

## ORIGINAL ARTICLE

**Awareness and Perceptions Regarding thalassemia Major and Premarital Screening in General Public of Cantonment areas of Rawalpindi**Ifat Noor<sup>1</sup>, Rukshana Roshan<sup>2</sup>, Rehama Gilani<sup>3</sup>**ABSTRACT**

**Objective:** To assess awareness and perception of general public regarding thalassemia and premarital screening and determine the association of various socio demographic variables with awareness of public.

**Study Design:** This was a descriptive cross-sectional study.

**Place and Duration of Study:** The study was conducted at Rawalpindi cantonment areas from 1<sup>st</sup> June 2017 to 20<sup>th</sup> December 2017.

**Materials and Methods:** This study was conducted among 200 people in 20 to 60 years age group, residing in different settings of Rawalpindi cantonment over a period of six months. Data was collected from respondents selected through multistage probability sampling by pretested and validated questionnaire.

**Results:** Statistical analysis showed 48.5% of participants had adequate knowledge about thalassemia and premarital screening, while 39.8% perceived its importance and 39.2% perceived that legislation will be beneficial for prevention of thalassemia in our country.

**Conclusion:** Based on study results it is concluded that majority of participants had adequate knowledge regarding thalassemia and premarital screening. Education is highlighted as significant factors towards their perception regarding importance of mandatory premarital screening legislation in Pakistan.

**Key Words:** Awareness, Genetic, Pre-Marital Screening, Thalassemia.

**Introduction**

Thalassemia is a hereditary blood disorder, which along with medical complications having psychological, social and financial impact at the patient, their family and whole society. It is categorized into alpha or beta thalassemia depending on absence of globin chain. Its occurrence is high in a broad belt which extends from Mediterranean basin through to Middle East, South East Asia, and Indian subcontinent. Globally 15 million patients have clinically apparent disorder.<sup>1</sup> In Pakistan, frequency of  $\beta$ -thalassemia gene is 5-8% and is present in all ethnic groups. It is estimated that approximately 9 million  $\beta$ -thalassemia carrier are

here leading to more than 5000 births of transfusion-dependent thalassemia (TDT) each year in Pakistan.<sup>2</sup> Presently there are estimated 100,000 cases of thalassemia in Pakistan, which making up for almost 5% of world cases. This situation is serious and alarming in our country as thalassemia can be a serious threat in coming years in absence of appropriate genetic counseling and proper screening. Consanguinity is the main factor to high prevalence in Pakistan.<sup>3</sup>

Thalassemia diagnosis is clinical along with laboratory assistance in the form of blood complete examination, Hb electrophoresis and confirmation by genetic analysis if obligatory. The treatment approach varies according to socioeconomic condition of parents and the country. The best treatment choice is bone marrow transplant that is available in our country but its high cost is a major hurdle. The other treatment options are supportive like repeated blood transfusion along with iron chelation therapy, splenectomy and Hb F augmentation. This lifelong transfusion therapy with iron chelation therapy puts a huge financial burden.<sup>4</sup> Thalassemia is a major public health problem, but it is preventable by adopting various preventive strategies and methods. Incidence of thalassemia major has been reduced in many countries through

<sup>1</sup>Lecturer, Department of Community Medicine, CMH Kharian Medical College, National University of Medical Sciences, Rawalpindi

<sup>2,3</sup>Department of Public Health, Armed Forces of Post Graduate Medical Institute (AFPGMI), National University of Medical Sciences, Rawalpindi

**Correspondence:**

Dr. Rehama Gilani

Senior Lecturer

Department of Public Health

National University of Medical Sciences, Rawalpindi

E-mail: rehama.gilani@numspak.edu.pk

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effective preventive programs. According to Pakistan Bureau of Statistics, per capita annual income during 2013 was \$1380 as, comparison to the estimated 6000 dollar per year cost of appropriate management of a thalassemia case.<sup>5</sup> Thalassemia screening preceding marriage is actually a more easier and cost-effective tool. Government of Pakistan is now planning for the implementation of a law for pre-marital screening as a mandatory procedure to curtail the burden of this disease. The aim of this study was to determine the awareness of general population about thalassemia and their perception regarding the pre-marital screening law for thalassemia, as no such survey has been conducted among the general population.

### Materials and Methods

This descriptive cross sectional study was conducted in areas of Rawalpindi cantonment during six months from 1<sup>st</sup> June 2017 to 30<sup>th</sup> December 2017. Study population comprised of general public residing in the sampled areas. People of both genders between age group of 20-60 years, willing to participate, were included in the study. The ethical approval was taken from Institution Review Board (IRB). Sample size was calculated based on the prevalence of knowledge about thalassemia in Pakistan.<sup>6</sup> Multistage probability sampling technique was used. At first stage of sampling, ward and areas were selected. Rawalpindi cantonment consists of twelve wards, each having 12-14 residential areas. Through simple random lottery mechanism, ward number eight was selected, which has twelve residential areas. From this ward every third area was selected by using simple random lottery again. Fifty participants were selected from each area by convenience sampling method to achieve a total sample size of 200 respondents. The data collection instrument used was a self-designed, self-administered questionnaire developed with the help of previous studies comprising of both open and close-ended questions. Data analysis was done by using version 22 of SPSS. In descriptive analysis mean and standard deviation of age and years of education was calculated. Frequency and percentage of all categorical variables like gender, marital status, consanguinity of parents, consanguinity of couples, family history of thalassemia and knowledge (adequate, inadequate) were determined. Chi square test was applied to

examine possible association between socio demographic characteristics and awareness of participants p- value < 0.05 was taken as significant.

### Results

The number of sampled participants completed the questionnaire were 200 with a response rate of 99.5%. The sociodemographic characteristics are given in table I. A significant number of study participants 140 (73.3%) claimed having awareness about thalassemia. Among them 115(61.5%) could correctly identify thalassemia as hereditary diseases. 140(76.1%) participants correctly identified pallor as most apparent sign of thalassemia. 157(87.2%) respondents correctly identified thalassemia can lead to decreased blood formation. 114 (62.3%) were not aware regarding availability of thalassemia screening test, 64(35.2%) identified television as the major source of information, 147(86.0%) correctly identified blood transfusion as main treatment of thalassemia, 119(66.9%) participants knew about the importance of premarital screening who identified it as a blood test of a couple before marriage. 74(39.8%) of participants strongly agreed that premarital screening is a reliable preventive measure for thalassemia. 71(35.5%) participants strongly agreed, that legislation is important. 105 (51.6%) considered that involvement of religious scholars will be one of the beneficial preventive strategies for thalassemia, adequate awareness was observed about thalassemia and premarital

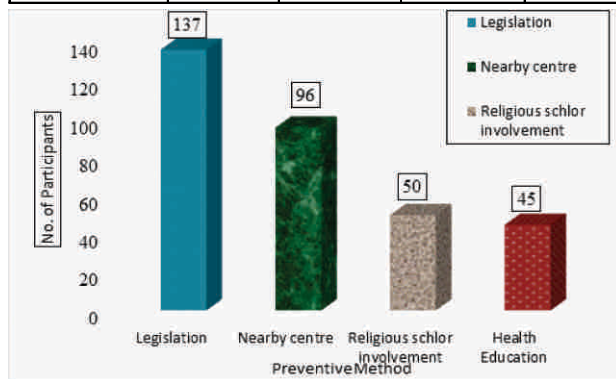
**Table I: Demographics Characteristics of Participants**

Serial	Variables	N (%)
1.	<b>Gender</b>	
	a. Male	105(52.5%)
	b. Female	95(47.5%)
2.	<b>Marital Status</b>	
	a. married	139(70.9%)
	b. unmarried	57(29.1%)
3.	<b>Consanguinity of Parents</b>	
	a. Yes	117(62.2%)
	b. No	71(37.8%)
4.	<b>Consanguinity of Couples</b>	
	a. Yes	85(43.8%)
	b. No	69(35.6%)
	c. Not applicable	39(20.1%)
5.	<b>History of thalassemia in family</b>	
	a. Yes	35(18.9%)
	b. No	135(73.0%)
	c. Do not know	15(8.1%)

screening in 103(51.5%) participants. Chi square test showed that educated participants were more likely to have adequate knowledge while consanguineous marriages had association with inadequate knowledge.

**Table II: Association between Demographic Characteristics and Awareness of Respondent about Thalassemia (N=200)**

Demographic characteristics	Awareness Score		Chi square (df)	P-value
	Adequate	Inadequate		
<b>Age</b>				
Mean and below mean	52(46.4%)	60(53.6%)	0.533(1)	0.457
Above mean	42(51.9%)	39(48.1%)		
<b>Gender</b>				
Male	50(47.6%)	55(52.4%)	0.69(1)	0.793
Female	47(49.5%)	48(50.5%)		
<b>Marital status</b>				
Married	64(46.0%)	75(54.0%)	1.649(1)	0.199
Unmarried	32(56.1%)	25(43.9%)		
<b>Educational status</b>				
Educated	89(66.9%)	44(33.1%)	40.86(1)	0.001
Uneducated	6(12.8%)	41(87.2%)		
<b>Consanguinity of couple</b>				
Yes	30(35.3%)	55(64.7%)	11.48(2)	0.003
No	38(55.1%)	31(44.9%)		
Not applicable	26(65.0%)	14(35.0%)		
<b>Consanguinity of Parents</b>				
Yes	56(47.9%)	61(52.1%)	0.143(1)	0.706
No	36(50.7%)	35(49.3%)		
<b>Family history of Thalassemia</b>				
Yes	17(48.6%)	18(51.4%)	1.654(2)	0.437
No	67(49.6%)	68(50.4%)		



**Fig 1: Opinion of Participants about Most Appropriate Preventive Method for Thalassemia**

**Discussion**

In this study, participants with different sociodemographic background were approached and their awareness and perceptions were assessed. Only education was found to be associated with better awareness while no association was found

among other variables (age, gender and marital status). This is in accordance with a study conducted in Kolkata.<sup>6</sup> Another study in Iran<sup>7</sup> showed females reflected better knowledge of thalassemia, and in Bahrain<sup>8</sup> university students and professionals who were married had better knowledge of thalassemia. Adequate awareness about thalassemia and premarital screening was observed in 48.5% of participants in our study which is higher than a study conducted in Karachi University where 78% students did not have adequate awareness about the disease and its consequences.<sup>9</sup> Kolkata<sup>6</sup> and Sri Lanka<sup>7</sup> study, conducted in general population showed 57.94% respondents had better knowledge about thalassemia. The study conducted at rural Bengal by Mittak et al<sup>8</sup> and at Lahore by Ishaq et al<sup>9</sup> showed 22.27% and 44.6% participants respectively were aware that thalassemia is a genetic disorder. Our study revealed that about 61.05% had adequate knowledge about the inherited nature of the disease; this is similar to Kolkata<sup>6</sup> study. It was also observed in Kolkata study<sup>6</sup> that two third of the study population were aware about blood transfusion as the essential treatment. The reason is the untiring efforts of many local and international thalassemia societies working at grassroot level in the communities. Another reason is that regular blood transfusion creates much economic strain on families that people near to them also become aware of this difficult treatment. Premarital screening is playing a vital role in reducing burden of disease in countries where it is mandatory by law. Studies conducted in Saudi Arabia<sup>10,11,12</sup> Oman<sup>13</sup> and Palestine<sup>14</sup> showed that majority of respondents were aware of premarital screening program but survey conducted at Quetta<sup>15</sup> showed only 35.2% respondents had awareness about premarital screening. The limitation of this study is the short duration of the project and it does not give insight about the disease among the rural population.

**Conclusion**

This study concluded that although our local population has adequate knowledge regarding thalassemia and premarital screening, it is imperative that government should implement the law in letter and spirit in order to reduce the burden of disease.

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