



Knowledge and Attitudes towards Thalassemia among Public University Students in Bangladesh

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Abstract

Background: Thalassemia is the most common congenital single-gene condition globally, characterized by a lack of or reduced synthesis of either the α - or β -globin chains and passed down from parents to offspring. This study aimed to determine the level of knowledge of thalassemia among Bangladeshi students from universities and their opinion on prevention. **Methods:** A cross-sectional descriptive online survey was conducted on public university students in Bangladesh using a structured questionnaire between June and November 2020, completed by students online. Demographic characteristics, knowledge, and attitude of the participants were assayed with 10 questions on each topic. The data were analyzed using Python. Descriptive statistics methods such as frequencies and percentages were used to present data. **Results:** A total of 660 students participated in the online survey. The average age of the respondents in this study was 21.97 years, with a standard deviation of 2.9. Most of the students, 611(89.72%), had heard about Thalassemia, yet only 248 (36.42%) students had good knowledge of Thalassemia. The knowledge level of students had no significant relationship with sex (p -value = 0.0819), marital status (p -value = 0.2281), and year of study (p -value = 0.4619), but

had a considerable difference with the field of study (0.0042). However, 478 (78.36%) participants showed a positive attitude toward "Premarital Screening" to prevent Thalassemia. **Conclusion:** Long-term and target-based preventive initiatives are recommended for university students and the general population of Bangladesh, where the rate of consanguineous marriage is high. These initiatives would provide crucial information and increase awareness of premarital screening and genetic counseling to prevent thalassemia.

Keywords: Thalassemia; Awareness; Student community; Bangladesh.

Abbreviations: CBC, Complete blood Counts; SOFT, Single Tube Osmotic Fragility Test; ANOVA, Analysis of Variance; CVS, Chorionic Villus Sampling; GDP, Gross Domestic Product; BDT, Bangladeshi Taka .

Introduction

Thalassemia is the most prevalent congenital single-gene disorder globally, characterized by a deficiency of or decreased synthesis of either the alpha- or beta-globin chains in the hemoglobin protein of red blood cells and is passed down from parents to children. Thalassemia is a genetic hematologic disorder in which most patients are unable to produce functional red blood cells and must depend on blood transfusions for the rest of their lives (Ishfaq, 2016). Although Thalassemia is preventable, it remains highly prevalent, and the absence of curative therapy made it a global health concern (Alam et al., 2020). Clinical manifestation of Thalassemia is classified into α , β ,

Significance | Prevention of Thalassemia with awareness

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γ , or δ - categories, α and β -thalassemia are the most widespread. Beta-thalassemia is classified into three categories based on severity and genetic mutation: severe, minor, and moderate. Inheritance of Thalassemia genes follows autosomal recessive trait. Mild forms of Thalassemia are caused when the offspring inherits one copy of the mutated allele of the globin gene from any parent and inherits a functional copy of the globin gene from another parent. Inheritance of two mutated copies of the globin gene from both parents manifests in the most severe life-threatening form of Thalassemia (Alam et al., 2020; Ebrahim et al., 2019).

Though preventable, Thalassemia is prevalent in Southeast Asia, the Indian subcontinent, the Mediterranean, Middle Asia, Central Asia, and West Africa (Alam et al., 2020). Historically, Thalassemic mutations are first reported from Mediterranean natives, that spread to Asia and Africa due to migration to non-endemic areas, Thalassemia spread across Europe and North America. It is a disease that can be avoided, as countries like Italy, Greece, and Cyprus have proved that Thalassemia could be prevented through pre-marital screening (Ishfaq, 2017). Repeated blood transfusions, which are symptomatic, or permanent therapies, such as bone marrow transplantation, are out of reach for most patients in developing nations (Ebrahim et al., 2019). Although no cure exists, prevention is possible, implementable, and successful in some areas (Karachi, 2017). Every year, over 14,000 Thalassemia children are born in Bangladesh, with the condition affecting 10% of the general population and more than 30% of the tribal population (*Thalassaemia: The Present and Future for Bangladesh* | *Daily Star*, n.d.).

The number of thalassemia patients increases due to a lack of understanding, poor educational activities, lack of awareness of the cause, detection, transmission, and management of the disease, socioeconomic causes, religious choices, and cultural limitations (Ishfaq, 2017). Thalassemia can be reduced through preventive health services, awareness, screening, pre-nuptial genetic counseling, and prenatal diagnosis in consanguineous marriages. Complete blood counts (CBC) combined with a single-tube osmotic fragility test (SOFT), and hemoglobin electrophoresis is used to corroborate the results. Chorionic villus sampling is also employed to screen unborn babies (Hashim et al., 2021).

Knowledge and social conscience of youth determine the quality of life for future generations. Accurate knowledge and comprehension of conditions regarding medical conditions made difference in the social management of medical conditions in several countries of the world (Miri-moghaddam et al., 2021). This study aims to determine the degree of awareness and attitudes toward Thalassemia among public university students in Bangladesh. Thus, the long-term goal of this study is to understand how awareness campaigns could be more effective in premarital screening and genetic counselling in preventing Thalassemia.

Methodology

Study Design

A cross-sectional descriptive online survey was designed, and the response was collected between June to November 2020 from public university students in Bangladesh. Graduate and undergraduate students from several public universities and students from various fields of study such as arts and humanities, science, business, and social science were included in the survey. Participants who used social media were also included (Facebook, Instagram, WhatsApp, etc.). Incomplete surveys and those who refused to participate in the study were disqualified. There were no incentives or rewards offered to participants, and all responses were anonymous and voluntary. The study participants were chosen using the snowball sampling technique.

Instruments

The research team devised a self-reported questionnaire after conducting a thorough literature review (Akter et al., 2020; Alam et al., 2020; Ebrahim et al., 2019; Hashim et al., 2021; Hossain et al., 2017a; Ishfaq, 2016; Ishfaq et al., 2016; Kolnagou & Kontoghiorghes, 2009; Miri-Moghaddam et al., 2014; Uddin et al., 2017) on individuals' thalassemia knowledge, attitudes, and practices. The questionnaire was in English. A brief explanation of the research background, aims, eligibility requirements, confidentiality statement, enrollment criteria, and the online consent form appeared along with the questionnaire. Participants then completed structured surveys with demographic information, an awareness section with ten multiple-choice questions, and an attitude section with ten questions.

Data collection

The researchers gathered data from social media networks (Facebook, WhatsApp) using google forms as an online survey tool. Participants were asked if they were willing to participate in the study via "yes/no" responses. They were provided access to the entire questionnaire if they replied "yes." Otherwise, a blank survey form was submitted right away. 685 people completed the online survey, with 660 qualifying the inclusion criteria in the final analysis after quality control.

Data Management and Analysis

Pandas (a Python-based data management application (<https://pandas.pydata.org/>)) was used to clean completed surveys exported as excel files from Google Forms. The study involved 681 students; however, only 660 responses were included in the final analysis. The cleansed data were examined using descriptive statistics such as frequency distribution, percentage, and mean age computation. The Chi-Square test was used to investigate the relationship between gender, the field of study, education level, and thalassemia knowledge and attitudes. T-test was used to compare the mean knowledge difference between two groups (Sex, Marital Status) and Analysis of Variance (ANOVA) to compare means between more

than two groups (Field of Study, Year of Study). A statistically significant p -value of 0.05 was considered.

Scoring of Knowledge Level

The participants were asked ten knowledge-related questions, which were graded on a scale of 0 to 10. Google forms auto-scoring methods were used to determine the knowledge scores. Poor, average, and good knowledge are the three levels of knowledge (rate of correct response poor \leq 33%, 33- 67% average, $>$ 67% good).

Results

An online survey on thalassemia awareness depicted the state of knowledge and attitude toward the dreaded disease and its management among university students in Bangladesh.

Table 1 shows the distribution of responses ($n=660$) to queries about thalassemia source information. 611 students (89.72%) had heard of Thalassemia before. On the other hand, 70 students (10.28%) were clueless. Electronic media (45.41%), friends and family (41.80%), healthcare professionals (18.20%), print media (25.90%), seminars and lectures (25.74%), and other sources were the primary sources of information for these 611 students (72%).

Table 2 summarizes the results of our socio-demographic variables. We've worked with students from public universities (students in undergraduate and Masters). The participants included 336 men (55.08%) and 274 women (44.92%). There were 562 unmarried students (92.13%) and 48 married students (7.87%). In this study, 414 students (67.87%) majored in science, 72 students (11.80%) majored in business, 69 students (11.31%) majored in humanities, and 55 students (9.02%) majored in social science. Around 240 students (39.34%) were in their first year, 114 (18.69%) in their second year, and 107 (17.54%), 101 (16.56%), and 48 (7.87%) in their third, fourth, and master's year, respectively.

No significant differences were observed between the males and females, and married and unmarried groups in terms of knowledge after the student t -test (p -value $>$ 0.05) (Figure 1A & 1B) (Supplementary Table 1). Again the Analysis of Variance (ANOVA) was used to identify the differences among various groups like students from different fields and years of study. In this case, a statistically significant differences (p -value $<$ 0.05) were observed among various groups representing different fields and years of study in terms of knowledge (Figure 2A & 2B) (Supplementary Table 2).

Table 3 shows the associations between sociodemographic factors and thalassemia knowledge among students. The academics had quite different perspectives on Thalassemia. Science students had the highest knowledge level (1.97%), followed by social and business students, with (3.61%) and (3.11%), respectively. A considerable number of science students (7.54% and 29.84%) had weak and average knowledge levels respectively. Students in the arts and humanities, social science, and business faculties all had low and average

knowledge levels that were nearly identical (1.97%, 2.13%, 2.46%). P -values for sociodemographic factors differ between students. For several variables such as sex, marital status, the field of study, and year of study, p -values of 0.0819%, 0.2281%, 0.0042%, and 0.4619% were discovered.

Table 4 shows the opinions of students about Thalassemia ($n=611$). The percentage of pupils made it up since they didn't know anything about Thalassemia. Only 35.25% of students would accept a thalassaemic association, while 29.67% were against social contact with Thalassemic patients and 35.08% were neutral. Nearly 77.05% stated they would consult a wedding planner before getting married. Only 78.36% favored blood testing before marriage to avoid the birth of a thalassaemic kid, while 4.92% were opposed, and 16.72% were undecided. Only 90.98% said thalassemia education should be available to the general public. The majority of people (91.48%) said they wanted to donate their bone marrow to their relatives. About 80.82% felt that taking part in a "Thalassemia Prevention Programme" if one is offered is a better approach to avoiding Thalassemia, while 3.11% were unsure.

Discussion

This study aimed to see how well Bangladeshi public university students understood Thalassemia and how they felt about it. Our research helped to fill knowledge gaps about Thalassemia. Thalassemia is a genetic hemoglobin synthesis disorder that causes anemia and insufficient erythropoiesis due to faulty and unequal globin chain production.

Our major findings reveal that awareness of Thalassemia is low, with one-third of the participants (10.28%) having never heard of the disease. Even many who had heard of Thalassemia lacked a basic understanding of the disease. The most common sources of information for people who had heard of Thalassemia were electronic media (41.41%), friends and relatives (41.80%), print media (25.90%), seminars, and lectures (25.74 percent%), and others (6.72%). Physicians performed a small impact on their patients' comprehension of Thalassemia (18.20%). This could be because the publications and awareness drives are all centered around International Thalassemia Day instead of throughout the year. In our study, 35.25% of students had positive attitudes toward Thalassemia and wanted to embrace a connection with a thalassaemic patient joyfully, while 29.67% had negative attitudes and 35.08% had neutral attitudes (Table 4). A negative attitude could stem from ignorance and a lack of empathy. When it came to the relevance of a blood test before marriage to prevent the birth of a thalassaemic child, 78.36% of students agreed, 4.92% disagreed, and 16.72% were undecided (Table 4). Nearly 77.05% of students agreed to visit a doctor before marrying to avoid Thalassemia. In our poll, 44.10% of respondents stated they would donate blood to a patient with Thalassemia (Table 4). Around 79.51%

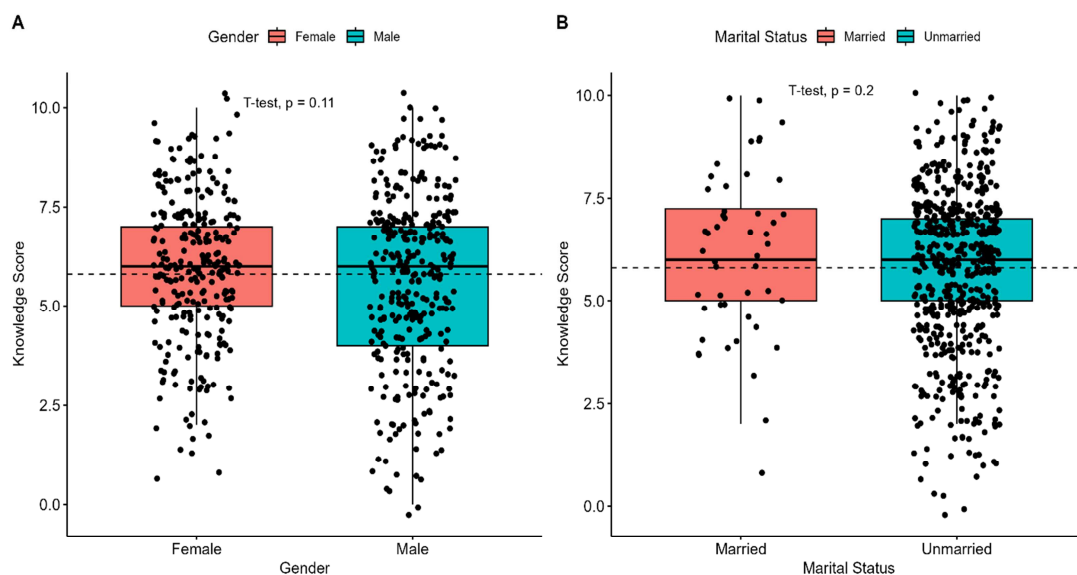


Figure 1 | (A) Knowledge score difference between male and female; (B) Knowledge difference between married and unmarried students. The student t-test showed that there was no statistically significant difference (p -value > 0.05) in knowledge among groups.

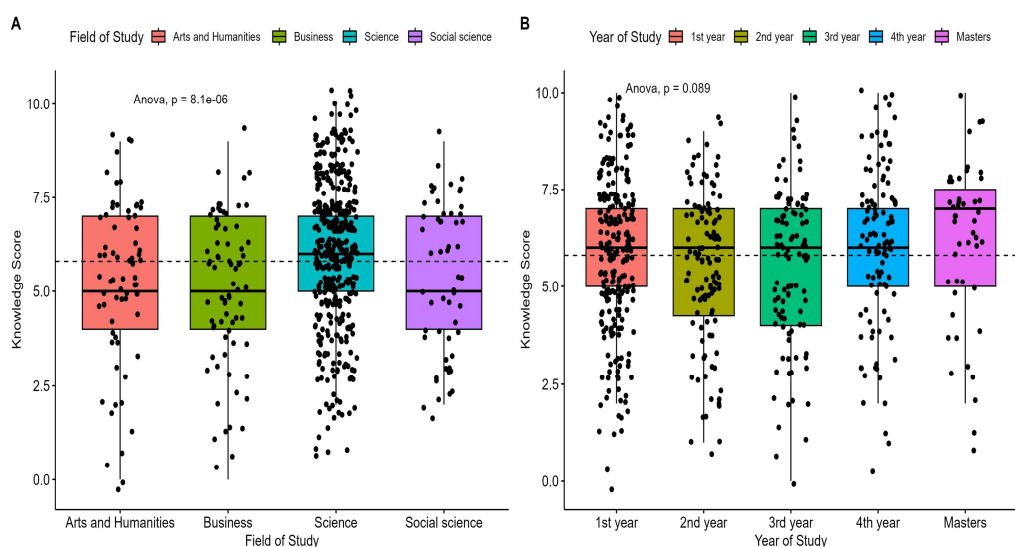


Figure 2 | (A) Knowledge score difference among students from different fields of study (B) Knowledge difference among the students who are studying in different years. The Analysis of Variance (ANOVA) was used to identify the differences among groups. The ANOVA results revealed that there was no statistically significant difference (p -value > 0.05) in knowledge among groups.

Table 1 | Distribution of responses (n = 660) to questions about the information source for thalassemia

Background Information	N (%)
Have you previously heard about thalassemia?	
Yes	611 (89.72)
No	70 (10.28)
If yes, what information sources did you hear about thalassemia?	
Electronic Media	277 (45.41)
Friends and Family	255 (41.80)
Healthcare Professionals	111 (18.20)
Print Media	158 (25.90)
Seminar & Lectures	157 (25.74)
Others	41 (6.72)

Table 2 | Demographic characteristics of participants and the proportion of the participants who heard about thalassemia

Variables	Response who heard about thalassemia n (%)
Sex	
Male	336 (55.08)
Female	274 (44.92)
Marital Status	
Unmarried	562 (92.13)
Married	48 (7.87)
Field of Study	
Science	414 (67.87)
Business	72 (11.80)
Arts and Humanities	69 (11.31)
Social science	55 (9.02)
Year of Study	
1st year	240 (39.34)
2nd year	114 (18.69)
4th year	107 (17.54)
3rd year	101 (16.56)
Masters	48 (7.87)

Table 3| Demographics of the participants in the survey for Thalassemia Awareness in Bangladesh

Variables	Level of Knowledge			p-value
	Weak	Average	Good	
Sex				
Male	56 (9.18)	142 (23.28)	138 (22.62)	0.0819
Female	30 (4.92)	134 (21.97)	110 (18.03)	
Marital Status				
Married	3 (0.49)	22 (3.61)	23 (3.77)	0.2281
Unmarried	83 (13.61)	254 (41.64)	225 (36.89)	
Field of study				
Science	46 (7.54)	182 (29.84)	186 (30.49)	0.0042
Arts & Humanities	12 (1.97)	36 (5.90)	21 (3.44)	
Social Science	13 (2.13)	20 (3.28)	22 (3.61)	
Business	15 (2.46)	38 (6.23)	19 (3.11)	
Year of Study				
1st-year	31 (5.08)	112 (18.36)	97 (15.90)	0.4619
2nd-year	19 (3.11)	56 (9.18)	39 (6.39)	
3rd-year	17 (2.79)	47 (7.70)	37 (6.07)	
4th-year	13 (2.13)	44 (7.21)	50 (8.20)	
Masters	6 (0.98)	17 (2.79)	25 (4.10)	

Table 4| Attitudes towards thalassemia awareness among participants (n = 611)

Questions	Attitudes towards Thalassemia		
	Positive N (%)	Negative N (%)	Neutral N (%)
I would happily accept a relationship with a thalassemic person	215 (35.25)	181 (29.67)	214 (35.08)
I would like to consult with a consultant before getting married.	470 (77.05)	34 (5.57)	106 (17.38)
I would undergo necessary blood tests before marriage to avoid the birth of a thalassemic child.	478 (78.36)	30 (4.92)	102 (16.72)
I would like to donate my blood to a thalassemia patient.	269 (44.10)	157 (25.74)	184 (30.16)
I would like to inform others about the dangers of thalassemia.	536 (87.87)	21 (3.44)	53 (8.69)
I would like to consider the importance of public education regarding thalassemia.	555 (90.98)	12 (1.97)	43 (7.05)
I would consider it if my family has a significant thalassemia patient and I am the only candidate for bone marrow transplantation.	558 (91.48)	10 (1.64)	42 (6.89)
I should accept the probability of a child just because of a family marriage.	485 (79.51)	14 (2.30)	111 (18.20)
I would like to participate in the "Thalassemia Prevention Program" if someone introduces it.	493 (80.82)	19 (3.11)	98 (16.07)
I would like to tell friends about thalassemia after completing this survey.	506 (82.95)	18 (2.95)	86 (14.10)

believed they should expect to have a child simply because they married into a family with a history of Thalassemia, whereas 2.30% strongly disagreed and 18.20% were undecided (Table 4). Approximately 87.87 percent of students stated they would inform others about Thalassemia's dangers. In the context of Thalassemia, about 90.98% were aware of the importance of public education (Table 4). This is supported by the fact that 80.82% of students stated they would participate in a "Thalassemia prevention program" if one was offered, whereas 16.07% said they were neutral.

Like lower-middle-income countries, Bangladesh doesn't have medical insurance or other social security/ safety net regarding high medical expenses (Hossain et al., 2017a). Access to cutting-edge interventions such as gene therapy or bone marrow transplant is minimal (Hossain et al., 2017a). The efforts to minimize preventable conditions such as Thalassemia are centered around awareness drives once a year, which is too little for a population with a high density of heritable hemoglobinopathy (Akter et al., 2020). Upto 10% of the Bangladeshi population could be Thalassemia carriers, with 15000 new Thalassemia-positive births annually. The cost of treatment comes to BDT 20,000 (USD 230) monthly, whereas the GDP per capita is USD 1969 (Regional Desk Review of South East Asia, WHO 2021). Treatment provisions are also limited, with one specialized hospital and several district hospitals offering transfusion and iron chelation/ hydroxyurea medication (Hossain et al., 2017b). The better option for fighting Thalassemia is the reduction of Thalassemia births with premarital screening, prenatal screening, and target screening (Hossain et al., 2017a). Cypress has reduced Thalassemia births to a negligible number over the last decade through an awareness campaign and premarital screening (Kolnagou & Kontoghiorghes, 2009). This study was an incremental step toward assaying the knowledge gap to devise an action plan that effectively disseminates information within the shortest time.

The findings of this study support the reports from other locations in Bangladesh. A nationwide survey of 1248 people revealed about half the participants was rightly informed about thalassemia and its risk factors, while 72.5% were aware of pre-marital blood test for Thalassemia screening, 68.2% were in favor of premarital screening and 85.3% were compassionate enough to donate blood for existing Thalassemic patients (N. E. Alam et al., 2022). The study by Hossain et al. (2020) revealed the urban-rural divide and prejudice against Thalassemic patients among college students. This study reported unwillingness from 39% of participants to donate blood for patients, however, 88% of participants were in favor of pre-marital screening (Hossain et al., 2017a). Pervin et al. (2021) reported 49%, 43.6%, and 7.1% of participants had poor, average, and good knowledge of Thalassemia and its management, and that good knowledge and positive attitude toward the prevention of Thalassemia was correlated

to science education, family history of Thalassemia and higher monthly income in the families (Pervin et al., 2021).

Our research has some limitations: for starters, all data for this study was not collected through face-to-face interviews because of the COVID-19 pandemic situations, and their responses may not be accurate due to social desirability factors. Second, we did not individually measure each student's level of awareness. Additional research is needed to discover differences in knowledge based on gender, education, marital status, and awareness level. Due to a lack of time, this study focused only on the non-medical community's management. Finally, because the questionnaire was not checked and was based on past research, the self-reported questionnaire may have resulted in response bias. Thalassemia is becoming a rising public health concern in Bangladesh. According to the study, highlighting the need to educate individuals about the dangers of consanguineous marriage is the most significant part of preventing Thalassemia.

Additionally, thalassemia testing for all couples should be made accessible and necessary. A thalassemia prevention program should be designed and interventions deployed throughout Bangladesh to eradicate the disease. According to this curriculum, students remembered their carrier status and took prophylactic measures.

Conclusion

Finally, this study accomplishes the investigation's purpose of analyzing thalassemia knowledge and attitudes among Bangladeshi public university students. They had inadequate knowledge and attitudes about Thalassemia, according to our findings. The bulk of the pupils was just vaguely familiar with the disease or knew very little about it. The majority of these students had no idea they had a hereditary condition. Furthermore, depending on their socioeconomic situation, kids' levels of knowledge and awareness can differ substantially. Large-scale experiments with a diverse study population are required to confirm the findings. Because they impact students' minds, the mass media (print, television, and radio) must contribute to thalassemia awareness. Despite a countrywide mandated thalassemia premarital examination screening program, the incidence of high-risk Thalassemia has not decreased much. On the other hand, a far larger scale of health education about thalassemia awareness and prevention is required. The study recommends hosting seminars and public lectures for thalassemic families and the general public to understand thalassemia disease and prevention better. People will recognize the disease's importance in their daily lives. Therefore raising awareness through community participation will be beneficial. As a result, implementing a complete prevention program that includes premarital counseling, genetic testing, prenatal screening, and community-based awareness campaigns may help reduce the disease burden. Overall, this paper will substantially contribute to

thalassemia prevention in resource-constrained nations like Bangladesh.

Author Contribution

Conceptualization: JH. Data collection: RGM, SAM, SM. Analysis and interpretation of data: JH, ST. Drafting of the manuscript: JH, SAM, RGM, SM. Editing: JH, ST. Critical revision of the manuscript: ST, JH, SS. Supervision: ST, SS.

Ethical Approval

This study adhered to the most significant ethical standards imaginable, and participants gave their informed consent. The Helsinki Declaration was observed in all procedures. Anonymity and confidentiality were maintained. Anonymity and confidentiality were maintained. We obtained ethical approval for this study from the Ethical Review Committee of CHIRAL Bangladesh (Reference No: CHIBAN24MAY2020-0001)

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Competing financial interests

The authors declare that they have no potential conflict of interest in publishing this research output.

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