Knowledge, Attitude and Practice (KAP) study for Thalassemia:

A Cross-sectional Study at BRAC University, Bangladesh

By

Afsana Mim

Student ID - 17226016

A thesis submitted to the Department of Mathematics and Natural Sciences in partial fulfillment of the requirements for the degree of

B.Sc. in Microbiology

Department of Mathematics and Natural Sciences

BRAC University

April 2023

Declaration

It is hereby declared that

1. The thesis submitted is our own original work while completing a degree at BRAC University.
2. The thesis does not contain material previously published or written by a third party, except where this is appropriately cited through full and accurate referencing.
3. The thesis does not contain material that has been accepted or submitted, for any other degree or diploma at a university or other institution.
4. We have acknowledged all the main sources of help.

Student's Full name & Signature:

_____

Afsana Mim

Approval

The thesis/project titled "Knowledge, Attitude and Practice (KAP) study for Thalassemia: A Cross-sectional Study at BRAC University, Bangladesh" submitted by

Afsana Mim

17226016

Of Summer 2022 has been accepted as satisfactory in partial fulfillment of the requirement for the degree of Bachelor of Science in Microbiology on the 9th of April, 2023.

Examining Committee:

Supervisor:

(Member)

_____

Akash Ahmed

Senior Lecturer, MNS Department

BRAC University

Program Coordinator:

(Member)

_____

Nadia Sultana Deen, PhD

Associate Professor, Department of Mathematics and Natural Sciences

BRAC University

Departmental Head:

(Chairman)

_____

A F M Yusuf Haider, PhD

Professor and Chairperson, Department of Mathematics and Natural Sciences

Brac University

Ethics statement

This study was conducted after obtaining ethical clearance from icddr,b with the reference code PR-22053.

Acknowledgement

I would like to express my sincere gratitude and appreciation to all those who have supported and guided me in completing my thesis. First and foremost, I would like to thank Dr. Sharmine Zaman Urmee, Manager, Clinical Hematology and Cancer Biology Lab, at icddr,b. Without her permission, I would not have been able to work in such a lab with an amazing environment and use the lab facilities.

I am also deeply grateful to my academic supervisor, Akash Ahmed, Senior Lecturer, at BRAC University, for his constant encouragement, guidance, and constructive feedback throughout this journey in my academic life. His invaluable support has been crucial in the successful completion of my thesis.

I would like to extend my special thanks to my co-supervisor, Anamul Hasan, Senior Research Officer, Clinical Hematology and Cancer Biology Lab, icddr,b. Without his support, dedication and assistance, I would not have been able to complete my thesis. He was incredibly generous with his time & knowledge, providing me with guidance and support whenever I needed it, despite his busy schedule.

Finally, I would like to show my sincere gratitude to all the 431 students who voluntarily participated in the survey which was necessary and a prime part of my thesis.

Abstract

Thalassemia is the most common non-communicable autosomal recessive blood disorder posing major public health concerns in many parts of the world including Bangladesh. Having definitive treatments remained largely inaccessible, the approach to reduce the burden is recommended by the prevention through screening. However, the implementation of such preventive measures is still poorly regulated in Bangladesh. So, thalassemia prevention and education are important to disseminate among the targeted youth population as they are the potential future generation of a country. This study aims to investigate the knowledge, attitude and practice (KAP) towards thalassemia among 431 students currently studying at BRAC University. This was a cross-sectional survey conducted from 1 October 2022 to 31 January 2023 to evaluate the participants' knowledge, attitudes, and practices towards thalassemia using a self-administered questionnaire constructed by Kobo Toolbox. The questionnaire comprised of 39 questions to assess KAP. The Bloom's cut-off points were interpreted as 80%–100% as good, 60%–79% as moderate and <60% as poor in our KAP assessment. The individual KAP scores on knowledge, attitude and practice showed heterogeneous outcome among the participants with approximately 30%, 50% and 19% good scores, respectively. The association between overall KAP score and different socio-demographic factors showed that being female, engagement in extracurricular activities, having parents as first-generation graduates and their occupation directly linked in health/education sectors demonstrated good KAP scores among the participants in this study. From this study, it can be extrapolated that having good knowledge, better attitude and the best practice towards thalassemia by the young population should genuinely be needed as a significant cultural shift in Bangladesh.

Table of Contents

List of Tables

List of Figures

1. Introduction

Anemia refers to a condition in which the body has decreased hemoglobin concentration or RBC mass compared with age-matched controls [1, 2] . The World Health Organization (WHO) has set a reference range for normal blood hemoglobin concentration based on age and sex in order to make a broad approach to the diagnosis of anemia By this criterion, anemia is present if the hemoglobin concentration in the blood is less than 13g/dL in men or 12g/dL in women [3] . Anemia results in tissue hypoxia and initiates compensatory processes. The signs and symptoms of anemia syndrome are the consequence of the interaction of these processes. Individuals with anemia may exhibit symptoms such as fatigue, dizziness, and dyspnea; however, moderate anemia sometimes presents with no outward symptoms. Pallor of the conjunctiva, face, nail beds, and palmar wrinkles are signs of anemia; nevertheless, the lack of pallor does not exclude the possibility of anemia. Anemia has become one of the most common reasons for medical visits due to its high incidence among children, young women, and the elderly. Because of malnutrition, hereditary, parasitic, or viral disorders, anemia is unusually prevalent in impoverished nations [2, 4]. Depending on factors including population, age, sex, and normal hemoglobin levels, anemia prevalence can range from 2.9% to 61% [5] .

We can categorize anemia from three aspects- pathogenesis, red cell morphology, and clinical presentation. In actuality, classification based on fundamental red cell morphological characteristics, such as mean corpuscular volume (MCV), enables a more rapid diagnostic approach. According to the mean corpuscular volume (MCV), anemia can be categorized as microcytic, normocytic, or macrocytic [4] Nonetheless, it is more practical to begin with the hemogram's analytical parameters in routine clinical practice. We can categorize anemia according to MCV into three categories: microcytic (MCV< 80 fL), normocytic (MCV = 80–100 fL), and macrocytic (MCV > 100 fL) [6] .

Correlations exist between MCV and mean corpuscular hemoglobin (MCH), which gives the average amount of hemoglobin found in a single erythrocyte as measured in picograms (normal range: 27-32 pg). As a result, MCV and MCH either decline together (microcytic, hypochromic anemia) or increase together (macrocytic, hyperchromic anemia). When dealing with microcytic anemia, the three main diagnostic options are iron deficiency anemia (IDA), thalassemia, and

anemia of chronic diseases (ACD). If there is no prior history of lead exposure, the fourth option, sideroblastic anemia is not taken into account while making the initial diagnosis. While dealing with normocytic anemia, determining the underlying reasons and potential for treatment is of paramount importance. The causes include a lack of nourishment, renal failure, and hemolytic anemia [4, 7] . Nutritional mixed anemia, which includes iron, folic acid, and vitamin B12 insufficiency, is common. Blood cell analyzers are often used to detect macrocytosis. Although 60% of patients with macrocytosis do not have anemia, the prevalence ranges from 1.7% to 3.9%. Macrocytosis is associated by megaloblastosis in vitamin B12 and folic acid depletion as well as in other conditions [4] .

Thalassemia is a set of inherited blood disorders resulting from defects in the synthesis of one or more globin chains that serve as the backbone of hemoglobin (alpha or beta). Classification of thalassemia is based on which globin chain is affected. There are two major types – alpha & beta thalassemia [8, 9] .

1.1 Alpha thalassemia

In case of alpha thalassemia, the production of alpha globin chains is either reduced or completely absent. Deletions in one or both alpha globin chains are the most common cause of alpha thalassemia whereas non deletional defects are less common [10] . The synthesis of the alpha chain is governed by four alpha genes, two of which are located on each copy of chromosome 16. Depending on how many of the four alpha globin genes are absent or inactive, the clinical severity increases. Alpha thalassemia can be classified broadly as Silent Carrier, Alpha Thalassemia Trait, Hemoglobin H disease, Hemoglobin Constant Spring, Hb Bart's [11] .

Silent Carrier (-α/αα): In this case, one alpha gene is absent or damaged, whereas the remaining three are normal. Even though the carriers are asymptomatic, they can still pass the defective gene to their offspring [12] .

Alpha Thalassemia Trait: People with alpha thalassemia minor [(-α/-α) or (--/αα)] have two defective alpha genes. The only conceivable health issue for someone who has the thalassemia trait is a mild case of anemia. This can be the result of a 'trans' deletion, in which the mutated genes are located on separate chromosomes, or a 'cis' deletion, in which they are located on the same

chromosome. Alpha thalassemia trait is commonly found in Southeast Asia, the Indian subcontinent, and some parts of the Middle East [13] .

Hemoglobin H disease: In this condition, three out of four alpha genes are missing or inactive. Therefore, there are inadequate number alpha globin chains to combine with beta chains in order to make normal hemoglobin. The excess beta globin chains subsequently bind together, forms tetramers and give rise to a form of hemoglobin called Hb H. Individuals with Hgb H typically experience a prolonged, consistent state of anemia. Due to its unstable & easily oxidizable nature, Hb H precipitates within mature erythrocytes and erythrocyte precursors. The typical consequences of this process are formation of insoluble inclusions, cell membrane damage, and ineffective erythropoiesis [10, 14, 15].

Alpha thalassemia major or hydrops fetalis: In this case, all four of the alpha globin-coding genes are deleted or inactive. As all the four genes are deleted, the production of alpha chains is inhibited. Due to the infant's inability to produce normal hemoglobin to deliver oxygen throughout the body, a fetus with this condition typically dies in the pregnancy or passes away shortly after birth [16] .

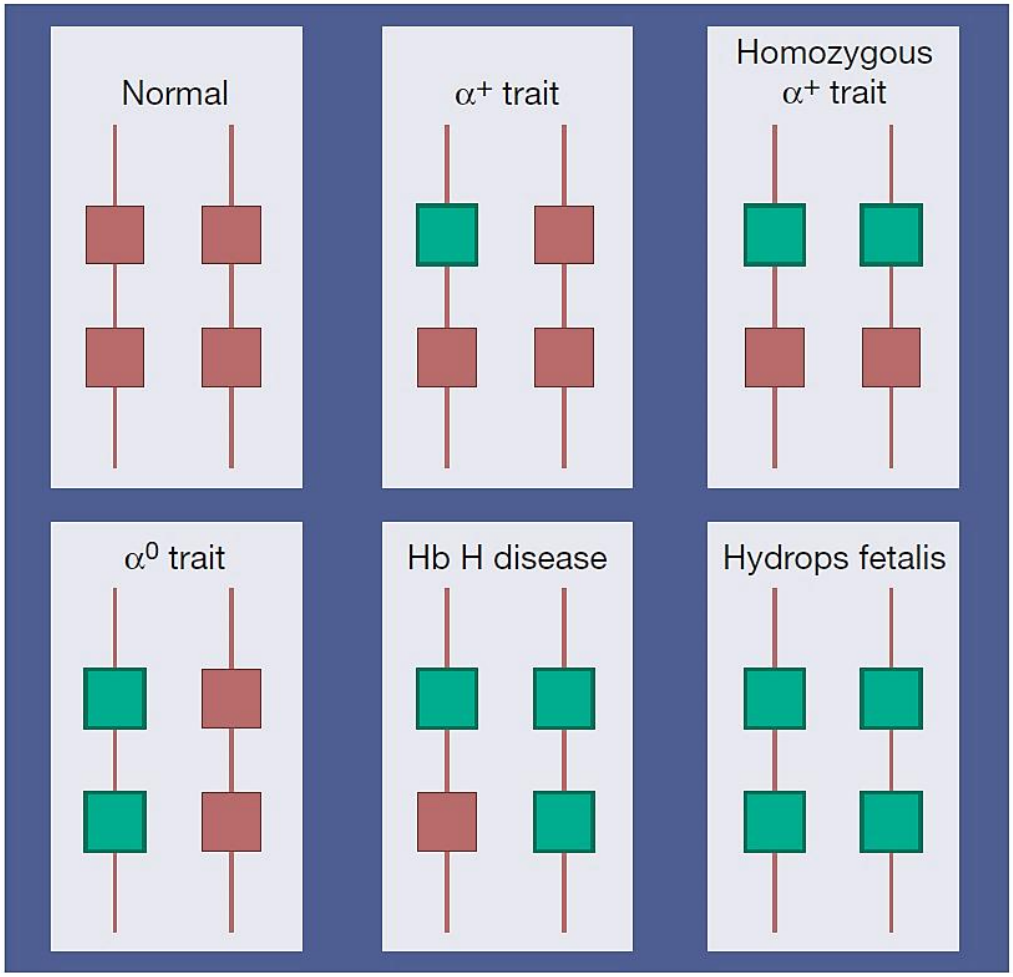

Figure 1: The genetics of α-thalassaemia. Each α gene may be deleted or (less frequently) dysfunctional. The maroon boxes represent normal genes, and the green boxes represent gene deletions or dysfunctional genes.[1]

1.2 Beta Thalassemia

With beta thalassemia, the production of beta globin chains of the hemoglobin tetramer is either reduced or totally absent. A partial or total globin chain deficiency occurs due to point mutation when one nucleotide is substituted by another in the beta globin chain present on chromosome 11. Beta thalassemia rarely results from gene deletions. It is mainly characterized as Beta thalassemia major, beta thalassemia minor and beta thalassemia intermedia [17] .

Beta thalassemia major (Cooley's anemia): If both parents are beta thalassemia trait carriers, this condition arises in around one in every four offspring. Either no beta chain (β^0) or a minimal quantity (β^+) is produced [18] .

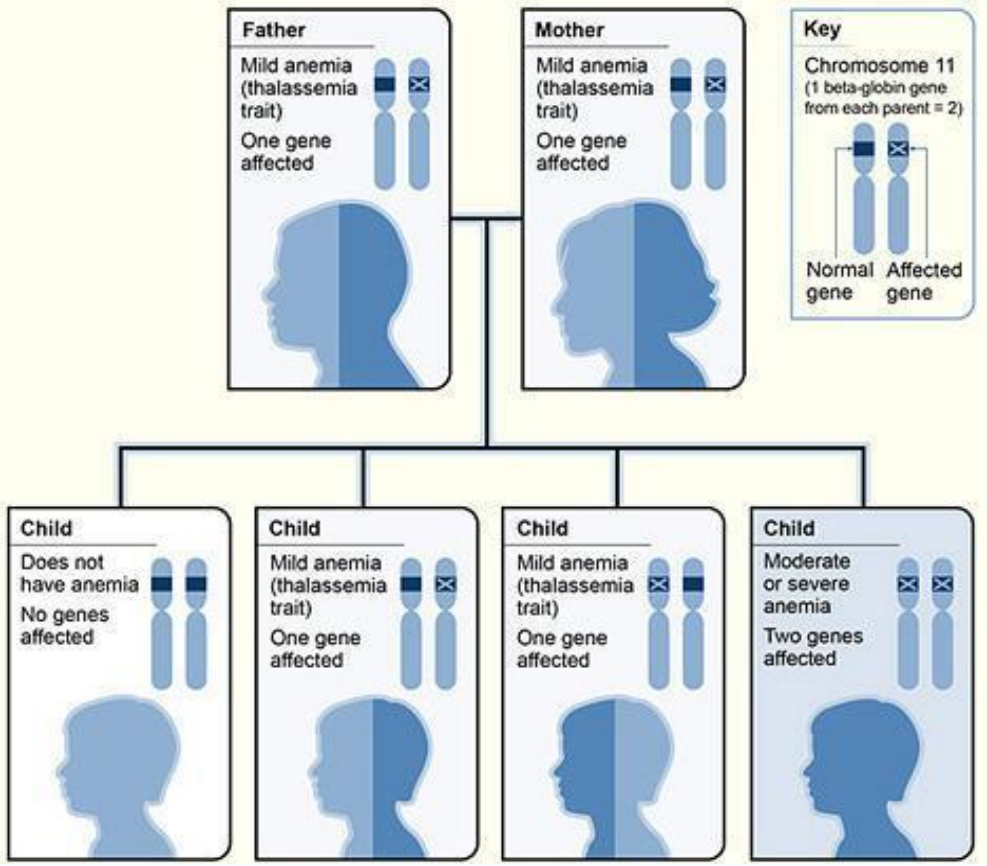

Figure 2 each parent has one altered beta globin gene. Each child has a 25% chance of inheriting two normal genes, a 50% chance of inheriting one altered gene and one normal gene (beta thalassemia trait), or a 25% chance of inheriting two altered genes (beta thalassemia major).

Beta thalassemia minor: It occurs when a person has one mutated gene that codes for defective beta globin chains or no beta globin chains at all. Individuals with beta thalassemia minor can still generate enough hemoglobin to meet the body's normal needs without significantly increasing erythroid hyperplasia [19] .

Beta thalassemia intermedia: Thalassemia intermedia is a clinical condition having intermediate severity between beta thalassemia major and beta thalassemia minor [20] .

1.3 Haemoglobinopathy

Haemoglobinopathy is another autosomal recessive blood disorder where altered hemoglobin production occurs due to mutation & gives rise to different Hb variants such as Hb E, Hb S, Hb D Punjab, Hb C etc. In Hb E variant, single point mutation (substitutional) occurs in the beta globin chain at position 26. With Hb S variant, single point mutation occurs at position 6 of the beta

globin chain. In case of Hb D Punjab, single point mutation occurs in the beta chain at position 121 [16, 21] .

1.4 Combination of Haemoglobinopathy & thalassemia:

Sometimes haemoglobinopathy can combine with thalassemia to create disorders such as Hb E / beta thalassemia. This condition is caused by inheriting the Hb E trait from one parent and the thalassemia minor trait from the other. It ranges from mild to fatal thalassemia where blood transfusion is required. The severity and clinical manifestations of the disease are affected by a number of factors, including the instability of Hb E, the imbalance of globin chain synthesis, and the levels of Hb F [21] .

1.5 Global Epidemiology of Thalassemia

According to Lilienfeld [22] , epidemiology refers to studying how a disease or physical condition is spread among the human population and the various factors that affect its spread. The distribution of an inherited disorder such as β-thalassemia is specific to certain regions, affecting particular people to a greater extent than others. The prevalence of this genetic condition has been influenced by environmental factors. In addition to this interaction between genetic and environmental factors, other confounding factors like customary marriages between relatives, programs to prevent disease, and population migrations have affected the number of carriers and people who are clinically affected globally. Among the various environmental factors that have influenced the epidemiology of thalassemia, the most crucial one is believed to be the protective effect of carriers when infected by Plasmodium falciparum. Because of this selection advantage, people carrying the mutant globin gene are more likely to live and reproduce in areas where the malarial parasite is or was dominant. The association between the sickle cell gene and α-thalassemia has been established more strongly. Still, the geographical coexistence of β-thalassemia and the malaria belt appears to reinforce the same relationship. Through epidemiological research, the well-known thalassemia belt has been mapped. Approximately 5-7% of the global population is estimated to carry a gene mutation that impacts the production or functioning of the hemoglobin molecule. These statistics indicate that around 330,000 infants are born each year with a hemoglobin-related genetic disorder, of which 83% are sickle cell disorders and 17% are thalassemia (approximately 56,000). The figures are based on data compiled by individuals and organizations that maintain databases using information from literature reports.

The specific numbers may vary from country to country. The Thalassemia International Federation (TIF) maintains its own database of thalassemia-related information [23].

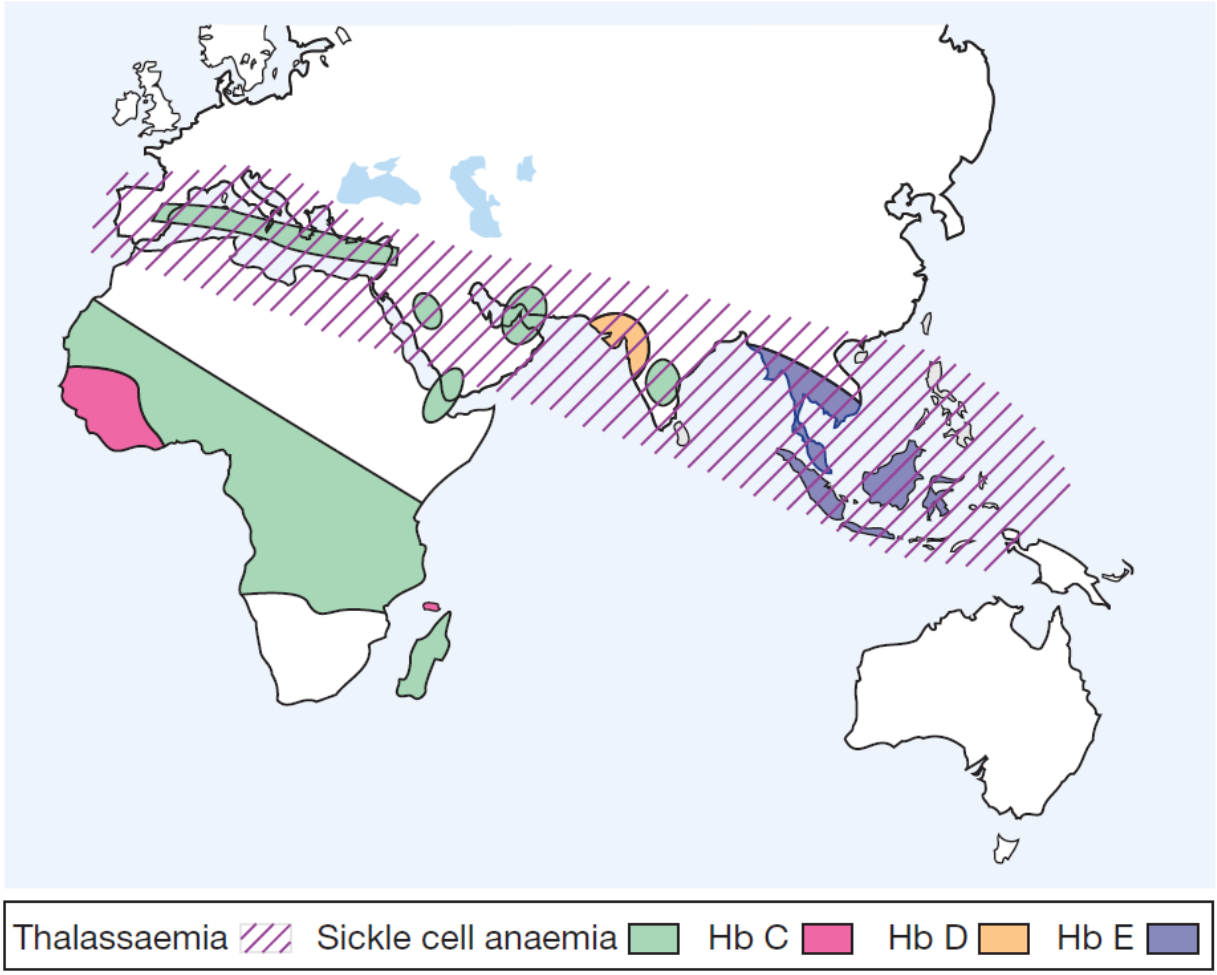

Figure 3: The geographical distribution of thalassemias and hemoglobinopathies.[1]

1.6 Epidemiology in Bangladesh

There are over 165 million people living in Bangladesh [24] . The under 5 mortality rate has steadily declined from more than 140/1000 Ibs in 1990 to roughly 30/1000 Ibs in 2020, and the IMR will be 24.7/1000 Ibs in that year, according to health indices. Improvements in essential interventions, such as the provision of health facilities, childhood immunizations, the management of diarrhea with oral rehydration salts and the treatment of tuberculosis have helped to attain these goals. Chronic illnesses like thalassemia management are still difficult. All regions have significant rates of beta thalassemia and Hb E prevalence, and regional prevalence has been established. With beta thalassemia, the total carrier frequency is 1-5% (mean 3.35%), while for Hb

E, it is between 6-10%. This would lead to a 0.35/1000 Ibs birth incidence of thalassemia syndromes. Its percentage is observed to be greater among endogamous tribal tribes, reaching 0.6/1000 Ibs [23, 25] .

Although being located in the thalassemia belt of the world, there is a paucity of knowledge regarding thalassemia's epidemiology, clinical course, mortality, complexity, and treatment outcome in Bangladesh. Bangladeshi general people have an inadequate understanding of the diseases. This lack of awareness is affected by geography and demographic characteristics, such as gender, marital status, education, employment, and socioeconomic level [26, 27]. In Bangladesh, more than two thirds individuals bear healthcare expenses out of pocket expenditure [28] . This financial burden may decrease their quality of life and have an impact on their reduced health seeking behavior. Besides, Bangladesh lacks a national health insurance system and a nationwide program to increase awareness, conduct career tests, and manage thalassemia patients [29] . Hence, the purpose of the study is to evaluate the level of knowledge, attitude & practice towards thalassemia among university students in Bangladesh.

1.7 Thalassemia Management

1.7.1 Blood Transfusion

Individuals with beta-thalassemia major (BTM) need frequent blood transfusions, supported by iron chelation therapy. They should get leuko-reduced RBCs containing at least 40 g of total hemoglobin. In addition, Anemia and/or clinical signs including failure to grow, reduced QoL, and co-morbidities like organ dysfunction and extramedullary hematopoiesis should be considered when deciding to initiate blood transfusions. Pretransfusion Hb levels are used to determine the volume of blood that will be transfused. In case of transfusion dependent thalassemia patients, it should be between 90 and 105 g/L, and posttransfusion Hb levels shouldn't rise above 140 to 150 g/L [30] .

1.7.2 Iron Chelation Therapy

Iron accumulation within tissues is the most critical result of life-saving transfusions in thalassemia leading to hepatic dysfunction and failure, endocrinopathies, and cardiac dysfunction. In order to perform this therapy, iron chelating agents such Deferasirox, Deferiprone and Deferoxamine are used [31] .

Deferasirox is taken by mouth once a day and causes iron excretion through feces. The dose is around 20 mg/k/d and can go up to 30 mg/k/d. It can be used to remove both hepatic and cardiac iron [8, 32]. Deferiprone is another oral chelator which binds with iron in a ratio of 3:1 and mainly eliminates iron through the urine. Around 90% of the DFP iron complex is eliminated in the urine, while the remaining 10% is eliminated in the feces. Although effective on its own, it can also be used in combination with deferoxamine on one or more days per week to get optimal results, as the two medications have an additive or even synergistic effect on iron excretion. When used alone, it is more effective at eliminating cardiac iron than deferoxamine [33] . The third medication, deferoxamine, has been used the longest. However, it is not orally active. Typically, it is given by subcutaneous infusion over eight to twelve hours for five to seven days per week. To further accelerate iron excretion, vitamin C might be provided. The majority of iron is lost in the urine, but up to a third of it can also be excreted through stools. Compliance is a serious concern due to the challenging administration. Patients with significant iron overload who are at risk of dying from cardiac failure receive this intravenously [16]

1.7.3 Bone Marrow Transplantation

Stem cell transplants are often only performed on persons with severe thalassemia who have not responded well to conventional treatments. It's crucial that a donor's human leukocyte antigen (HLA) type matches the recipient's HLA. The possible treatment to cure beta thalassemia major is an allogeneic bone marrow transplant. In this process, large levels of chemotherapy or radiation are used to eliminate the cells that are responsible for making abnormal blood cells. After that, the defective blood cells are subsequently replaced with bone marrow cells from a donor. In a 2016 study, researchers evaluated the outcomes among 1,493 thalassemia major patients who underwent a bone marrow transplant. They found high survival rates when siblings volunteered as donors and the recipient was younger [34, 35] . Another study found that when the donor wasn’t related to the person with thalassemia, the survival rates ranged from 62% to 100% [36] .

1.7.4 Gene Therapy

It is possible to cure thalassemia with gene therapy. In a procedure known as Beti-cel, stem cells are drawn out of the patient's blood and functional genes are introduced to their DNA using a viral vector. Chemotherapy is used to remove abnormal stem cells from the patient's body and the added stem cells are reinfused. Long-term hemoglobin synthesis is sustained by the functional genes [37]

1.8 Prevention

Prevention is the most significant advance in the field of thalassemia. Mediterranean countries like Greece, Italy, Sardinia and Cyprus successfully achieved it. The following four key aspects can help prevent the diseases: spreading awareness, detecting carriers, effective counseling, and prenatal diagnosis [32] .

Genetic Counseling**:** The most significant part of thalassemia prevention is Genetic counseling. Genetic counseling intends to enhance people's control over their own and their families' health by educating them about the resources available for diagnosis, treatment, and prevention. It also aims to clarify misconceptions regarding the origins of genetic disease [38]

Public Awareness and Education: The key requirement for the prevention of thalassemia is to increase awareness and education among health professionals, high-risk groups, the general population, and policymakers [39] .

1.8.1 Thalassemia screening

The key objective of thalassemia screening is to detect couples who are likely to have children affected by severe forms of thalassemia. Knowing whether or not one is a carrier of thalassemia can assist individuals in making decisions about their reproductive choices. In 1983, Cyprus implemented its first national prevention program, which included mandatory premarital thalassemia carrier screening and prenatal and antenatal diagnosis. Due to the implementation, the incidence of babies born with thalassemia in Cyprus decreased significantly from around 30 each year prior to 1983 to 0 in 2000 [40, 41] .

Antenatal Screening**:** Considering that most, if not all, pregnant women are given antenatal counseling, screening for severe thalassemia is feasible. If a pregnant woman is found to be a carrier, she can then undergo further testing, such as a full hemoglobin study, to determine the specific type of thalassemia she carries and the risk of having a child with a severe form of the disease. After that her husband will then be screened to determine his carrier status. If both couples are carriers of the same type of thalassemia, genetic counseling will be provided in addition to an invasive prenatal test to identify the fetal globin genotype. In order for antenatal screening to effectively prevent severe cases of thalassemia, abortion must be acceptable to the parents and legal in the area [42] .

1.9 KAP Study

KAP study, also known as knowledge, attitude & practice, was first introduced in the disciplines of family planning and population research in the 1950s. It intends to obtain what is known, believed, and done in relation to the subject of interest. In addition, KAP study is comparatively easy to design, execute, evaluate, and draw conclusions from. The study's findings offer the inputs necessary for creating a successful program as well as the starting point for assessing the program's effectiveness in the future [43] .

1.9.1 KAP Study on Thalassemia

While KAP studies have been conducted in several countries like India, Pakistan, and Indonesia, it has not been done effectively in Bangladesh before [44-46]. A recent study conducted in Bangladesh found that only one third of the participants had heard of thalassemia which is alarming. In addition, the overall knowledge of participants who claimed to be aware of the disease was inadequate. Many of them refused to undergo thalassemia testing before marriage due to the fear of stigmatization [29] . So, KAP study on thalassemia is much needed in Bangladesh to clear up misconceptions and fill in knowledge gaps regarding the disorder. Given the large population of Bangladesh, conducting a survey on the entire population is nearly impossible. Thus, this study was conducted on a selected group of individuals who were students of BRAC University.

2. Method and Materials

2.1 Study design and study participants

This is a cross-sectional survey conducted only in different departments at BRAC University, Bangladesh from 1 October 2022 to 31 January 2023. We tried to evaluate the participants' knowledge, attitudes, and practices on thalassemia and its corresponding different issues using a questionnaire constructed by Kobo Toolbox. However, the media of data collection were based on both online and offline. Our online survey forms were distributed through emails. Few surveys were conducted in-person by maintaining minimum social distancing and ensuring other precautionary measurements from both ends (respondents and surveyors). The inclusion criteria of participants were Bangladeshi by born, voluntary participation, filled-up consent form, capability to read and understand English, and finally, minimum age of 14 years.

2.2 Questionnaire design and data collection

A structured questionnaire (given as Supplementary Materials) was designed in two parts:

1. socioeconomic and demographic part and
2. KAP comprised of three sub-sections [47].

In total, 39 questions were tabulated and divided into socioeconomic and demographic information (e.g. age group, sex, type of residence, education level, household income, etc.), and three sub-sections of KAP- Knowledge, Attitude and Practice related to thalassemia in Bangladesh. The questionnaire was reviewed multiple times by the investigators' team at the Clinical Hematology and Cancer Biology laboratory, icddr,b by launching a feasibility survey among 25 participants to test the reliability of the questionnaire and estimate the time needed in both online and offline versions. The data were reviewed by corresponding investigators and the co-supervisor at the Clinical Hematology and Cancer Biology laboratory, icddr,b on a daily basis so that they were appropriately collected, curated and archived.

There were 15 questions in the sociodemographic and economic part. Few questions had corresponding sub-sections. On the other hand, there were eight questions related to Knowledge parts. However, three out of eight questions were considered for knowledge score calculation. Among those three questions, two questions were based on True/False type multiple check where checking tick on false information would carry 0 point, but leaving them unchecked would consider 1 point. Rest of the questions were trichotomous containing "Yes" (coded as 2), "I don't know" (coded as 1) and "No" (coded as 0). In the Attitude part, there were ten 5-point Likert scale questions. In nine questions, "Strongly agree" was assigned as 5-point while "Strongly disagree" was designated as 1 point. Practice part composed of 6 questions with subsections in two questions. For calculating practice scores, 5 questions were considered. Among them, there were two 5-point Likert scales and the other three were multi-stratified, dichotomous and trichotomous each. In the 3-point trichotomous scale, "Yes", "No" and "Not sure" were designated as 2, 0 and 1 point, respectively. On the other hand, the response options were 1 = "Yes", 0 = "No" in a dichotomous scale. Multi-stratified questionnaire was trichotomous in nature as well. Finally, "Strongly agree" and "Strongly disagree" were designated as 5 and 1, respectively in two 5-point Likert scale questions.

2.3 Data processing

Different terminology used in the same nationality or occupations were unified. Corresponding typos were corrected. Inconsistent responses were correctly modified in an interpretable direction. The scores of three subsections- Knowledge, Attitude and Practice were calculated in 1 eventually. For instance, the question on the lifestyle for a person with thalassemia (see supplementary section) contained 6 points in total. In order to ensure an isometric level, the total scores obtained from this particular question for every participant would be divided into 6. However, the divisor would be 5 for every question in the Attitude sub-section. But this would create an unequal result for three subsections as there were unequal question distributions for three subsections in the questionnaire for calculating corresponding KAP scores (Table 1). So, every obtained score from each question (in scale 1) would be aggregated and then divided into the total number of questions in that particular sub-section, thus formulating each sub-section as an equal scale. As an example, there were 10 questions in the Practice sub-section. Now, the value from each question would be aggregated and then would be divided into 10 to make the final score suitable for a uniform scale. Ranges for each sub-section of KAP score have been tabulated in table 1.

Table 1: Responses of KAP in the study

Variable	**Range**
Knowledge	
K.6 Thalassemia overview	0 - 7
K.7 Blood test	0 - 2
K.8 Lifestyle for thalassemia cases	0 - 6
Attitude	
A.1 – A.10 5-point Likert scale	1 – 5
Practice	
P.1 Multi-stratified question on screening	0 - 1
P.2 Binary question	0 - 1
P.3 Trichotomous question	0 - 2
P.4 & P.5 5-point Likert scale	1 - 5

2.4 Statistical analyses and outcome measures

Statistical analyses were conducted by using various software whichever required. We have used R (v.4.1.2), STATA (v.16), GraphPad Prism (v.9.4.0) and MS Excel (v.2019) for data entry, analysis, interpretation and graphical representation. The homoscedasticity and normality of data were tested by the Shapiro–Wilk and F- tests [47].

The widely adopted Bloom's cut-off points were interpreted as 80%–100% (good), 60%–79% (moderate) and <60% (poor) in our KAP assessment as the concordance with other corresponding studies [46, 48-50].

3. Result

3.1 Socio-demographic and economic information

The study encompassed a total of 431 participants, out of which the highest number of students (64) belonged to the Department of Computer Science and Engineering. The School of Pharmacy, Department of Mathematics, Natural Sciences, Department of Architecture, and BRAC Business School followed closely behind with 57, 56, 55, and 54 participants, respectively. However, the Department of Electrical and Electronic Engineering and the School of Law had comparatively fewer participants, with 41 and 44 respectively. Finally, the Department of English and Humanities, along with the Department of Economics and Social Sciences, had the lowest number of participants, both with 30 students (**Table 2).**

Table 2: Different departments and Schools at BRAC University among the study participants (N = 431)

Departments/Schools	**Frequency (%)**
Department of Computer Science and Engineering	64 (14.85)
School of Pharmacy	57 (13.23)
Department of Mathematics and Natural Sciences	56 (12.99)
Department of Architecture	55 (12.76)
BRAC Business School	54 (12.53)
School of Law	44 (10.21)
Department of Electrical and Electronic Engineering	41 (9.51)
Department of English and Humanities	30 (6.96)
Department of Economics and Social Sciences	30 (6.96)
Total	**431 (100)**

All of the 431 participants who participated in the survey were Bangladeshi citizens. The majority of the participants (54.99%) were male, and the remaining 45.01% were female. Most of the participants (82.83%) belonged to the age group of 19-23 years, followed by 16.01% in the age group of 24-28 years. A very small percentage of participants belonged to the age groups of 14-18 years and 29-33 years (0.46% each), while only one participant was over 33 years old. Almost all participants (97.45%) were unmarried, and the rest (2.55%) were married. When asked about their occupation, most participants (75.41%) mentioned being only students, while the remaining 24.59% reported having other occupations. In terms of monthly household income, the majority of participants (38.28%) fell in the income range of 50-100 thousands BDT, followed by 24.83% in the 100-150 thousands BDT range, 13.69% in the 150-200 thousands BDT range, 12.06% in the less than 50 thousands BDT range, and 11.14% in the more than 200 thousands BDT **(Table 3)**.

Table 3: A summary of the demographic and socioeconomic status of survey respondents		
Sociodemographic characteristics	**Total (N = 431)**	
	Frequency, n	**Percentage, %**
Gender		
Male	237	54.99
Female	194	45.01
Age as group (year)		
14-18	2	0.46
19-23	357	82.83
24-28	69	16.01
29-33	2	0.46
33+	1	0.23
Marital status		
Unmarried	420	97.45
Married	11	2.55
Occupation besides studentship		
No	325	75.41
Yes	106	24.59
Monthly household income (1 = 1000 BDT)		
<50	52	12.06
50 – 100	165	38.28
100 – 150	107	24.83
150 – 200	59	13.69
>200	48	11.14

Participants were asked whether they participated in any extracurricular activities during their college life. The findings revealed that a significant proportion of the students (302) were involved in extracurricular activities, while the remaining 129 were not **(Figure 4)**.

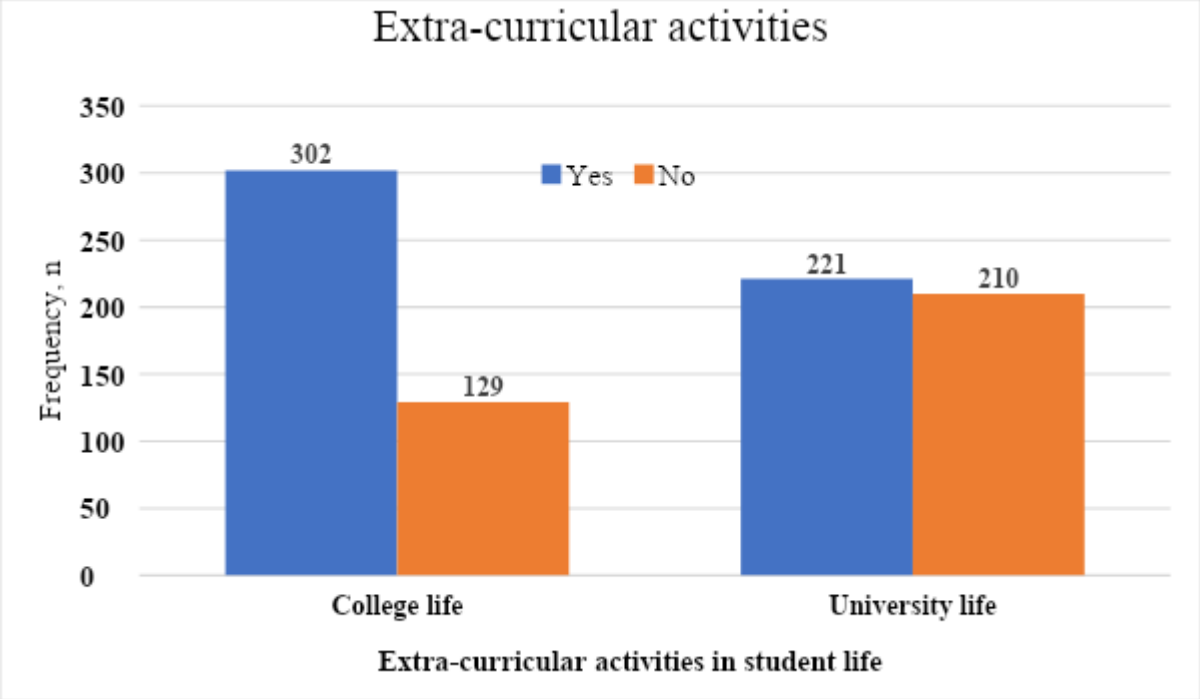

Figure 4: Involvement of study participants in extra-curricular activities in college and university life

Additionally, participants were asked whether they participated in any extracurricular activities during their university life. The responses were split almost evenly, with 221 participants answering affirmatively leaving the rest of the participants answering "No".

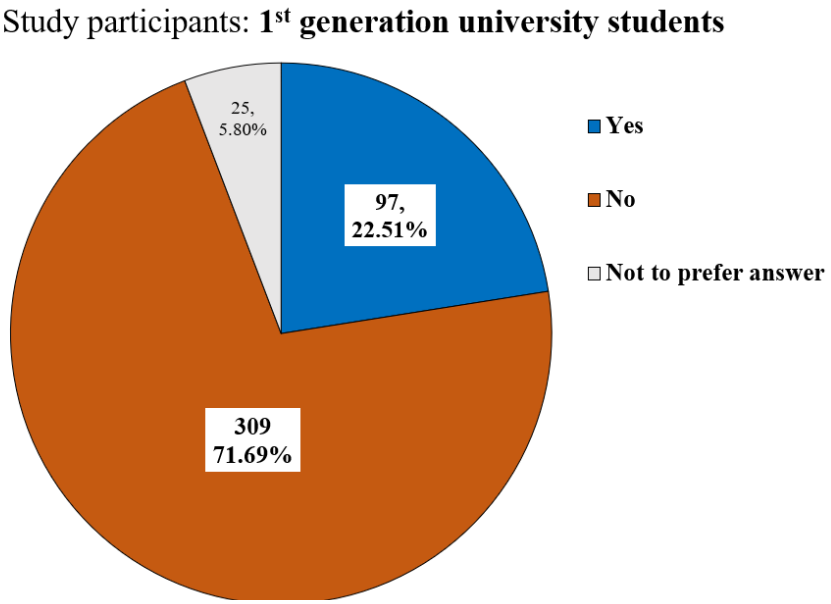

Figure 5: Study participants whether they are the 1st generation university student (or not)

Out of the 431 participants who responded to the survey, the majority of the participants (71.69%) answered that they were not 1st generation university-going students of their families **(Figure 5)**. Either their father or mother or both their parents are university graduates. Moreover, a few participants (22.51%) answered negatively, referring to none of their parents graduating from a university. However, the rest of them (5.80%) did not prefer to answer.

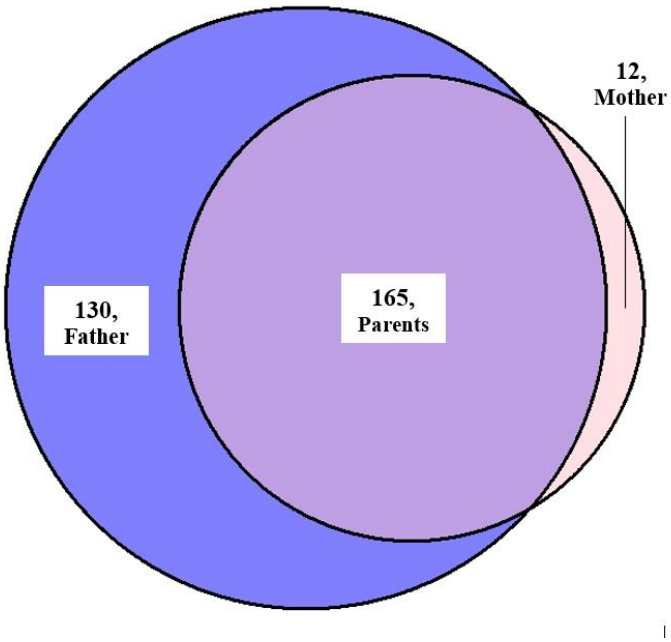

Figure 6: Pairwise Venn diagram of study participants whose parents were the 1st generation university students.

Out of the 309 participants who answered "No" to the question, they were asked a follow-up question. The question was asked to identify whether it was their father or mother or both. The majority of them (295) answered that their father graduated from university. The remaining participants (177) answered otherwise and responded that it was their mother. After creating a pairwise Venn diagram, it was found that 165 participants had both their father and mother as university graduates **(Figure 6)**.

Then, study participants were asked about their parents' occupation in an open-ended style. During data curation, parents' occupations were modified and classified as direct relationship of occupation with health/education sectors or not. Based upon that re-classification, the occupation

of participants' parents related to health/education sectors were 12.53% and 18.33%, respectively for father and mothers' occupation **(Table 4)**.

Table 4: Occupation of participants' parents related to health/education sectors		
Occupation in health/education sectors	Father	Mother
	Frequency (%)	Frequency (%)
Yes	54 (12.53)	79 (18.33)
No	358 (83.06)	345 (80.05)
Not to prefer answer	19 (4.41)	7 (1.62)
Total	431	100

After generating a Venn diagram using the 133 participants who responded affirmatively to this question, it was revealed that 23 participants had both their father and mother employed in the health/education sector (**Figure 7)**.

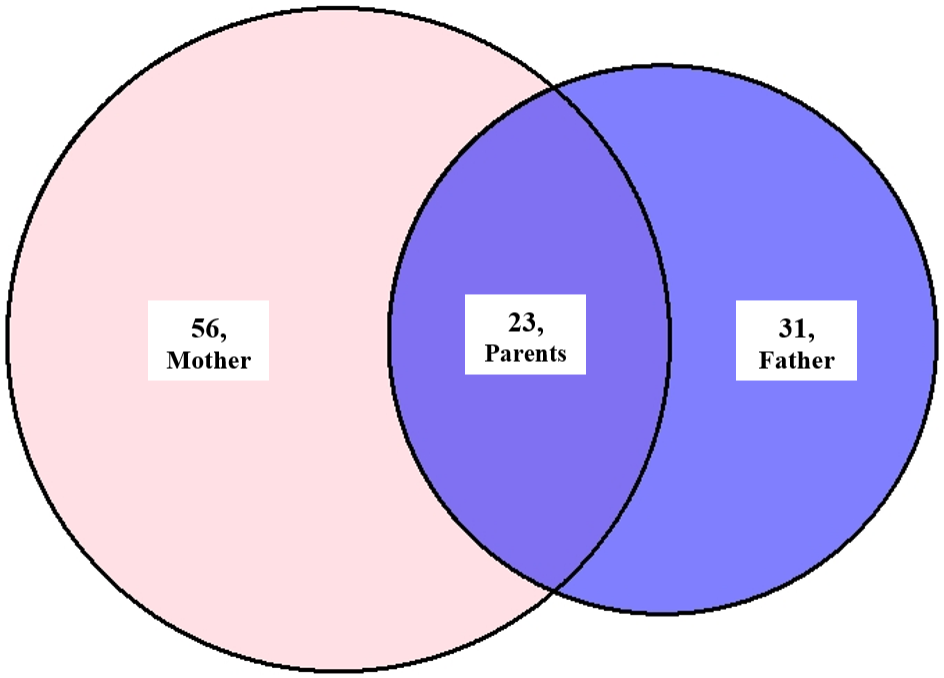

Figure 7: Pairwise Venn diagram depicts parent's occupation linked to health or education sectors.

3.2 Knowledge

Regarding participants' knowledge about thalassemia, Of the total respondents, the vast majority of the participants (84.69%) were familiar with thalassemia, while some of the respondents (15.31%) had never heard of it **(Table 5)**.

Table 5: Participants' knowledge about thalassemia		
Previously heard of thalassemia	Frequency, n	Percentage, %
Yes	**365**	84.69
No	66	15.31
Total	431	100

Subsequently, participants (n = 365) were asked to select the source or sources from which they had learned about thalassemia **(Figure 8)**. The results indicated that the majority of the participants (180) reported that they had learned about thalassemia from friends and family. The second most common source of knowledge was social media, with 179 participants reporting that they had learned about thalassemia from online platforms such as Facebook, Instagram, or Twitter. Seminars and other events were the third most commonly cited source of knowledge about

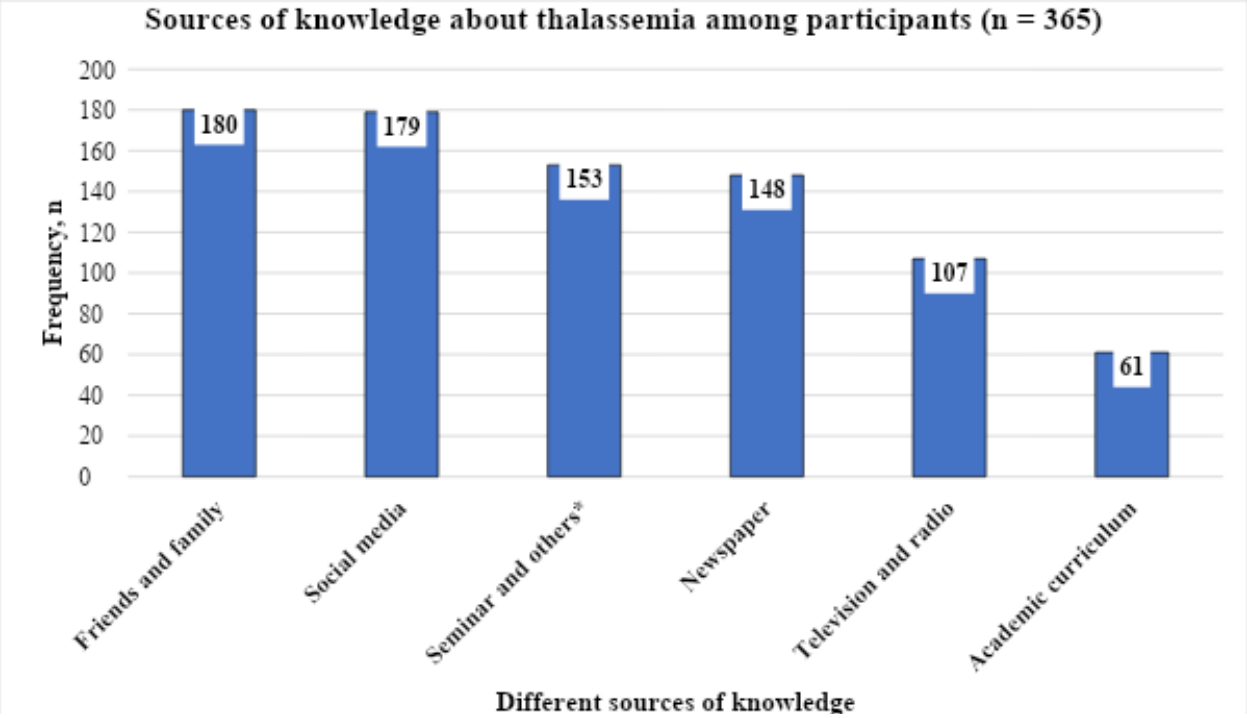

Figure 8: Different sources of knowledge regarding thalassemia among the study participants (n = 365)

thalassemia, with 153 participants. They reported that they had learned about thalassemia through club activities, web portals, online scientific articles, etc. Newspapers were also a significant source of knowledge, with 148 participants reporting that they had learned about the condition through print media. Television and radio were cited by 107 participants as a source of knowledge about thalassemia. Finally, the academic curriculum was the least commonly cited source of knowledge about thalassemia, with only 61 participants reporting that they had learned about the condition through formal education of academic curricula.

Regarding the participants' knowledge about their own blood group, almost all the participants (98.48%) knew their blood group, while only a small percentage (1.16%) were unsure or unaware of their blood group **(Table 6)**.

Table 6: Participants' knowledge about their own blood group

Knowledge regarding own blood group	Frequency, n	Percentage, %
Yes	**426**	98.84
No	5	1.16
Total	431	100

In terms of participants' knowledge about them being thalassemia carriers or patients, approximately two-thirds of the participants (66.59%) claimed that they were neither carriers nor patients. Around one-third (30.63%) of the participants were unaware of their status as thalassemia patients or carriers. The remaining 2.78% of participants answered positively, indicating that they were aware of being a thalassemia carrier or patients **(Table 7)**.

Table 7: Participants' knowledge about their status of having thalassemia (or not)		
Knowledge of being thalassemia carrier or patient	Frequency, n	Percentage, %
Yes	12	2.78
No	**287**	66.59
I don't know yet	**132**	30.63
Total	431	100

Furthermore, participants were asked to select which statements about thalassemia they believed to be true or false **(Table 8)**. The majority of participants (70.3%) had a basic understanding of thalassemia as a genetic disorder that can be passed from parents to children. Similarly, most of the participants (60.56%) responded correctly that thalassemia is a disease caused by abnormalities in red blood cells. Around one-third of the respondents (37.35%) knew that consanguineous marriage, or inter-relative marriage is closely associated with thalassemia, which is true. Only 29.47% of respondents had the idea that thalassemia is preventable. In terms of misconceptions, some of the participants (17.63%) chose the false statement that thalassemia is the same condition as blood cancer. Similarly, around 17.17% of participants believed that thalassemia is not a treatable disorder, which is also false. Finally, only 1.62% of participants selected the false statement that thalassemia is contagious, like COVID-19.

Table 8: Knowledge check on thalassemia among study participants	
Knowledge check on **true statements**	Frequency (%)
Thalassemia is a genetic disorder. It can be passed from parents to children.	303 (70.3)
Thalassemia is a disease caused due to abnormalities in red blood cells.	261 (60.56)
Thalassemia is closely associated with consanguineous marriages (inter-relative marriage)	161 (37.35)
Thalassemia is preventable	127 (29.47)

Knowledge check on **false statements**	Frequency (%)
Thalassemia is the same condition like blood cancer	76 (17.63)
Thalassemia is not a treatable disorder	74 (17.17)
Thalassemia is contagious like COVID-19	7 (1.62)

Additionally, when asked if they knew if thalassemia could be detected through a blood test, the majority of participants (303) responded affirmatively, while 114 participants did not know about it yet **(Table 9)**. Only a few participants (14) believed that thalassemia could not be detected via a blood test.

Table 9: Knowledge regarding the statement,

Thalassemia can be detected from blood tests	Frequency, n	Percentage, %
Yes	303	70.3
No	14	3.25
I don't know yet	114	26.45
Total	431	100

As part of the study, participants were presented with a checkbox to indicate which statements they believed to be true regarding the lifestyle of individuals with thalassemia **(Table 10)**. The first statement was related to maintaining a healthy diet, and the majority of respondents (77.26%) agreed with it. The second statement emphasized the importance of preserving health hygiene, and a large number of participants (70.3%) marked it as true. The third statement highlighted the need for regular exercise, with over half of the respondents (56.38%) agreeing with it. The fourth statement pertained to the importance of having a supportive relationship, but less than half of the participants (46.17%) marked it as true. The fifth statement emphasized the need to keep vaccinations up to date, and 42.23% of participants marked it as true. Lastly, there was one false statement, and only a small proportion of respondents (10.67%) marked it as true.

Table 10: Knowledge check on lifestyle for one with thalassemia	
Knowledge check on **true statements**	Frequency (%)
Eat healthy diet	333 (77.26)
Maintain health hygiene	303 (70.3)
Regular exercise	243 (56.38)
Have supportive relationship	199 (46.17)
Keep vaccinated up-to-date	182 (42.23)
Knowledge check on **false statement**	Frequency (%)
Having isolated during marriage	46 (10.67))

3.3 Attitude

The findings are presented in the form of a multiple stacked bar chart, with each statement analyzed and displayed separately **(Figure 9)**. Starting with the most agreed-upon statement, "Having a friend with thalassemia is not an issue," and the results indicate that the majority of participants strongly agreed with this sentiment (64.5%), while 26.68% agreed, and only 6.96% were neutral. The next statement, "Organizing various awareness programs within the university," which also received high levels of agreement with 48.03% of participants strongly agreeing and

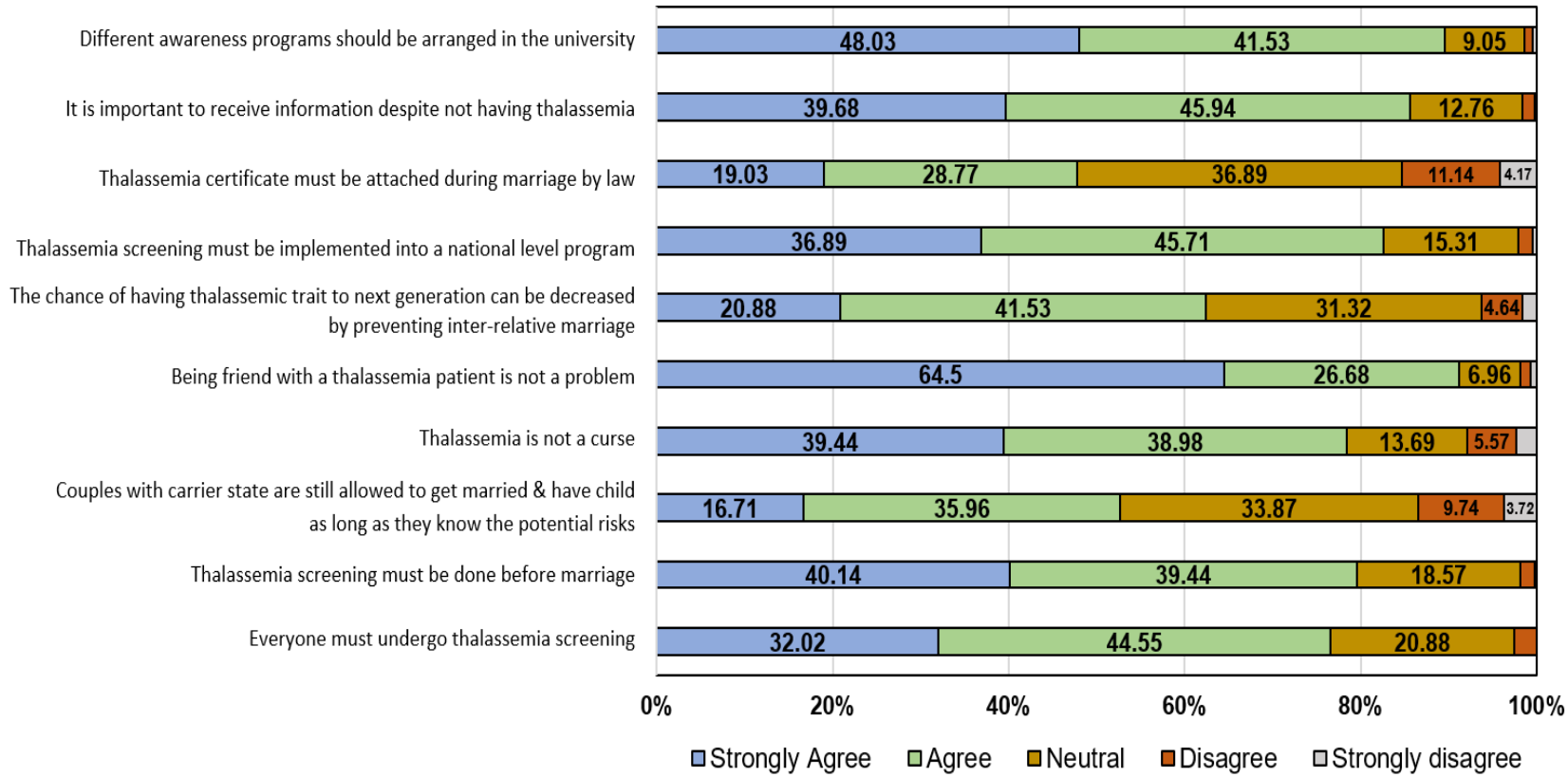

Figure 9: Study participants' attitude towards thalassemia and its corresponding management, policy and strategy

41.53% agreeing. Only 9.05% of respondents were neutral on this statement. Moving on to the statement, "Screening for thalassemia should be conducted prior to marriage," with the majority of participants indicating agreement with this statement. Specifically, 40.14% strongly agreed, 39.44% agreed, and 18.57% were neutral on this topic.

Regarding the statement, "Receiving information about thalassemia is important even if one does not have the disease," 39.68% of participants strongly agreed, 45.94% agreed, and 12.76% were neutral. A small percentage of participants (1.30%) disagreed with the statement, and 0.32% strongly disagreed. For the statement "Having thalassemia is not a curse," the majority of participants agreed with this statement, with 39.44% strongly agreeing, 38.98% agreeing, 13.69% being neutral, 5.57% disagreeing, and 2.32% strongly disagreeing.

Regarding the statement "Thalassemia screening should be integrated into a nationwide initiative," 36.89% of participants strongly agreed, 45.71% agreed, and 15.31% were neutral. A small percentage of participants (1.01%) disagreed with this statement, and 1.08% strongly disagreed. The statement "Thalassemia screening should be made mandatory for all individuals" also received majority agreement, with 32.02% strongly agreeing, 44.55% agreeing, and 20.88% being neutral. A small percentage of participants (1.45%) disagreed with this statement, and 1.09% strongly disagreed.

Regarding the statement "Preventing inter-relative marriage can decrease the likelihood of passing on the thalassemia trait to the next generation," there were mixed responses, with 20.88% strongly agreeing, 41.53% agreeing, 31.32% being neutral, 4.64% disagreeing, and 1.63% strongly disagreeing. For the statement "A thalassemia certificate should be legally required for marriage," responses were also mixed, with 19.03% strongly agreeing, 28.77% agreeing, 36.89% being neutral, 11.14% disagreeing, and 4.17% strongly disagreeing. Finally, the statement "A couple who are carriers of thalassemia trait can still choose to get married and have children, as long as they are aware of the potential risks associated with the diseases" also received mixed responses, with 16.71% strongly agreeing, 35.96% agreeing, 33.87% being neutral, 9.74% disagreeing, and 3.72% strongly disagreeing.

3.4 Practice

When participants were asked whether they had previously undergone screening for thalassemia, a very small number of respondents (45) reported that they had been screened for thalassemia. A significant portion of respondents (347) responded that they never had it checked. The rest of the participants (39) were unsure about their testing status **(Table 11)**.

Table 11: Study participants previously undergone thalassemia screening

Respondents' options			**Frequency, n**
Yes			**45**
No			**347**
Planning to get tested later?	Yes	When to plan for screening	132
		As soon as possible	26
		Before marriage	56
		After marriage	4
		Before having child	4
		Not decided yet	42
	No		80
	Not decided		135
Not sure			**39**
Planning to get tested later?	Yes	When to plan for screening	14
		As soon as possible	3
		Before marriage	6
		After marriage	0
		Before having child	1
		Not decided yet	4
	Not decided		25
Total			**431**

Participants who responded no (347) were asked a follow up question to find out if they intended to undergo testing in the future. Among them, 132 respondents reported yes, some of the

participants (80) said no and the remaining (135) claimed that they hadn't made up their minds. Participants who replied positively (132) were asked another question to identify when they intend to get tested. a significant portion of them (56) were willing to undergo testing before marriage, some of them (26) were eager to get tested as quickly as possible, a small proportion of respondents (4) wanted to be tested after marriage, and a similar amount (4) wanted to be tested prior to having kids. Finally, a large number (42) of respondents stated that they had not decided yet.

Participants who responded unsure (39) to the initial inquiry were also asked if they planned to undergo thalassemia testing in the future. A large number of participants (250) reported that they had not decided, while only 14 participants gave affirmative responses. These positive respondents were asked another follow up question to find out when they plan for thalassemia screening. Some of them (6) wanted to get tested before marriage, 3 respondents wanted to undergo screening as soon as possible, only 1 participant wanted to get tested before having a child. However, 4 respondents had not made up their mind.

Table 12: encouraging friends and families to undergo thalassemia screening in the past		
I encouraged my friends and families to undergo thalassemia screening	Frequency, n	Percentage, %
Yes	321	74.48
No	110	25.52
Total	431	100

When participants were asked if they encouraged their friends and families to undergo thalassemia screenings, the majority of the respondents (74.48%) said no while the rest of them (25.52%) replied affirmatively (**Table 12)**.

Table 13: willingness to encourage friends and families to undergo thalassemia screening in the future		
I will encourage my friends and families to undergo thalassemia screening	**Frequency, n**	**Percentage, %**
Yes	282	65.43
No	112	25.99
Not to prefer answer	37	8.58
Total	431	100

When participants were asked if they will encourage their friends and families to undergo thalassemia screenings in the future, most of the respondents (65.43%) replied yes, some of them were unsure (25.99%) and a very small number of participants replied negatively (8.58%) **(Table 13)**.

The participants were asked if they would be interested in seeking more information about thalassemia. A majority of them (45.01%) shared a similar opinion with this statement, with a further 30.63% indicating a strong agreement. A total of 21.81% remained neutral in this regard, while a small minority disagreed (2.09%) or strongly disagreed (0.46%) with the idea of seeking more information **(Table 14)**.

Table 14: Willingness to spend some time to find more information about thalassemia		
5-point Likert scale	Frequency, n	Percentage, %
Strongly agree	132	30.63
Agree	194	45.01
Neutral	94	21.81
Disagree	9	2.09
Strongly disagree	2	0.46
Total	431	100

Participants were presented with a statement asking if they would like to test their partner's thalassemia status before marriage if they were a carrier themselves. The majority of respondents (47.33%) strongly agreed with the statement, while 35.03% agreed with it. A significant proportion of participants (15.55%) remained neutral on the matter. Only a small percentage of respondents (1.62% and 0.46%, respectively) disagreed or strongly disagreed with the statement **(Table 15)**.

Table 15: Willingness to test partners' condition before marriage considering (if) the participants being thalassemia carrier

5-point Likert scale	Frequency, n	Percentage, %
Strongly agree	204	47.33
Agree	151	35.03
Neutral	67	15.55
Disagree	7	1.62
Strongly disagree	2	0.46
Total	431	100

3.5 Association between KAP and socio-demographic factors

According to the pie chart, in terms of participants' knowledge of thalassemia, the majority (47.56%) had moderate knowledge, while 30.16% had good knowledge, and only 22.27% had poor knowledge. Participants' attitudes toward thalassemia were mostly positive, with 46.87% having a good attitude, 51.51% having a moderate attitude and 1.62% having a poor attitude. However, the majority of participants (53.36%) had poor practice toward thalassemia, with only 28.07% having moderate practice and 18.56% having good practice. Overall, the majority (55.22%) of participants had a moderate overall KAP (knowledge, attitude, and practice) toward thalassemia, while 23.43% had poor KAP and 21.35% had a good KAP score.

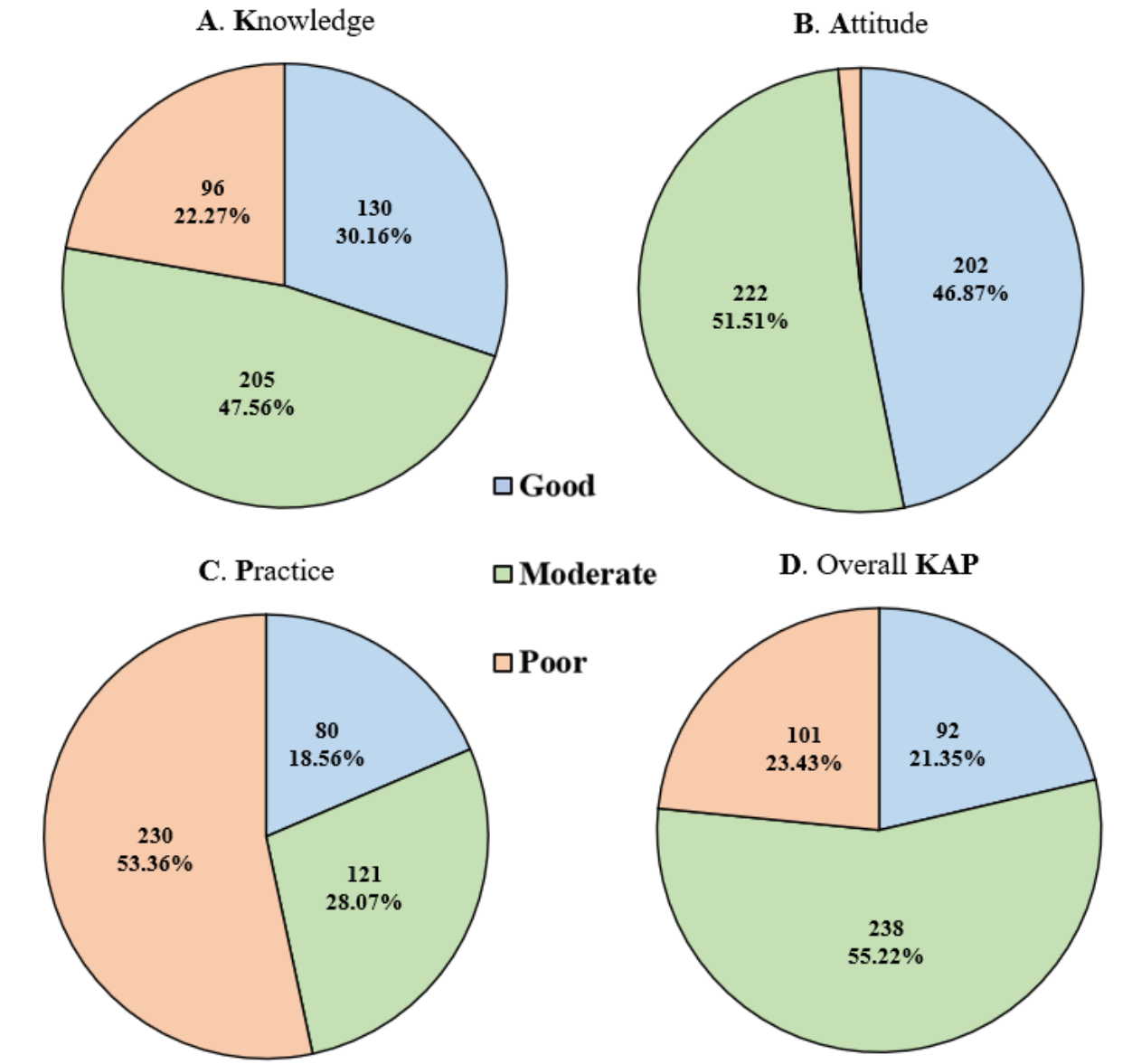

Figure 10: Individual KAP scores in **A**. Knowledge, **B**. Attitude, **C**. Practice and **D**. Overall KAP score among the study participants shown in pie charts.

Overall, female participants' Knowledge, Attitude, and Practice (KAP) scores were distributed as follows: 57.22% scored good, 25.26% scored moderate, and 17.53% scored poorly **(Table 16)**. For male participants, 18.14% scored good, 53.59% scored moderate, and 28.27% scored poorly. Regarding extracurricular activities, 52.38% of participants who engaged in such activities in universities scored moderate, 26.67% scored poorly, and 20.95% scored good. Among participants

who did not engage in extracurricular activities in universities, 57.92% scored moderate, 21.72% scored good, and 20.36% scored poorly. Looking at first-generation university students, 65.66%

Table 16: Overall KAP scores in different socio-demographic and other variables described in the KAP study on thalassemia

KAP categories	**Frequency, n Column percentage, %**											
	Sex		Engagement in extracurricular activities in university		1st generation university student[1]		Occupation beside studentship		Parents occupation related to health/education			
									Father[2]		Mother[3]	
	Female	Male	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes
Good	49 25.26	43 18.14	44 20.95	48 21.72	70 22.80	18 18.18	67 20.62	25 23.58	72 20.11	15 27.78	72 20.87	19 24.05
Moderate	111 57.22	127 53.59	110 52.38	128 57.92	162 52.77	65 65.66	184 56.62	54 50.94	202 56.42	28 51.85	191 55.36	42 53.16
Poor	34 17.53	67 28.27	56 26.67	45 20.36	75 24.43	16 16.16	74 22.77	27 25.47	84 23.46	11 20.37	82 23.77	18 22.78
Total	194 100	237 100	210 100	221 100	307 100	99 100	325 100	106 100	358 100	54 100	345 100	79 100

1. Frequency of "Not to prefer answer", n = 25 has been omitted
2. Frequency of "Not to prefer answer", n = 19 has been omitted
3. Frequency of "Not to prefer answer", n = 7 has been omitted

scored moderate, 18.18% scored good, and 16.16% scored poorly. Among non-first-generation university students, 52.77% scored moderate, 22.80% scored good, and 24.43% scored poorly. Regarding employment status, among students who had jobs, 50.94% scored moderate, 25.47% scored poorly, and 23.58% scored good. Among students with no occupation besides being a student, 56.62% scored moderate, 22.77% scored poorly, and 20.62% scored good. Regarding the fathers, the majority of those who have occupations related to health/education (51.85%) had a moderate score, followed by 27.78% with a good score, and lastly, 20.37% with a poor score. Meanwhile, among fathers who do not have occupations related to health/education, most of them (56.42%) had a moderate score, followed by (23.46%) with a poor score and (20.11%) with a good score. For the mothers, 53.16% of those who have occupations related to health/education had a moderate score, followed by 24.05% with a good score and 22.78% with a poor score. On the other

hand, for those mothers who do not have occupations related to health/education, 55.36% had a moderate score, followed by 23.77% with a poor score and lastly 20.87% with a good score.

4. Discussion

With 431 responses gathered from all nine departments of BRAC University, this study disclosed the level of thalassemia awareness and behavioral patterns among university students. Though this study revealed some interesting findings, there were few areas where we did not find significant outcomes like in Age group, Marital status, Parents' ethnicity. Those areas were omitted in this study.

4.1 Individual KAP scores

4.1.1 Knowledge

Knowledge and understanding about thalassemia screening can be improved if public education and awareness are prioritized, observed in other studies. It has been observed that education provided through mass media, training of health professionals and lectures disseminated to the general population had significant roles in acquiring higher levels of knowledge of thalassemia [51]. Our study revealed that about 85% of the participants had previously heard of thalassemia. Interestingly, this was a significant finding compared to other studies conducted in other thalassemia prevalent countries like Indonesia (74.5%), Bahrain (65%), Italy (85%), Saudi Arabia (48%), Malaysia (76.4%), Greece (95%) and Turkey (58%).[46, 51-56]

Even though our study has found that most participants were familiar with thalassemia, less than one-third (30.16%) had a core or good knowledge of the disease, similar to other peer studies conducted previously.[46, 57] However, around a 50% individuals had a moderate level of knowledge regarding thalassemia. Majority of the respondents (70.3%) knew that thalassemia could be detected from blood tests. It was significant than other study where less than half respondents (45.6%) had correct information.[58] More than two-third of participants (70.3%) were aware about the inheritance pattern of thalassemia that it can be passed through generations, unlike other study findings.[40, 58, 59] However, only 37.35% of individuals were aware of this link, despite its significant risk factor. Consanguinity increases the likelihood of a child being born with thalassemia. This is because the chances of homozygosity rate are quite high in inter-relative marriages due to the limited gene pool and greater expression of recessive alleles as compared to

unrelated marriages. As a result, mutations tend to cluster within certain communities, further increasing the risk of a child being born with the disease.[60, 61] Similar pattern of lower percentage was observed when participants were given the option regarding the knowledge about the preventive condition of thalassemia (29.47%). However, very few respondents thought that thalassemia was the same as blood cancer (17.63%), unable to be treated (17.17%) and contagious like COVID-19 (1.62%). Such conception is inversely influenced to have a good/moderate knowledge score eventually.

4.1.2 Attitude

Out of 431 respondents, only a very few numbers of participants (1.62%) showed poor attitude towards thalassemia. The majority of respondents believed that being friends with a thalassemia patient is not an issue. This is in contrast to another study where approximately 40% of students were neutral or did not want to be friends with thalassemia patients [29] . Additionally, many respondents believed that thalassemia carriers are still able to marry and have children, as long as they understand the potential risks involved. Around one-third participants remained neutral on this statement, possibly indicating a lack of awareness about the risks associated with thalassemia. They are perhaps unaware of the fact that if both parents are thalassemia carriers, their children face a 25% risk of being born with the condition, a 50% risk of inheriting the carrier status [62] .

4.1.3 Practice

Despite the fact that the majority of participants exhibited a positive and moderate attitude toward thalassemia, more than half (53.36%) of respondents exhibited poor practice. A mere 10.44% of participants reported having undergone thalassemia screening, with the majority declining. When asked about their preferred timing for screening, most respondents indicated that they would prefer to be tested before marriage rather than as soon as possible. Many participants had yet to make a decision on whether or not to undergo screening. When asked about their preferred timing for screening, most respondents indicated that they would prefer to be tested before marriage rather than as soon as possible. Even if people knew their carrier status before getting married, this could still cause problems because there may be tremendous social pressure to get married and a fear of being stigmatized. When participants were asked if they had encouraged their friends and families to undergo thalassemia screening in the past, a significant portion of participants (74.48%) responded negatively. However, when asked if they would encourage their loved ones to get tested

in the future, the majority of respondents (65.43%) answered positively, indicating that this study positively impacted their practice towards thalassemia.

4.2 KAP scores on thalassemia and socio-demographic factors

According to Bloom's cut-off points, a respondent would be said to have a good concept on KAP towards thalassemia and its relevant matters if the corresponding KAP scores was between 80% and 100%, moderate when it was 60% - 79% and <60% would represent poor performance.

According to the findings of our study, females had Good KAP than males. This finding was similar to the findings from studies in Iran & Indonesia [46, 63]. However, in a study conducted in Kolkata, males demonstrated better thalassemia knowledge to females [58]. Perhaps our findings are due to the fact that women are marginally more inclined than men to share health-related content on social media [64]. Another factor might be the additional pressure women experience to learn about inherited disorders while they carry and raise the child [46] . Participants who were not involved in extracurricular activities had poor KAP. A study found that participation in academic clubs helps to build up communication skills [65]. Thus, Students regularly interact with a large number of people, which helps them learn more about a wide range of topics. So, this may explain why participants who were not involved in extracurricular activities had poor KAP.

References

1. Hoffbrand, V. and D.P. Steensma, *Hoffbrand's essential haematology*. 2019: John Wiley & Sons.
2. Irwin, J. and J.T. Kirchner, *Anemia in children.* American family physician, 2001. **64**(8): p. 1379.
3. *Nutritional anaemias. Report of a WHO scientific group.* World Health Organ Tech Rep Ser, 1968. **405**: p. 5-37.
4. Chulilla, J.A.M., M.S.R. Colás, and M.G. Martín, *Classification of anemia for gastroenterologists.* World Journal of Gastroenterology: WJG, 2009. **15**(37): p. 4627.
5. Beghé, C., A. Wilson, and W.B. Ershler, *Prevalence and outcomes of anemia in geriatrics: a systematic review of the literature.* The American journal of medicine, 2004. **116**(7): p. 3-10.
6. Sanap, S.A., M. Nagori, and V. Kshirsagar. *Classification of anemia using data mining techniques*. in *Swarm, Evolutionary, and Memetic Computing: Second International Conference, SEMCCO 2011, Visakhapatnam, Andhra Pradesh, India, December 19-21, 2011, Proceedings, Part II 2*. 2011. Springer.
7. Tefferi, A. *Anemia in adults: a contemporary approach to diagnosis*. in *Mayo Clinic Proceedings*. 2003. Elsevier.
8. Viprakasit, V., et al., *Iron chelation therapy in the management of thalassemia: the Asian perspectives.* International journal of hematology, 2009. **90**: p. 435-445.
9. Weatherall, D.J., *The thalassemias: disorders of globin synthesis.* Williams hematology, 2010. **8**: p. 675-707.
10. Galanello, R. and A. Cao, *Alpha-thalassemia.* Genetics in medicine, 2011. **13**(2): p. 83-88.
11. Piel, F.B. and D.J. Weatherall, *The α-thalassemias.* New England Journal of Medicine, 2014. **371**(20): p. 1908-1916.
12. Muncie Jr, H.L. and J.S. Campbell, *Alpha and beta thalassemia.* American family physician, 2009. **80**(4): p. 339-344.

13. Silberstein, P., *Thalassemia*, in *xPharm: The Comprehensive Pharmacology Reference*. 2008, Elsevier Inc. p. 1-6.
14. Chen, F.E., et al., *Genetic and clinical features of hemoglobin H disease in Chinese patients.* New England Journal of Medicine, 2000. **343**(8): p. 544-550.
15. Chui, D.H., S. Fucharoen, and V. Chan, *Hemoglobin H disease: not necessarily a benign disorder.* Blood, 2003.
16. Hoffbrand, A.V., *Hoffbrand's Essential Haematology*. 7th ed. 2015, Oxford: Wiley.
17. Cao, A., *Galanello R. b-thalassemia.* Genet Med, 2010. **12**(2): p. 61-76.
18. de Dreuzy, E., et al., *Current and future alternative therapies for beta-thalassemia major.* Biomedical journal, 2016. **39**(1): p. 24-38.
19. Needs, T., L.F. Gonzalez-Mosquera, and D.T. Lynch, *Beta thalassemia.* 2018.
20. Asadov, C., et al., *β-Thalassemia intermedia: a comprehensive overview and novel approaches.* International journal of hematology, 2018. **108**(1): p. 5-21.
21. Awadallah, S., *Protein antioxidants in thalassemia.* Adv Clin Chem, 2013. **60**: p. 85-128.
22. Lilienfeld, D.E., *Lilienfeld's Foundations of Epidemiology*. 2015: Oxford University Press.
23. Androulla and M.A. Eleftheriou, *Global Thalassemia Review*. 2022, THALASSAEMIA INTERNATIONAL FEDERATION: Nicosia, Cyprus.
24. Hasan, M., *Census 2022: Bangladesh population now 165 million*, in *Dhaka Tribune*. 2022: Dhaka.
25. Sadiya, S., et al., *Carrier detection of thalassaemia and haemoglobinopathies in tribal population of Bangladesh.* Bangladesh Medical Research Council Bulletin, 2018. **44**(2): p. 89-92.
26. Abu-Shaheen, A., et al., *Epidemiology of thalassemia in Gulf Cooperation Council countries: a systematic review.* BioMed research international, 2020. **2020**.
27. Alam, N.E., et al., *The scenario of knowledge, attitude and practice of the Bangladeshi population towards thalassemia prevention: A nationwide study.* PLOS Global Public Health, 2022. **2**(10): p. e0001177.
28. Byron, R.K., *Address out-of-pocket spending on healthcare*, in *The Daily Star*. 2023: Dhaka.

29. Hossain, M.S., et al., *Lack of knowledge and misperceptions about thalassaemia among college students in Bangladesh: a cross-sectional baseline study.* Orphanet Journal of Rare Diseases, 2020. **15**: p. 1-10.
30. Shah, F.T., et al., *Challenges of blood transfusions in β-thalassemia.* Blood reviews, 2019. **37**: p. 100588.
31. Saliba, A.N., A.R. Harb, and A.T. Taher, *Iron chelation therapy in transfusion-dependent thalassemia patients: current strategies and future directions.* Journal of blood medicine, 2015: p. 197-209.
32. Agarwal, M., *Advances in management of thalassemia.* The Indian Journal of Pediatrics, 2009. **76**: p. 177-184.
33. Berdoukas, V., et al., *Treating thalassemia major-related iron overload: the role of deferiprone.* Journal of blood medicine, 2012: p. 119-129.
34. Huang, C., et al., *Hematopoietic stem cell transplantation for thalassemia major using HLA fully-matched and mismatched donor grafts.* Translational Pediatrics, 2021. **10**(6): p. 1552.
35. Srivastava, A. and R.V. Shaji, *Cure for thalassemia major–from allogeneic hematopoietic stem cell transplantation to gene therapy.* haematologica, 2017. **102**(2): p. 214.
36. Mohamed, S.Y., *Thalassemia major: transplantation or transfusion and chelation.* Hematology/Oncology and Stem Cell Therapy, 2017. **10**(4): p. 290-298.
37. Locatelli, F., et al., *Betibeglogene autotemcel gene therapy for non–β0/β0 genotype β-thalassemia.* New England Journal of Medicine, 2022. **386**(5): p. 415-427.
38. Cao, A. and R. Galanello, *Beta-thalassemia.* Genetics in medicine, 2010. **12**(2): p. 61-76.
39. Angastiniotis, M., et al., *The Prevention of thalassemia revisited: a historical and ethical perspective by the thalassemia international federation.* Hemoglobin, 2021. **45**(1): p. 5-12.
40. Han, K.E., A.M. Han, and T.T. Myint, *Thalassemia in the outpatient department of the Yangon Children's Hospital in Myanmar: knowledge, attitudes and practice in relation to thalassemia.* Southeast Asian J Trop Med Public Health, 1992. **23**(2): p. 269-72.
41. Kolnagou, A. and G.J. Kontoghiorghes, *Advances in the prevention and treatment are changing thalassemia from a fatal to a chronic disease. experience from a Cyprus model and its use as a paradigm for future applications.* Hemoglobin, 2009. **33**(5): p. 287-295.
42. Ip, H.W. and C.C. So, *Diagnosis and prevention of thalassemia.* Crit Rev Clin Lab Sci, 2013. **50**(6): p. 125-41.

43. Andrade, C., et al., *Designing and conducting knowledge, attitude, and practice surveys in psychiatry: practical guidance.* Indian Journal of Psychological Medicine, 2020. **42**(5): p. 478-481.
44. Ahmed, N., et al., *Knowledge, attitude and practices (KAP) of The families of B-thalassemia patients in a thalassemia Center of Karachi.* Int J Curr Med Pharm Res, 2020. **6**: p. 4972-6.
45. Basu, M., et al., *Knowledge, attitude, and practice of budding doctors in prevention of thalassemia.* International Journal of Preventive and Public Health Sciences, 2016. **2**(4): p. 18-24.
46. Wahidiyat, P.A., et al., *Cross-sectional study on knowledge, attitude and practice towards thalassaemia among Indonesian youth.* BMJ open, 2021. **11**(12): p. e054736.
47. Qutob, N. and F. Awartani, *Knowledge, attitudes and practices (KAP) towards COVID-19 among Palestinians during the COVID-19 outbreak: A cross-sectional survey.* PLoS One, 2021. **16**(1): p. e0244925.
48. Akalu, Y., B. Ayelign, and M.D. Molla, *Knowledge, attitude and practice towards COVID-19 among chronic disease patients at Addis Zemen Hospital, Northwest Ethiopia.* Infection and drug resistance, 2020: p. 1949-1960.
49. Feleke, B.T., M.Z. Wale, and M.T. Yirsaw, *Knowledge, attitude and preventive practice towards COVID-19 and associated factors among outpatient service visitors at Debre Markos compressive specialized hospital, north-west Ethiopia, 2020.* Plos one, 2021. **16**(7): p. e0251708.
50. Kaliyaperumal, K., *Guidelines for Conducting a Knowledge, Attitude and Practice (KAP) Study. Community Ophthalmology, IV (1), 7-9.* 2004.
51. Armeli, C., S.J. Robbins, and D. Eunpu, *Comparing knowledge of β-thalassemia in samples of Italians, Italian-Americans, and non-Italian-Americans.* Journal of Genetic Counseling, 2005. **14**: p. 365-376.
52. Olwi, D.I., L.A. Merdad, and E.K. Ramadan, *Thalassemia: a prevalent disease yet unknown term among college students in Saudi Arabia.* Journal of community genetics, 2018. **9**: p. 277-282.
53. Okyay, R.A., et al., *Haemoglobinopathy awareness among young students in Turkey: outcomes of a city-wide survey.* PLoS One, 2016. **11**(7): p. e0159816.

54. Al Arrayed, S. and D. DHCG, *Public awareness of beta thalassemia in Bahrain.* Bahrain Medical Bulletin, 2012. **34**(1): p. 26-29.
55. Wong, L.P., E. George, and J.-A.M.A. Tan, *Public perceptions and attitudes toward thalassaemia: Influencing factors in a multi-racial population.* BMC public health, 2011. **11**(1): p. 1-9.
56. Politis, C., C. Richardson, and J.G. Yfantopoulos, *Public knowledge of thalassemia in Greece and current concepts of the social status of the thalassemic patients.* Social science & medicine, 1991. **32**(1): p. 59-64.
57. Noeriman, A.R., I. Fitrianingrum, and I. Armyanti, *Knowledge level about thalassemia among high school students in Pontianak City, West Kalimantan, Indonesia.* Mutiara Medika: Jurnal Kedokteran dan Kesehatan, 2020. **20**(2): p. 85-91.
58. Basu, M., *A study on knowledge, attitude and practice about thalassemia among general population in outpatient department at a Tertiary Care Hospital of Kolkata.* Journal of Preventive Medicine and Holistic Health, 2015. **1**(1): p. 6-13.
59. Srivastava, J., et al., *Knowledge, attitude and practice study of beta-thalassemia in rural Bengal.* Genet Clin, 2011. **4**: p. 13-15.
60. Kumar, R., V. Arya, and S. Agarwal, *Profiling β Thalassemia mutations in consanguinity and nonconsanguinity for prenatal screening and awareness programme.* Advances in hematology, 2015. **2015**.
61. Bittles, A.H. and M.L. Black, *Consanguineous marriage and human evolution.* Annual Review of Anthropology, 2010. **39**: p. 193-207.
62. Gulani, A. and T. Weiler, *Genetics, autosomal recessive*, in *StatPearls [Internet]*. 2022, StatPearls Publishing.
63. Miri-Moghaddam, E., et al., *High school knowledge and attitudes towards thalassemia in southeastern Iran.* International Journal of Hematology-Oncology and Stem Cell Research, 2014. **8**(1): p. 24.
64. Hausmann, J.S., et al., *Adolescent and young adult use of social media for health and its implications.* Journal of Adolescent Health, 2017. **60**(6): p. 714-719.
65. Christison, C., *The Benefits of Participating in Extracurricular Activities.* BU Journal of Graduate Studies in Education, 2013. **5**(2): p. 17-20.

KAP Study for Thalassemia: A cross-sectional study at BRAC University

The information we will collect from this research project will be kept confidential. Your information will be stored in a file that will not have your name but a number assigned to it. The corresponding personal details for each ID will be kept under lock and key and will not be divulged to anyone except the researchers. At the end of the study, a report about the study results will be produced. The report will not bear any personal information relating to you, e.g., your name or where you live. Therefore, we are asking for your consent to fill up the questionnaire.

Department:

Department of Mathematics and Natural Sciences

School of Pharmacy

Department of Architecture

Department of Computer Science and Engineering

Department of Economics and Social Sciences

Department of Electrical and Electronic Engineering

Department of English and Humanities

James P Grant School of Public Health

Brac Business School

School of Law

Others

Please specify

Socio-demographic information

1. Did you get involved in any extra-curricular activities in your college life?

Yes

No

2. Are you currently engaging in any extra-curricular activities in your university?

Yes

No

3. Gender

Male

Female

4. Age group (in years)

14 - 18

19 - 23

24 - 28

29 - 33

33+

5. Are you the first-generation university student of your family?

Being a first-generation university student means that you are the first person in your family to attend university. Neither of your parents have a university degree.

Yes

No

Not to prefer answer

5.1. Who is the first-generation university student of your family, then?

You may select multiple options

Mother

Father

6. Marital status

Your current status

Unmarried

Married

6.1. If you are married, then do you have any child?

No

Yes

7. Occupation besides studentship:

No

Yes

8. What is your father's occupation:

9. Paternal district:

Please mention the district name of your father

10. What is your father's ethnicity?

Bengali

Others

10.1. What is your father's ethnic background? Please specify:

Chakma

Garo

Monipuri

Marma

Santal

Mru

Khasi

Meitei

Tanchangya

Tripura

Khumi

Munda

Bihari

Other

10.1.1. Please specify:

11. What is your mother's occupation:

12. Maternal district:

Please mention the district name of your mother

13. What is your mother's ethnicity?

Bengali

Others

13.1. What is your mother's ethnic background? Please specify:

Chakma

Garo

Monipuri

Marma

Santal

Mru

Khasi

Meitei

Tanchangya

Tripura

Khumi

Munda

Bihari

Other

13.1.1. Please specify:

14. Monthly household income (in Bangladeshi Taka)

Total income of your family

Less than 50, 000

50, 000 - 100, 000

100, 000 - 150, 000

150, 000 - 200, 000

More than 200, 000

Knowledge

K1. Have you previously heard of thalassemia?

Yes

No

K2. What is the source of your information regarding thalassemia?

You may select multiple options if applicable

Friends and family

Newspaper

Television and radio

Social media (Facebook, YouTube, etc)

Web portal and online scientific articles

Others

Please specify

K3. Do you know your blood group?

Yes

No

K4. Are you a thalassemia carrier or patient?

In case of thalassaemia carrier, thalassaemia will not be developed; but in case of thalassemia patient, thalassemia will be developed.

Yes

No

I don't know yet

K5. Does any member of your family (parents, siblings) receive routine blood transfusion only due to thalassemia?

Yes

No

I don't know yet

K6. Please select the statements that you think are true

You may select multiple options if applicable.

- Thalassemia is a genetic disorder. It can be passed from parents to children.
- Thalassemia is contagious like COVID-19
- Thalassemia is the same condition like blood cancer
- Thalassaemia is closely associated with consanguineous marriages (inter-relative marriage) -
- Thalassemia is preventable
- Thalassemia is a disease caused due to abnormalities in red blood cells.
- Thalassemia is not a treatable disorder

K7 Thalassemia can be detected from blood tests.

Yes

No

I don't know

K8 Please select the statements that you think are true. The lifestyle for a person with thalassemia should...

A healthy lifestyle is important for everyone. For people living with thalassemia, it is especially important to know the healthy lifestyle. The lifestyle of a person with thalassemia ...

- Eat healthy diet
- Maintain health hygiene
- Regular exercise
- Keep vaccinated up-to-date
- Have supportive relationship
- Have isolated during marriage

Practice

P1. Have you previously undergone screening for thalassemia?

Yes

No

Not sure

P1.1 Are you planning to get yourself tested in the future?

Yes

No

I haven't decided yet

P1.2 Do you plan to get yourself tested in the future?

Yes

No

I haven't decided yet

P1.1.1 When are you planning to undergo screening for thalassemia?

As soon as possible

Before marriage

After marriage

Before having child

I haven't decided yet

P1.2.1 When are you planning to undergo screening for thalassemia?

As soon as possible

Before marriage

After marriage

Before having child

I haven't decided yet

P2. Previously, I encouraged my friends and family to undergo thalassemia screening.

Yes

No

P3. In the future, I will encourage my friends and family to undergo thalassemia screening.

Yes

No

Not sure

P4. I will spend some times to find more information about thalassemia.

Strongly agree

Agree

Neutral

Disagree

Strongly disagree

P5. If I were a thalassemia career, I would like to test my partner's condition before marriage.

Strongly agree

Agree

Neutral

Disagree

Strongly disagree

P6. Do you donate blood at regular interval?

Yes, I donate blood at regular interval

No

Yes, but irregularly (once or twice in life)

P6.1 Have you ever donated blood to any thalassemia patients?

Yes

No

Not sure

P6.2Have you ever donated blood to any thalassemia patients?

Yes

No

Not sure

Attitude

A1. I think, everyone must undergo thalassemia screening?

Strongly agree

Agree

Neutral

Disagree

Strongly disagree

A2. I think, thalassemia screening must be done before planning for marriage?

Strongly agree

Agree

Neutral

Disagree

Strongly disagree

A3. I think, couples (thalassemia carrier) are still allowed to marry and have children as long as they understand the potential risks.

Strongly agree

Agree

Neutral

Disagree

Strongly disagree

A4. I think, thalassemia is not a curse.

Strongly agree

Agree

Neutral

Disagree

Strongly disagree

A5. I think, being friend with a thalassemia patient is not a problem.

Strongly agree

Agree

Neutral

Disagree

Strongly disagree

A6. I think, by preventing consanguineous (inter-relative marriage), the chance of passing the thalassemia trait to the next generation can be decreased.

Strongly agree

Agree

Neutral

Disagree

Strongly disagree

A7. I think, thalassemia screening must be implemented into a national level program.

Strongly agree

Agree

Neutral

Disagree

Strongly disagree

A8. I think, thalassemia certificate must be attached to the marriage certificate by law.

Strongly agree

Agree

Neutral

Disagree

Strongly disagree

A9. I think it is important for me and my family to receive information about thalassemia even if we are not thalassemia carriers or patients.

Strongly agree

Agree

Neutral

Disagree

Strongly disagree

A10. I think, different awareness programs like seminars, open forum discussions should be arranged in the university.

Strongly agree

Agree

Neutral

Disagree

Strongly disagree

Do you have any suggestion(s) regarding thalassemia and/or this questionnaire?

Your any suggestion is highly appreciable and helpful. It is optional (not mandatory).