

## Comparison of knowledge among millennials studying in non-medical universities regarding premarital and prenatal thalassemia screening policies in Pakistan

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### Abstract

Thalassemia awareness among the youth is vital for policy-making to reduce the disease burden in our country. A descriptive cross-sectional study was conducted via simple random sampling technique for which data was collected from May 2020 to May 2021 through Google forms.

Results showed that out of a total of 394 non-medical university students, the majority, i.e. 265 (67.3%), were not aware of prenatal screening. Majority, i.e. 117 (29.7%), agreed that the couple should be screened before marriage, and 190 (48.2%) strongly agreed, while 46 (11.7%) had no knowledge. Students, however, believed premarital screening was either unavailable, not possible, or expensive. Other reasons included custom and culture of arranged marriages and religious reasons. The query that if both the parents are carriers and the foetus has thalassemia major should they have an abortion, showed mixed results.

The key to controlling thalassemia is awareness of future parents.

**Keywords:** Thalassemia, Disease prevention, Carrier screening.

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### Introduction

Thalassemia is an inherited blood disorder in which haemoglobin synthesis is defective which results in life-threatening anaemia. It requires regular blood transfusions for survival.<sup>1</sup> The prevalence of thalassemia is high in a resource-limited country like Pakistan where definitive treatment of thalassemia, i.e. bone marrow transplantation, is not readily available. The cost of regular transfusions and managing its complications not only add to the burden on

the family but also is an economic burden at the national level. Most of the thalassemia patients who are on regular blood transfusions will die from iron overload unless they have access to proper iron chelator therapy.<sup>2</sup> Worldwide, 40,618 children are born with  $\beta$  thalassaemia annually, of which about 25,511 are transfusion-dependent; while annually 2,989 (11.7%) start transfusion; 22,522 die annually because they do not receive transfusions. About 97,630 known patients are currently living with regular transfusions; 37,866 (39%) obtain iron-chelation therapy and 3,000 die annually in their teens or early 20s due to iron overload.<sup>3</sup> An estimated 5,000-9,000 children with  $\beta$ -thalassemia are born per year in Pakistan, although no documented registry is available. The estimated carrier rate is 5-7%, with 9.8 million carriers in the total population.<sup>4</sup> Estimated data reveal that there are more than 50,000 children with thalassemia major in Pakistan.

Thalassemia affects a significant amount of Pakistani population. Thalassemia has a great impact on the life of not only the sufferer but also the family. Thalassemia is difficult to cure and that too in a small proportion of patients only, but its incidence can significantly be reduced through proper screening programmes and by raising awareness among the population as has already been done in many countries like Iran, Cyprus, Maldives, Srilanka and Taiwan. Level of awareness among the young adults about the subject of thalassemia will frame their practices in future as today's youth will be tomorrow's parent. Recently, the government of Punjab has launched a thalassemia prevention programme, Punjab Thalassemia prevention programme (PTPP), in which free-of-cost carrier screening and prenatal screening is provided to extended families and general population (<https://ptpp.punjab.gov.pk/>).<sup>5</sup> The passage of a bill for making pre-marital testing easy and compulsory, even maybe free, would be a ray of hope, especially since tradition of cousin marriages are so strong in our country. This study was conducted to determine the understanding of thalassemia among the youth attending universities, which will provide us with the significant information about the perception of disease in the young population seeking education, which in turn will be beneficial in designing an effective framework for future control programme.

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### Material and methods

The data was collected from May 2020 to May 2021. Mode of collection was Google forms, Study design used were descriptive cross-sectional study. The study was conducted at the main non-medical universities of Karachi. Non-medical university students included Lahore University of Management sciences (LUMS), NED University of Engineering and Technology (NED, Engineering colleges, Institutes of business management (IBA) and some dental colleges including Bahria Dental College and Altamash Dental Institute. Names of institutes were not included in data sheet. Only departments and subjects they studied, such as humanities, social sciences, business etc. The sample size was calculated by using the formula  $N = \frac{Z^2 (pq)}{d^2}$ , estimated as 392. Direct reference from a similar parent article published in 2013 by Arslan M et al. (2013). Thalassaemia and Premarital Screening: Potential for Implementation of a Screening Program Among Young People in Pakistan.<sup>6</sup>

The Sampling technique used was simple randomised technique.

Inclusion criteria was students between 18 and 30 years of age, attending non-medical universities. Exclusion criteria included medical students, below 18 years or above 30 years of age, and those not willing to participate. Data analysis was done using SPSS software version 25 to conduct standard statistical analysis.

### Results

A total of 394 non-medical university students of Karachi between ages 18 and 30 participated in the study. The mean age was  $22.98 \pm 3.088$  years.

To the query whether the future couple should be screened for thalassaemia before marriage is shown in Table 1.

The question that if both the parents are carriers and the foetus is thalassaemia major, should they have an abortion, showed mixed results; 98 (24.9%) agreed, 56 (14.2%) strongly agreed, 146 (37.1%) did not know, 48 (12.2%) disagreed, while 19 (4.8%) strongly disagreed.

The knowledge on the availability of prenatal screening

**Table 1:** Do you agree that the future-couple should be screened for thalassaemia before marriage.

	n (%)	Valid Percent
<b>Valid</b>	27 (6.9)	6.9
Agree	117 (29.7)	29.7
Disagree	10 (2.5)	2.5
Do not know	46 (11.7)	11.7
Strongly Agree	190 (48.2)	48.2
Strongly disagree	4 (1.0)	1.0
<b>Total</b>	394 (100)	100.0

Scale for awareness analysis

Strongly agree	Agree	Do not know	Disagree	Strongly disagree
1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

Do you know or have heard about Thalassaemia? If yes, please specify what you know. You can tick on one of the 5 grades. Please give your level of agreement or disagreement.

**Table 2:** Do you know that the testing of the baby in womb for this diseases is available in Pakistan.

	n (%)	Valid Percent
<b>Valid</b>	27 (6.9)	6.9
Agree	49 (12.4)	12.4
Disagree	11 (2.8)	2.8
Do not know	265 (67.3)	67.3
Strongly Agree	30 (7.6)	7.6
Strongly disagree	12 (3.0)	3.0
<b>Total</b>	394 (100)	100.0

being available in Pakistan was present in 49 (12.4%) whereas 265 (67.3%) did not know, while 11 (2.8%) and 12 (3%) did not agree. (Table 2)

Reasons for not screening the future couple before marriage were that majority thought that the test is either unavailable, not possible, or very expensive. Other reasons included custom and culture of arranged marriages; few also cited religious reasons for not screening future couples.

### Discussion

Our study shows the awareness level of the Pakistani youth studying in non-medical institutes regarding Thalassaemia. Results revealed that young students are not aware of the fact that although Thalassaemia is a hereditary blood disorder, its debilitating effects or the expenses of treatment.

A recent study carried out in India among the university students showed that 73.6% of the students enrolled in the study had no knowledge about Thalassaemia.<sup>7</sup>

Our study claims that the majority students approved that premarital screening should be done. Students who had doubts related to pre marriage testing mainly because they believed such a test was not possible, although the facility of diagnosing the carrier status is available since early 1980s in Pakistan.<sup>8</sup> Some even thought it would not be of any use as people would still marry persons of their choice even if they knew the carrier status. Also tradition of cousin marriage is so strong in our country that not much heed would be given to such a test.

A similar study done in 2013 in Pakistan showed that only 297(54.5%) of 380 students had heard of the disease while most were aware of the concept of premarital screening. The positive approach towards premarital screening even

with limited information regarding the disease indicates the need of an awareness drive and application of a premarital screening programme.<sup>6</sup>

Pakistan has a very high incidence of  $\beta$ -thalassemia but lacks an effective screening programme for the prevention.<sup>9</sup>

Another pillar of the awareness and control programme should be prenatal screening in carrier couples and option of legal termination of pregnancy in case of affected foetus.

Our study showed that prenatal testing was strongly disapproved by the educated youth mainly because they feel that it won't be religiously or legally allowed. The religious customs could come in the way of prenatal screening and possible miscarriage.

A recent study done in Bangladesh, showed similar barriers due to religious constraints and also because of deep rooted cultural tradition of consanguineous marriages, for retention of family wealth, family feuds and other issues. They also believe that a sick child is Gods will and they could not fight against fate.<sup>10</sup>

This emphasis the need for a properly planned thalassemia awareness programme and a screening programme which covers most of the barriers faced by our educated youth regarding premarital and prenatal screening. It will help policy makers to draft an effective prevention programme and reduce the burden.

### Conclusion

The way forward for control of thalassemia is awareness among university students, i.e. the future parents, about premarital screening, prenatal screening, and other methods of prevention. More research is required in this field by including interviews and multiple city surveys.

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**Conflict of Interest:** None

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