Thalassemia Awareness And Factors Associated With Carrier Screening Among Undergraduate Students In Lahore, Pakistan

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ABSTRACT

Introduction: Thalassemia stands as a prevalent genetic blood disorder, burdening numerous countries across the globe. Unfortunately, preventive measures for thalassemia, particularly in Asian nations, are lacking. In Pakistan, the high carrier frequency of 5 to 8% highlights thalassemia as a substantial health concern, posing a significant threat to future generations.

Objective: To determine the thalassemia awareness and factors associated with carrier screening among undergraduate students in Lahore, Pakistan.

Methods: A descriptive cross-sectional study included 335 students from Punjab University and the University of Engineering and Technology, Lahore, selected through convenient sampling. An adapted questionnaire assessed thalassemia awareness and its association with carrier screening. Data was analyzed with SPSS version 25, presenting categorical variables as frequencies, percentages, and bar graphs. The Chi-Square test determined the link between thalassemia awareness and the willingness for carrier screening.

Results: Out of 335 students, awareness about Thalassemia was found to be “Good” among 54% students, while 45.4% demonstrated average knowledge and only 0.6% students had poor knowledge about thalassemia disease. Regarding carrier screening, only 18% students poses good knowledge of thalassemia carrier screening.

Conclusion: Overall awareness among students regarding thalassemia disease, treatment and its complication were quiet satisfactory. But knowledge about carrier screening was found extremely poor among participants. The findings of the study indicate that there is an urgent need for further research in this area in order to strengthen screening programmes or polices for the youth of the population.

Keywords: Thalassemia Awareness, Carrier screening and College Students

1 Introduction

Hemoglobinopathies include thalassemia and abnormal hemoglobin variants, affecting 330,000 births annually, with 60,000–70,000 severe thalassemia cases, mainly in developing countries. Globally, over 360 million individuals carry significant hemoglobin variants, with 100 million thalassemia carriers, totaling 5.2% of the population (1). Thalassemia, a global genetic disorder, involves deficient hemoglobin due to faulty alpha and beta globin synthesis. In 2009, 1.5 million cases were diagnosed, with 56,100 new cases annually. Projections indicate the global thalassemia burden may rise to 900,000 cases by 2030 (Yousaf et al., 2015). The annual incidence of β-thalassemia is approximately 1 in 100,000 worldwide and increases to 1 in 10,000 in European countries (2). A recent study results have shown that the prevalence of thalassemia in the United States has increased from 0.6% to 7.5% over the last five decades due to migration of people from the thalassemia affected regions (Kattamis et al., 2020). Most thalassemia cases occur in Asian and Middle Eastern countries, including Pakistan, with an estimated 7,000-9,000 affected children born annually. More than 10 million carriers are present in Pakistan's population of approximately 225 million (3). Thalassemia in Pakistan stems from factors like gene mutations, a high birth rate, a large population, and consanguineous marriages (Ehsan et al., 2020).

Recent literature shows that Pakistan has one of the highest rates of consanguineous marriages 65-70%, followed by India 55%, Saudi Arabia 50%, Afghanistan 45%, Iran 30%, Egypt, and Turkey 20% (Iqbal et al., 2020). Marriages between close relatives without genetic checks are a main reason for the high thalassemiase rate in Pakistan. The Pakistan Demographic and Health Survey (PDHS) found that almost half of married women are married to
their first cousins, and about 8.3% to their second cousins. (Shenk et al., 2016). Treating thalassemia is very expensive for families and caregivers. Patients need regular blood transfusions, iron chelation therapy, and bone marrow transplants, along with frequent checkups. In Pakistan, it’s even more costly, at $4,500 annually, which is higher than the country's average income per person. (Kantharaj and Chandrashekhar, 2018). In Pakistan, thalassemia patients typically have a life expectancy of 10-15 years, while patients in the Western world live longer due to improved treatment and prevention measures (Ehsan et al., 2020).

Preventing thalassemia is a more cost-effective strategy than treating it, based on global research. Carrier screening, like the "Punjab Thalassemia Prevention Program," offers a cost-effective approach. However, its reach remains limited, with only 36,793 individuals screened in the past four years, despite a high thalassemia carrier ratio in Pakistan (4). High thalassemia prevalence and low carrier screening rates in Pakistan underline the importance of educating the population. This study focuses on assessing students’ awareness and willingness for carrier screening. Addressing these factors and improving awareness can lead to informed decisions, including carrier screening and marriage choices, critical for thalassemia prevention in Pakistan.

Hemoglobinopathies, common worldwide, are a major health issue burdening families. Thalassemia, an inherited blood disorder, results in reduced or missing production of normal globin chains. It impacts 56,000 pregnancies globally, with 30,000 cases of Thalassemia Major, mainly in midle- and low-income countries (Badagabetu et al., 2022). Pakistan has a high prevalence of hemoglobinopathies, especially thalassemia. Thalassemia minor affects 5-7% of the population, and there are currently around 100,000 thalassemia major patients, with 5,000 to 9,000 new cases each year (Ebrahim et al., 2019).

Treating thalassemia is costly due to regular blood transfusions and iron chelation treatment for thalassemia-major patients. In Pakistan, the annual treatment cost for 60,000 registered thalassemia patients is around 7.8 billion rupees (Ghafoor et al., 2021). Even though there have been many campaigns in Pakistan to inform people about thalassemia, the disease is still very common. As a nurse and researcher, I’ve seen that many people in our culture don’t know much about thalassemia, and there isn’t a practice of checking for thalassemia carriers before marriage. This lack of awareness and screening is making thalassemia more common. A study in Pakistan found that many mothers who carried thalassemia didn’t know it and had children with the severe form of the disease.

2 Research Hypothesis:

Null hypothesis $H_0$: There is no association between thalassemia awareness level and willingness towards carrier screening.

Alternative hypothesis $H_1$: There is an association between thalassemia awareness level and willingness towards carrier screening.

Methodology: A descriptive cross-sectional research design to investigate thalassemia awareness and its associated factors with carrier screening among undergraduate college students. This study was conducted in collaboration with the Institute of Nursing, University of Health Sciences, Lahore, at two major public sector universities in Lahore, the University of the Punjab (PU), and the University of Engineering & Technology (UET). The study population consisted of undergraduate non-medical college students aged between 18 and 24 years, and data collection took place over a six-month period from December 2022 to May 2023. Sample size calculations were performed to ensure the study's accuracy, with a presumed good awareness level set at 32.1%. Data was collected using a non-probability convenient sampling method, which selects readily available samples from the target population. Selection criteria were applied, with inclusion criteria for students aged 18-24, of any gender, currently enrolled in college, and unmarried. Exclusion criteria included individuals with known thalassemia carriers, psychiatric illnesses, healthcare professionals, or those unwilling to participate voluntarily. The data collection instrument consisted of a questionnaire with three sections. Section A covered demographic variables, including age, gender, family income, parents' educational status, family history, consanguineous marriages, family history of genetic diseases, and thalassemia history. Section B contained a 20-item questionnaire on thalassemia awareness, addressing various aspects of the condition, such as its meaning, heredity, classifications, disease presentations, diagnosis, complications, treatment, and prevention. Responses were in "Yes" or "No," with one correct answer. Knowledge scores were computed based on the number of correct answers, categorized into poor (0-6), average (7-13), and good (14-20). Section C explored factors associated with thalassemia carrier screening. Students' responses were categorized as "Strongly Agree," "Agree," "Unsure," "Disagree," or "Strongly Disagree" on a 5-point Likert scale. Factors with scores greater than 3 were considered strong, while scores equal to or less than 3 were considered weak. The
questionnaire's validity and reliability were assessed, with a Cronbach's alpha of 0.69 for the Thalassemia Knowledge Questionnaire and 0.75 for Factors Associated with Thalassemia Carrier Screening. Data collection commenced after obtaining permission from the universities' Directorate of Student Affairs. The research underwent ethical review, with formal permissions granted by the universities and informed consent obtained from the participating students to ensure confidentiality. Data analysis was performed using the Statistical Package for the Social Sciences (SPSS) 25 software. Descriptive statistics were used to summarize the data, including mean ± SD for demographic variables, frequencies, percentages, and graphs. The Chi-Square test was employed to assess associations between thalassemia awareness and willingness for carrier screening, with a p-value of ≤ 0.05 considered statistically significant.

3 Results:

Figure-1: Gender of participants.

Figure-1 illustrates the gender distribution of participants. Out of 335 participants, 154 (46%) were male, and 181 (54%) were female.

Figure-2: Age distribution of study participants

The age distribution among the participants who were 18 years old was 42, which constituted 12.5% of the total. Approximately 21.5% of the participants were around 20 years old, with 72 individuals in this age group. Those aged 21 years accounted for 25.7% with 86 individuals, and 22-year-olds made up 17.9% of the group, totaling 60 participants.
Figure 3: Frequency Distribution of participants according to their degree programme.

Figure 3 illustrates the distribution of students by their undergraduate programs among the 335 study participants. The majority, 110 students (32.8%), were enrolled in the environmental engineering program. Following that, 76 students (22.7%) were in electrical engineering, 65 (19.4%) in the Fine Arts department, 51 (15.2%) in the IT department, and only 33 students (9.9%) were from the Civil engineering program.

Figure 4 Frequency Distribution of Parent's Educational status

In Figure 4, the educational status of the parents is depicted. Among the participants, 148 parents (44.2%) had completed their graduation, 97 (29%) had finished their secondary education, 62 (18.5%) held postgraduate degrees, and only 3 parents (0.9%) were illiterate.
In Figure 5, the monthly family income distribution is depicted. Among the participants, 229 (68.4%) had a family income exceeding 50,000 per month. Additionally, 89 participants (26.6%) reported a family income ranging between 25,000 and 50,000 per month, while only 17 participants (5.1%) had a family income below 25,000 per month.

As per Figure 6, 195 participants (58.2%) responded "yes," indicating a history of consanguineous marriages, while 140 participants (41.8%) responded "no." Among the 195 participants with a history of consanguinity, 103 (53.0%) had a history of 1st-degree consanguineous marriages, 70 (35.8%) had a history of 2nd-degree consanguinity, and only 22 (11.2%) had a history of 3rd-degree consanguineous marriages.
Figure 7: Family history of thalassemia disease:

In Figure 7, 21 participants (6.3%) reported a family history of Thalassemia, while 314 participants (93.7%) reported no such history.

Figure 8 Specify type of Thalassemia

In Figure 8, out of the 21 participants with a family history of Thalassemia, only 13 (3.9%) reported a strong family history of Thalassemia major.

Table 2: Distribution of students with respect to their Awareness Level of Thalassemia (N = 335)

<table>
<thead>
<tr>
<th>Level of Awareness</th>
<th>No. of Students</th>
<th>Percent</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Good</td>
<td>181</td>
<td>54.0</td>
<td>54.0</td>
</tr>
<tr>
<td>Average</td>
<td>152</td>
<td>45.4</td>
<td>99.4</td>
</tr>
<tr>
<td>Poor</td>
<td>02</td>
<td>0.6</td>
<td>100.0</td>
</tr>
<tr>
<td>Total</td>
<td>335</td>
<td>100</td>
<td></td>
</tr>
</tbody>
</table>

Utilizing a Tertile scoring system, we classified the scores for thalassemia awareness (13.51 ± 2.46) into three distinct categories: Good, Average, and Poor awareness. According to this categorization, we found that a mere 2 (0.6%) students fell into the Poor awareness category, while 152 (45.4%) exhibited Average awareness, and 181 (54.0%) demonstrated Good awareness.

Table 3: Factor Analysis for willingness towards carrier screening for Thalassemia
Participants used a 5-point Likert Scale to rate factors. Factors with scores >3 were considered strong, while those with scores ≤3 were considered weak. In the table, 177 participants (52.8%) expressed a willingness for carrier screening. Among them, 100 (54.6%) strongly agreed, and 60 (34.0%) agreed that screening prevents disease transmission to offspring. Additionally, 63 (35.5%) strongly agreed, and 68 (38.5%) agreed that screening would inform them about their carrier status. Analysis of the table revealed that the mean scores for "Prevent disease transmission to offspring" and "it will inform me about my carrier status" were >3, indicating they were the strongest factors influencing willingness for thalassemia carrier screening. On the other hand, "Having a strong family history of genetic diseases," "Having a strong history of consanguineous marriages in my family," and "Having a strong history of thalassemia in my family" had mean scores ≤3, classifying them as weak factors in influencing the willingness for thalassemia carrier screening.

Table 4: Factors Analysis for Refusal towards carrier screening for Thalassemia.
I am afraid of being stigmatized as (thalassemia carrier).

| Percentage | 54 (34.1%) | 28 (18.0%) | 35 (22.4%) | 15 (9.1%) | 26 (16.4%) | 3.1 | Strong |

Premarital screening is not accepted in our culture.

| Percentage | 42 (26.3%) | 49 (31.0%) | 18 (11.3%) | 24 (15.2%) | 25 (16.1%) | 3.3 | Strong |

I think that the carrier status (positive) could negatively impact on my marital proposal.

| Percentage | 27 (17.0%) | 60 (38.2%) | 32 (20.3%) | 26 (16.4%) | 13 (8.1%) | 3.4 | Strong |

My parents are not willing for my carrier testing.

| Percentage | 16 (9.9%) | 24 (15.5%) | 53 (33.4%) | 33 (21.2%) | 32 (20.0%) | 2.7 | Weak |

In my family there is no culture of cousin marriages so, I think carrier testing is not important for me.

| Percentage | 19 (11.9%) | 40 (25.1%) | 28 (17.6%) | 41 (26.0%) | 30 (19.4%) | 2.8 | Weak |

* Factor Analysis 5 point Likert Scale

In the study, 158 participants (47.2%) refused carrier screening, with 65 (41.2%) strongly agreeing and 46 (29.3%) agreeing with the statement, "I won't carry this disease." Additionally, 53 participants (33.4%) strongly agreed with the statement, "There is no history of thalassemia in my family, so I am not at risk," and 54 (34.1%) strongly agreed that they declined screening due to the "fear of being stigmatized as a thalassemia carrier." Furthermore, 42 participants (26.3%) strongly agreed with the statement that "Premarital screening is not accepted in our culture," and 27 (17.0%) strongly agreed with the statement, "Positive carrier status could negatively impact on my marital proposal."

Upon analyzing the data, it became evident that factors like "I believe that I won't carry this illness," "There is no history of thalassemia in my family, so I am not at risk," "Premarital screening is not accepted in our culture," "fear of being stigmatized as a thalassemia carrier," and "positive carrier status could negatively impact on my marital proposal" all had mean scores exceeding 3, indicating that they were the most influential factors contributing to the refusal of thalassemia carrier screening.

Table 5: Showing Association between Awareness Level on thalassemia and willingness towards carrier screening.

<table>
<thead>
<tr>
<th>Willingness towards carrier screening</th>
<th>Knowledge Level Regarding Thalassemia</th>
<th>P- Value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Poor</td>
<td>Average</td>
</tr>
<tr>
<td>Yes</td>
<td>1</td>
<td>68</td>
</tr>
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</table>

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These findings align with a study by Wahidiyat in 2020 among Indonesian youth, which also found that over half of exhibit signs and symptoms of the disease. Additionally, 85% believed that thalassemia carriers needed treatment. Alam et al. in 2022 revealed that 72.5% of participants knew that a blood test can diagnose thalassemia carrier status. Parents were aware of the thalassemia carrier test, while 64.7% were not determine thalassemia carrier status. A similar finding of fazal and colleagues study observed that only 35.3% of carrier testing. Our study showed that only 18.8% of students were aware that a simple blood test is used to determine thalassemia carrier status. A majority (81.2%) had limited knowledge about thalassemia screening. In this present study of a total of 335 students, 58.2% of participants had a history of consanguineous marriages. In the current research involving 335 students, it was found that 58.2% of the participants had a background of consanguineous marriages. In contrast, a study carried out in India by Badagabettu, Archana, and Jomon in 2022 showed that only 7.2% of participants had a history of consanguineous marriage. Furthermore, a study by Nouri et al. conducted in the USA indicated that consanguineous relationships are generally prohibited in most states of the USA and are strongly socially stigmatized in other states.

This study found that 6.3% of participants had a family history of thalassemia, which aligns with the results from a study led by Vasudeva Murthy, Zulkiflee, Venkateswaran, and Barua in 2015, where only 4% of medical students and 5.3% of non-medical students reported thalassemia in their family. A similar outcome was observed in an Indonesian study led by Suryawan, Ningtiar, Irwanto, and Ugrasena in 2021, which showed 7% (8). In contrast, a study conducted by Faizan-ul-Haq et al. in Karachi, Pakistan, in 2016 revealed that 56% of patients had a positive extended family history of thalassemia, and 28% had family members who had died from thalassemia (9). Regarding thalassemia awareness, our study found that 89% of students were familiar with thalassemia, which aligns with a similar study in Bangladesh by M. J. Hossain et al. in 2022, where 89.72% of students had heard about thalassemia (10). In contrast, a study in urban areas of Karachi, Pakistan, conducted by Ebrahim et al. in 2019 reported that only 53% of respondents were aware of thalassemia (11). However, a previous study by M. S. Hossain et al. in Bangladesh in 2020 found that two-thirds (67%) of students had never heard about thalassemia (12). While many participants claimed to have heard about thalassemia, a majority (81.2%) had limited knowledge about thalassemia carrier testing. Our study showed that only 18.8% of students were aware that a simple blood test is used to determine thalassemia carrier status. A similar finding of fazal and colleagues study observed that only 35.3% of parents were aware of the thalassemia carrier test, while 64.7% were not (13). In contrast, a study in Bangladesh by Alam et al. in 2022 revealed that 72.5% of participants knew that a blood test can diagnose thalassemia carrier status (14). An intriguing discovery in this study was that 72.5% of students thought that thalassemia carriers would exhibit signs and symptoms of the disease. Additionally, 85% believed that thalassemia carriers needed treatment. These findings align with a study by Wahidiyat in 2020 among Indonesian youth, which also found that over half of the respondents believed that thalassemia carriers would show symptoms of the disease (15). In contrast, a study by

### Table: Awareness of Thalassemia among Students

<table>
<thead>
<tr>
<th>No</th>
<th>Count</th>
<th>%</th>
<th>1</th>
<th>84</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>% of Total</td>
<td></td>
<td>2</td>
<td>152</td>
<td>45.4%</td>
</tr>
<tr>
<td>Total</td>
<td>Count</td>
<td>2</td>
<td>152</td>
<td>84</td>
<td>25.1%</td>
</tr>
</tbody>
</table>

The Pearson's chi-square test was employed to investigate potential links between the scores related to thalassemia awareness and the inclination to undergo carrier screening. The analysis outcome revealed a statistically significant correlation between the students' awareness scores and their willingness to undergo carrier screening, with a χ2 value of 7.398 and a P-value below 0.025.

### 4 Discussion

This chapter discusses the results that have generated from the current study while taking into consideration the associated studies conducted previously on “awareness level on thalassemia and factors associated with thalassemia carrier screening”. The main objective of the present study was to determine the awareness on thalassemia and its factors associated with carrier screening among undergraduate college students. The main findings of the study are divided into three main parts Socio-demographic characteristics of the participants, Knowledge items on thalassemia awareness and Factors associated with thalassemia carrier screening. A chronic condition and a global public health concern, thalassemia requires lifelong treatment including frequent blood transfusions, iron chelation and also, bone marrow transplant. Pakistan carries a significant number of thalassemia carriers, in turn increasing the number of actual thalassemia patients. Consequently, it places not only a huge financial, but also social, emotional, and psychological burden on the patients as well as their families. This also continues to drain our healthcare system, given that this is a preventable disease. Hence, the best and only preventive technique to reduce this rising burden of thalassemia is by creating awareness and educating the people. Striving to play the crucial role of practicing prevention, this study aimed to assess the awareness level of thalassemia and the factors associated with carrier screening among undergraduate college students. In this present study of a total of 335 students, 58.2% of participants had a history of consanguineous marriages. In the current research involving 335 students, it was found that 58.2% of the participants had a background of consanguineous marriages. In contrast, a study carried out in India by Badagabettu, Archana, and Jomon in 2022 showed that only 7.2% of participants had a history of consanguineous marriage. Furthermore, a study by Nouri et al. conducted in the USA indicated that consanguineous relationships are generally prohibited in most states of the USA and are strongly socially stigmatized in other states.

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Mat, Yaacob, and Zakaria in 2020, which assessed parental knowledge about thalassemia, found that more than half (57.5%) of the individuals believed that thalassemia carriers are asymptomatic and do not require any treatment (16). In the current study, 88% of students were aware that thalassemia is a genetic disorder, and 71% knew that consanguineous marriages increase the risk of thalassemia transmission. These findings are consistent with a study in Malaysia by Mat et al. in 2020. On the other hand, a study by Manzoor and Zakar in Lahore found that 76.9% of individuals knew about the role of cousin marriages in thalassemia transmission. However, Ebrahim et al.’s study in Pakistan reported that 60% of respondents were unaware of the genetic nature of the disease and the role of consanguineous marriages. In the current study, 70.7% believed that thalassemic individuals can lead normal lives, and 77% knew that thalassemia can be treated with regular blood transfusions, which aligns with the Malaysian study by Mat et al study conducted in 2020 (16). But only 48.7% recognized the need for lifelong blood transfusions in thalassemia. In contrast, a study by Sidra et al. reported that only 9.4% of respondents knew that blood transfusion is the treatment for thalassemia major (17). Regarding the necessity of premarital screening, 63% of participants in the current study knew it was essential, similar to Ahmed et al.’s findings. However, M. S. Hossain et al.’s study in Bangladesh revealed that 91% of respondents were unaware of premarital screening. In the present study, 60% of respondents knew that thalassemia is common in South Asian countries, while 35% recognized β-thalassemia as the most common type in Pakistan. Similar results were reported by Ahmed and colleagues study (18).

Regarding iron overload, 58% of participants in the current study were aware of the issue, matching findings in a study by Khalid and colleagues (19). In contrast, a study in India by Jain and colleagues. found that 56% of parents had poor knowledge about iron overload (20). In the current study, 68% knew that thalassemia can be prevented, and 66% were aware of treatment options. This is consistent with a study in Indonesia by Wahidiyat and colleagues (15). In contrast, a study in Chattogram, Bangladesh, reported that 52.9% of parents believed thalassemia could not be cured (21).Regarding the financial and psychological impact of thalassemia, 87% of participants in the current study recognized the financial strain, which is supported by an economic burden study in Malaysia. Similarly, 78% of participants knew about the psychological impact, which is consistent with the findings of a study in Rawalpindi (22). In terms of knowledge scores, 54% of participants in the current study had good knowledge, 45.4% had average knowledge, and only 0.6% had poor knowledge about thalassemia. Similar results were seen in a hospital study in Mysore, India (23).

5 Conclusion:
The study found good overall awareness of thalassemia among students. However, awareness regarding carrier screening for thalassemia prevention is inadequate, contributing to increased thalassemia prevalence. Past research highlights the effectiveness of health education and outreach programs in controlling the disease. Thus, the study emphasizes the need for a comprehensive thalassemia prevention program, including education, carrier screening, and premarital counseling, and community awareness initiatives, particularly targeting marriage-ready and child-bearing youth. Knowledge level was significantly associated with willingness to undergo carrier screening, underscoring the role of awareness in disease prevention. Strengthening education and screening programs is crucial to alleviate thalassemia’s burden on patients, families, society, and the healthcare system.

References


