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University Students' Knowledge, Attitudes, Awareness and Practices Regarding Thalassemia in a Carrier Screening Campaign in Bangladesh

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ABSTRACT

Introduction: Thalassemia is the most common inherited hemoglobin disorder in the world. A thalassemia carrier is a recessive condition carrying one of the faulty genes that cause thalassemia. There is a 25.0% probability in every pregnancy of having this life-threatening disorder in a child. This study aims to investigate university students' knowledge, attitudes, awareness and practices (KAP) towards thalassemia by conducting a pre-KAP study in a thalassemia carrier screening campaign in Bangladesh.

Methods: A cross-sectional descriptive study was conducted at Jahangirnagar University, Bangladesh, from January 2021 to March 2021. The study involved 290 university students participating in a thalassemia carrier screening campaign, who completed a self-administered questionnaire about thalassemia.

Results: The pre-KAP study showed that 82.6% of students were familiar with thalassemia, but 76.4% of students answered incorrectly that thalassemia spreads through blood. More than 90.0% of the students (93.7%) believed that premarital screening is necessary to reduce the occurrence of thalassemia, and (92.7%) believed that raising social awareness for thalassemia is important. There were no notable distinctions between male and female participants in terms of their knowledge, attitudes, and practices regarding thalassemia.

Conclusions: The study highlights the need for increased awareness of thalassemia and suggests that identifying carriers is crucial in reducing the occurrence of this life-threatening disorder.

Keywords: Thalassemia, Pre-KAP study, Attitudes, Blood disorder, Awareness, Practices, University students

Introduction

Thalassemia is a hereditary abnormality marked by measurable deficits in globin chain production [1, 2]. It is a genetic blood condition that results in anemia due to accelerated red blood cell disintegration. This genetic blood condition has a high prevalence in the so-called "thalassemia belt," which includes Southeast Asia, the Indian subcontinent, the Mediterranean, and the Middle East [3,4]. Given its significant public health burden, a comprehensive understanding of its transmission dynamics and preventive strategies is essential [5, 6].

Thalassemia is divided into two types: dominant and recessive [2, 7]. Dominant thalassemia includes alpha or beta-thalassemia major, while the recessive condition involves thalassemia carriers having hypochromic and microcytic anemia. In thalassemia, RBCs are destroyed, leading to anemia, ischemia, fatigue, lethargy, stunted growth, and mortality [8], as well as severe anemia and hemolysis due to insufficient erythropoiesis. Hepatomegaly and splenomegaly are also observed [9, 10]. Thalassemia carriers are generally healthy but typically have mild anemia, which has been linked to an increased risk of liver and kidney damage [11-13]. Iron cannot be cleared by the excretory system; it is irreversible in human metabolic pathways. Therefore, iron accumulates in important organs such as the liver, heart, spleen, and endocrine organs [14, 15, 16]. Increased liver enzymes, such as Alanine Aminotransferase (ALT), Aspartate aminotransferase (AST), and Alkaline phosphatase (ALP) are signs of iron overload [14, 15, 17, 18].

Thalassemia affects 1.0–5.0% of the world's population as carriers [4]. In South and Southeast Asia, countries such as India, Pakistan, Sri Lanka, Thailand, and Bangladesh collectively account for a substantial proportion of the global thalassemia burden [19]. The estimated prevalence of β-thalassemia carriers in India ranges from 2.7% to 4.0%, corresponding to an absolute burden of roughly 30–48 million carriers nationwide [20-22]. In Pakistan, where the carrier frequency is reported to be between 5.0% and 7.0%, the number of β-thalassemia carriers is estimated to fall between 5 and 12 million individuals [20, 23, 24]. In Bangladesh, thalassemia poses a considerable health challenge. More recent data from a study on Bangladeshi school children indicated higher carrier rates, at 4.1% for beta-thalassemia and 6.1% for Hb-E [25]. The birth of a child with thalassemia major, a life-threatening condition, can only be prevented by identifying carriers and advising against marriage between two carriers [26].

The effective control of genetic disorders such as thalassemia depends heavily on public awareness and engagement, underscoring the investigation of knowledge, attitudes, and practices (KAP), a crucial approach [3, 27]. KAP studies have been instrumental in designing and implementing successful public health interventions for various chronic and genetic conditions, including diabetes [28] and hypertension [29,30], by identifying gaps in understanding and addressing behavioral barriers [31]. Despite the high prevalence of thalassemia in Bangladesh, there is a notable scarcity of comprehensive research on the KAP of the general population regarding this condition [27].

University students constitute a particularly important target group, as they are future parents, potential policymakers, and influential members of society who can disseminate accurate health information within their families and communities. Previous studies conducted among university students in different countries have revealed substantial gaps in knowledge and misconceptions regarding thalassemia transmission, carrier screening, and prevention, despite generally positive attitudes toward screening programs [32-34]. However, data on pre-KAP assessment related to thalassemia among university students in Bangladesh remain scarce. Evaluating knowledge, attitudes, awareness, and practices in this population is, therefore, critical for designing evidence-based awareness programs, strengthening national carrier screening initiatives, and reducing the future burden of thalassemia in Bangladesh [35, 36].

This study builds upon previous work by the authors, which focused on a more limited sample of biological faculty students at Jahirnagar University [27]. The current research expands this investigation to a broader student body across various faculties who participated in a thalassemia carrier screening campaign. By targeting university students, who are poised to become future community leaders, this study aims to create a ripple effect of awareness [27]. The findings provide critical insights into the existing knowledge gaps and positive attitudes, which can inform the development of more effective and targeted public health interventions to mitigate the incidence of thalassemia in Bangladesh [27].

Methods

Study design and participant selection

This study utilized a cross-sectional descriptive design to evaluate the KAP of Jahangirnagar University students who voluntarily consented to thalassemia carrier screening in our laboratory. Previously, we conducted a pre-KAP study among 911 students of the Biological Faculty of Jahangirnagar University, which generated a positive response among students to learn more about thalassemia, and we were able to encourage them to join our Thalassemia carrier screening campaign [27].

In 2021, due to a substantial positive response, 290 participants aged 20 to 28 years from various faculties volunteered for thalassemia carrier screening. The study population comprised all students at Jahangirnagar University, estimated at 14,000 individuals. To determine a scientifically justified sample size, the standard formula for cross-sectional studies was used [37] :

$$n_\theta = \frac{z^2 \cdot \rho \cdot (1-P)}{e^2}$$

Where Z = 1.96 for 95% confidence, p = 0.5 (assumed proportion for maximum variability), and e = 0.05 as the margin of error. This calculation yielded an initial sample size of 384 participants. Applying the finite population correction for N = 14,000 resulted in an adjusted sample size of approximately 374 students [38].

Inclusion Criteria were individuals admitted to any department of Jahangirnagar University within the past 5–6 years and aged 18 years or older. Individuals unwilling to participate, those who did not provide written informed consent, or participants with incomplete questionnaire responses were excluded from the study.

Due to voluntary participation in the screening campaign, the initial sample comprised 290 students, of whom one participant was excluded due to an incomplete response, comprising a final sample size of 289, corresponding to a margin of error of approximately 5.7%, which remains acceptable for a descriptive KAP study.

Data collection

All participants provided written informed consent and completed a questionnaire covering demographic information, anthropometric variables, and hematological and biochemical parameters. They also completed a self-administered questionnaire

concerning thalassemia under the supervision of qualified students, which consisted of five sections, including personal information, knowledge, attitudes, practices, and awareness regarding thalassemia.

The first section covered personal information such as age, sex, academic background, home district, marital status, religion, and family history of thalassemia. The knowledge section consisted of six multiple-choice questions covering the understanding of thalassemia. The attitudes section was assessed through three multiple-choice questions, evaluating beliefs about thalassemia screening and marriage. The practices section assessed participants' views on informing others about thalassemia and encouraging blood donations for patients through three multiple-choice questions. The awareness section consisted of five multiple-choice questions, evaluating participants' knowledge about the causes and consequences of thalassemia.

Statistical analysis

Descriptive statistics were used to summarize demographic data [39]. Normality testing was conducted using the Kolmogorov–Smirnov test, depending on sample size [40]. Data were analyzed using SPSS version 19.0 (IBM Corporation, Armonk, New York, USA) and Microsoft Excel. Chi-square analyses were used to evaluate the statistical significance of differences in categorical data [41]. The level of statistical significance was set at 0.05 [42].

Ethical approval

The study protocol was approved by the Biosafety, Biosecurity and Ethical Committee of Jahangirnagar University, with the ethical approval reference number JU/BBEC/BIO/02/2021. All participants provided written informed consent, and their privacy was strictly maintained throughout the study. Participation was entirely optional.

Results

The study initially involved 290 participants, of whom one was excluded for incomplete responses. The study sample, therefore, has 289 final participants, consisting of 196 male participants (67.8%) and 93 female participants (32.1%) (Table 1).

Table 1 Gender distribution of participants in the pre-KAP study

Gender	n%
Female	93 (32.1)
Male	196 (67.8)
Total	289 (100.0)

Regarding personal and family history of thalassemia, one participant (0.3%) reported a positive response, indicating a personal and family history of thalassemia. With a sample size of 289, the Kolmogorov-Smirnov test was used to assess the normality of the age distribution (participants aged 18 years or older), which revealed a non-normal distribution (p-value < 0.05). Consequently, the Chi-square test was applied to compare categorical responses (knowledge, attitudes, and practices) between male and female participants, ensuring the appropriateness of the statistical methods.

It was found that 82.6% of participants had heard of the term thalassemia before, with 79.5% of male participants and 89.25% of female participants having prior knowledge. 15.9% of participants were unaware of the disease. 76.4% of students answered that thalassemia is spread through blood, while 18.3% thought it was spread through semen. 84.0% of participants correctly identified a connection between the disease and marriage, while 14.8% gave incorrect answers. Over 50.0% of participants were not aware of the treatment for thalassemia, and 29.4% of students knew someone affected by the disease. No significant differences in knowledge about thalassemia were evident between male and female participants (Table 2).

Table 2 Knowledge of participants in a carrier screening program about thalassemia (n=289)

Knowledge	Total (n=289) n (%)	Male (n=196) n (%)	Female (n=93) n (%)	χ^2	p-value
Have you heard the term thalassemia before?					
Yes	239 (82.6)	156 (79.5)	83 (89.2)	2.96	0.085
No	46 (15.9)	36 (18.3)	10 (10.7)		
Do you know how this disease spread?					
Blood	221 (76.4)	144 (73.4)	77 (82.7)	0.412	0.521
Semen	53 (18.3)	37 (18.8)	16 (17.2)		
Is there any connection to this disease with marriage?					
Yes	243 (84.0)	164 (83.6)	79 (84.9)	0.00	0.995

Knowledge	Total (n=289) n (%)	Male (n=196) n (%)	Female (n=93) n (%)	χ^2	p-value
No	43 (14.8)	29 (14.7)	14 (15.0)		
Do you know the treatment of thalassemia?					
Yes	110 (38.0)	78 (39.7)	32 (34.4)	1.08	0.297
No	174 (60.2)	113 (57.6)	61 (65.5)		
Do you know any thalassemia patient(s)?					
Yes	85 (29.4)	62 (31.6)	23 (24.7)	1.32	0.250
No	203 (70.2)	134 (68.3)	69 (74.1)		
What is your relationship with the patients?					
Parents	3 (1.0)	2 (1.0)	1 (1.0)	1.10	0.775
Cousins	4 (1.3)	2 (1.0)	2 (2.1)		
Neighbors	7 (2.4)	4 (2.0)	3 (3.2)		
No relation	224 (77.5)	155 (79.0)	69 (74.1)		

Statistical significance was considered at p-value < 0.05

The majority of students (93.7%) believed that premarital screening was necessary to prevent thalassemia, while 5.8% did not support this idea. 92.3% of students supported prenatal screening of neonates if the parents were carriers of thalassemia, while 4.8% did not. 62.6% of participants thought they would give birth to an affected neonate after screening, while 27.6% believed that abortion was the best way to prevent thalassemia. There was no significant difference between the male and female participants' attitudes towards thalassemia (Table 3).

Table 3 Attitude of participants in a carrier screening program towards thalassemia (n=289)

Attitudes	Total (n=289) n (%)	Male (n=196) n (%)	Female (n=93) n (%)	χ^2	p-value
Do you think that thalassemia screening is necessary before marriage?					
Yes	271 (93.7)	186 (94.8)	85 (91.3)	0.70	0.400
No	17 (5.8)	10 (5.1)	7 (7.5)		
Do you think prenatal screening of neonatal is important before pregnancy, if parents are thalassemia carriers?					
Yes	267 (92.3)	184 (93.8)	83(89.2)	0.13	0.716
No	14 (4.8)	9 (4.5)	5 (5.3)		
What should you do when you find that the neonatal is thalassemia-affected after screening?					
Give birth	181 (62.6)	126 (64.2)	55 (59.1)	0.22	0.637
Abortion	80 (27.6)	58 (29.5)	22 (23.6)		

Statistical significance was considered at p-value < 0.05

71.2% of participants believed that thalassemia is only a blood disorder, while 27.3% did not. 79.9% of students responded negatively when asked if thalassemia was caused by malnutrition, while 15.2% responded positively. 77.1% of participants agreed that thalassemia can be caused by marrying between blood relatives, while 17.3% did not. 92.7% of students thought that raising social awareness for thalassemia is important, but 3.1% did not. 85.8% of students thought that thalassemia patients need blood transfusions throughout their life, while 8.9% responded 'no'. No significant difference in awareness between male and female participants was evident (Table 4).

Table 4 Awareness of the participants in a carrier screening program about thalassemia (n=289)

Awareness	Total (n=289) n (%)	Male (n=196) n (%)	Female (n=93) n (%)	χ^2	p-value
Is thalassemia only a blood disorder?					
Yes	206(71.2)	137 (69.8)	69 (74.1)	1.26	0.261
No	79 (27.3)	58 (29.5)	21 (22.5)		
Is thalassemia caused by malnutrition?					
Yes	44 (15.2)	32 (16.3)	12 (12.9)	0.32	0.569
No	231 (79.9)	158 (80.6)	73 (78.4)		
Can thalassemia be caused by marrying between blood relatives?					
Yes	223 (77.1)	151 (77.0)	72 (77.4)		
No	50 (17.3)	38 (19.3)	12 (12.9)	1.31	0.251
Raising social awareness for thalassemia is important?					
Yes	268 (92.7)	184 (93.8)	84 (90.3)		
No	9 (3.1)	7 (3.5)	2 (2.1)	0.33	0.561
Do you think that thalassemia patients need blood transfusions throughout his/her life?					
Yes	248 (85.8)	170 (86.7)	78 (83.8)	0.00	0.943
No	26 (8.9)	18 (9.1)	8 (8.6)		

Statistical significance was considered at p-value < 0.05

Most participants (77.8%) were willing to inform others about the consequences of thalassemia, while 1.7% were not. 75.4% of participants knew that blood transfusion was the main treatment for Thalassemia, while 18.6% did not. 89.9% of participants would encourage others to give blood to a thalassemia patient, and 5.8% would not. There was no significant difference in the responses related to the practice of thalassemia between male and female participants (Table 5).

Table 5 Practice of the participants in a carrier screening program about thalassemia (n=289)

Practice	Total (n=289) n(%)	Male (n=196) n(%)	Female (n=93) n(%)	χ^2	p-value
Do you think you should inform other people about its consequences?					
Yes	225 (77.8)	138 (70.4)	87(93.5)		
No	5 (1.73)	4 (2.04)	1 (1.0)	0.72	0.396
Do you know blood transfusion is the main treatment for thalassemia?					
Yes	218 (75.4)	149 (76.0)	69 (74.1)		
No	54 (18.6)	40 (20.4)	14 (15.0)	0.66	0.413
Will you encourage others to give blood to thalassemia patients?					
Yes	260 (89.9)	179 (91.3)	81 (87.0)		
No	17 (5.8)	11 (5.6)	6 (6.4)	0.12	0.722

Statistical significance was considered at p-value < 0.05

Discussion

This study provides insights into the knowledge, attitudes, and practices of university students participating in a carrier screening program for thalassemia in Bangladesh. In February of 2021, we launched a comprehensive initiative that combined a carrier screening program with an awareness campaign targeting university students to enhance their understanding of thalassemia. The aim was to educate them about the genetic nature of the disease and its potential impact on their conjugal life and future generations if both partners are carriers. We encouraged student participation in the campaign and testing for carrier status. Blood samples were collected at our laboratory for screening.

Our study revealed that the majority of students (82.6%) were aware of thalassemia, and 84.0% believed it was related to marriage. However, 76.4% of students held the false belief that the disease spreads through blood. Only 50.0% of the students had adequate knowledge about the treatment of thalassemia. The results indicated that the overall understanding of thalassemia among university students was unclear.

This perception regarding the association between thalassemia and marriage is particularly relevant in the context of disease incidence and screening practices in Bangladesh. Bangladesh lies within the global "thalassemia belt" and carries a substantial burden of hemoglobinopathies, with an estimated 6.0–11.0% of the population being carriers of β-thalassemia trait and hemoglobin E (Hb-E) trait [43,44]. As thalassemia is inherited in an autosomal

recessive manner, marriage between two asymptomatic carriers remains the principal determinant for the birth of children with thalassemia major. In Bangladesh, where nationwide mandatory premarital carrier screening is not yet implemented, carrier-unaware marriages continue to contribute to the persistent incidence of thalassemia [45, 46]. Therefore, the high proportion of students in our study who correctly associated thalassemia with marriage (84.0%) reflects an encouraging alignment between students' knowledge and the genetic basis of disease transmission in the country. Previous studies from Bangladesh have reported limited community-level awareness of inheritance patterns and poor uptake of voluntary carrier screening [3, 45]. Evidence from South Asian settings suggests that improved understanding of the relationship between marriage and thalassemia is strongly associated with positive attitudes toward premarital screening and informed marital decision-making [47]. In this context, university-based awareness and screening initiatives may play a critical role in bridging the gap between disease burden and preventive practices in Bangladesh.

The study found that a higher percentage of female students (89.2%) compared to male students (79.5%) had heard about thalassemia, which is consistent with findings from studies conducted in Iran [48] and Bahrain [49]. Our study revealed a higher level of understanding about thalassemia among university students compared to a study conducted in Bahrain among university students, professionals, and married individuals [49].

In our study, 93.7% of students believed that premarital screening is necessary to reduce the incidence of thalassemia, and 92.3% felt that prenatal screening was important before pregnancy. However, a previous study in Bangladesh reported a poor understanding of thalassemia that led to negative attitudes [50]. In Oman, sociocultural factors such as fear of test results, embarrassment, marriage cancellations, and others contributed to the poor response to carrier screening [51, 52] . Negative attitudes towards carrier screening in Pakistan were influenced by factors such as fear of rejection, a potential increase in abortion rates, and stress [53].

In our research, 77.8% of students expressed a willingness to educate others about the consequences of thalassemia, and 89.9% stated that they would encourage others to donate blood to thalassemia patients. A previous study in Bangladesh found that 60.8% of college students were willing to donate blood to thalassemia patients, while 39% either declined or were uncertain about donating blood [3]. Our study aimed to increase awareness of thalassemia among university students so they could learn about the disease and its carrier form before entering into a safe relationship or marriage. A study by Hossain et al. focused on increasing awareness of this disease among college students [3].

Since there is no appropriate treatment for thalassemia besides blood transfusion, carrier screening, and increased knowledge before marriage are the only protective actions to reduce its frequency across generations. Previous studies have shown that a significant proportion of respondents knew that thalassemia is a hereditary disease, such as 60.0% in a study conducted at Kolkata Tertiary Care Hospital [54] and 82.6% in a study in Pakistan [55]. However, our research found that 71.2% of participants believed that thalassemia is a blood disorder only. Our study also showed that 92.7% of students felt that raising awareness about thalassemia is important, which is similar to a study in Saudi Arabia where 92.9% of Taif University students agreed to contribute to raising awareness about the importance of premarital screening [56].

In 1975, Silverstroni and the team in Latium, Italy, started the first pre-marriage thalassemia screening as part of a school-based preventive initiative [57]. During the 1970s, screening programs were established across Canada, Cyprus, Greece, Italy, and the UK. However, due to low literacy rates and limited knowledge and awareness in Bangladesh, the success of thalassemia prevention is hindered. To address this, mandatory screening policies are necessary in Bangladesh.

The findings of this study should be interpreted in light of certain limitations. First, it relied on a convenience sample of students who voluntarily joined the carrier screening, which may not represent the wider student body or the general population. Their positive attitudes might be a consequence of their decision to participate [3]. Second, the cross-sectional design captures a single point in time and does not allow for the establishment of causal relationships or the tracking of changes in KAP over time [58]. Finally, the use of a self-administered questionnaire may have introduced social desirability bias, potentially inflating favorable responses [59].

Conclusions

The findings of this study indicate that university students in Bangladesh lacked sufficient knowledge about thalassemia, particularly regarding the hereditary nature of the disease, with many respondents incorrectly perceiving it as blood-borne. These gaps reflect limitations in existing public health communication and emphasize the importance of more personalized interventions. However, university students demonstrated strong support for preventive measures, including premarital and prenatal screening, which provide a unique opportunity to advance national strategies. To mitigate these challenges, it is recommended to implement targeted educational

campaigns emphasizing the genetic nature of thalassemia, advocate for mandatory premarital screening policies, and integrate accessible genetic counselling services for carriers and affected families. Through dispelling prevalent misconceptions and capitalizing on favorable attitudes, Bangladesh has the potential to achieve meaningful reductions in the future burden of thalassemia.

Competing interests

The authors declare that they have no competing interests.

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