1%)
	Yes	214 (52.2%)
	No	126 (30.7%)
Knowledge about premarital screening	Yes	365 (89%)
	No	45 (11%)
Importance of premarital screening	No knowledge	45 (11.0%)
	Preventive measure to control thalassaemia	117 (28.5%)
	Easily detection of carrier	139 (33.9%)
	Easy decision for parent to get married with carrier	109 (26.6%)
Knowledge about prenatal diagnosis	Yes	362 (88.3%)
	No	48 (11.7%)
Knowledge blood transfusion to patient throughout life	Yes	405 (98.8%)
	No	5 (1.2%)
Knowledge about prevention of thalassaemia	Don't know	31 (7.6%)
	Genetic counselling	55 (13.4%)
	Premarital screening	292 (71.2%)
	Prenatal diagnosis	32 (7.8%)

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 thallasaemia.

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

Table-2: Attitude regarding Thalassaemia.

Attitude Responses	SA	A	UC	DA	SD
1. Intermarriage of thalassaemia carrier	4 (1.0%)	23(5.6%)	30 (7.3%)	172(42.0%)	181(44.1%)
2. Carrier couple have children	10(2.4%)	237(57.8%)	50(12.2%)	97(23.7%)	16(3.9%)
3. PMS is necessary for general public	169(41.2%)	223(54.4%)	13(3.2%)	2(0.5%)	3(0.7%)
4. Termination of pregnancy due to TM	159(38.8%)	200(48.8%)	36(8.8%)	10(2.4%)	5(1.2%)
5. Need of legislation of premarital screening	259(63.2%)	133(32.4%)	8(2.0%)	7(1.7%)	3(0.7%)

SA = Strongly agree, A= Agree, UC = Uncertain, DA= Disagree, SA= Strongly Disagree.

Table-3: Practices regarding Thalassaemia.

Practices	Response	Frequency (%)
Personal practices of Spouse for test of thalassaemia	Yes, both (Wife and Husband)	315(76.8%)
	Yes (Only Husband)	11(2.7%)
	Yes (Only Wife)	40(9.8%)
	Not tested	44(10.7%)
Practices regarding CVS test	Yes	173(42.2%)
	No	237(57.8%)
Practice of abortion due to positive CVS	Yes	82(47.40%)
	No	91(52.60%)
Practice regarding other children screening for thalassaemia	Yes	367(89.5%)
	No	43(10.5%)
Practices regarding motivation of other for screening	Yes	357(87.1%)
	No	53(12.9%)
Wish for more children although children is sick	Yes	157(38.3%)
	No	238(58.0%)
	Don't Know	15(3.7%)
Child's disease known to the relatives	Yes	403(98.3%)
	No	7(1.7%)
Practice of sharing food with child	Yes	388(94.6%)
	No	22(5.4%)
Practice regarding rituals believes	Yes	224(54.6%)
	No	186(45.4%)
Received genetic counselling	Yes	338(82.4%)
	No	72(17.6%)

CVS: Choronic villus sampling.

thalassaemia.

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 thallasaemia.

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.[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 counseling 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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