

Knowledge and Attitude towards Thalassaemia among Secondary School Teachers in Dhaka City

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Abstract

Background : Thalassaemia is an important child health issue in Bangladesh and prevention is the key strategy to combat this problem. Teachers can play a significant role in preventing this disease provided they have a good knowledge about the disease.

Objective : The Knowledge and practice on thalassaemia among school teachers are unknown. The present study was, therefore, conducted among secondary school teachers of Dhaka City to assess their knowledge and attitude about thalassaemia.

Materials & Methods : This cross-sectional study was carried out in 8 secondary schools in Dhaka from January 2018 to June 2018. Out of 24 Govt. Secondary schools of Dhaka city, 8 schools were selected using random table. Four hundred school teachers from the 8 government schools were then selected using systematic sampling method. A semi structured questionnaire was used to evaluate knowledge of the respondents about thalassaemia. The test statistics used to analyze the data were descriptive statistics. The questionnaire also assessed preventive strategy and difference in attitude towards thalassaemia.

Result : The majority of the secondary school teachers are informed about thalassaemia, but their knowledge is inadequate regarding occurrence, nature and prognosis of thalassaemia. Among the respondents 6% had a good level of knowledge, 20% had average and 74% had poor level of knowledge. Regarding views on prevention, 16.5% thought the necessity of prenatal diagnosis of the carrier couples and 24.4% agreed that thalassaemia carriers should not marry each other. About 32.5% of the respondents were in agreement that premarital screening is essential for the prevention of thalassaemia to next generation.

Conclusion : Most of the secondary school teachers have poor knowledge in general aspects and preventive measures of thalassaemia. Majority of the teachers did not have positive attitude towards premarital screening for thalassaemia carrier, however majority of them showed positive attitude towards creation of an academically friendly environment for the thalassaemic patients.

Key words : Thalassaemia, knowledge, schoolteachers.

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Background

Thalassaemia is a serious autosomal recessive genetic disorder that is prevalent among people of Mediterranean, Middle Eastern and South Asia (India, Pakistan, and Bangladesh) origin.¹ It occurs when there is decreased or absent production of one of the globin chains (most commonly either α or β), that causes insufficient amount of normal structure of globin chains results in unable to make sufficient and sustainable adult haemoglobin (Hb), so they require regular monthly blood transfusions.² There are two major types such as α - thalassaemia and β - thalassaemia. It was thought that thalassaemia is not a curable condition but more than 3000 patients of β -thalassaemia major were cured by the treatment with hematopoietic stem cell transplantation. In low-risk HLA-matched sibling patients at least 90% survival and an 80% event-free survival has been

observed. All children who have an HLA-matched sibling should be offered the option of bone marrow transplantation.³ Gene therapy for β -Thalassaemia is still on trial and a hope for future¹. WHO has estimated that about 7% of the world's population might be carrier of β -thalassaemia (β/β) and that about 300000-400000 severely affected infants are born every year.⁴ Maldives has the highest incidence of thalassaemia in the world with a carrier state of 18% of the population.⁵ The estimated prevalence is 3-8% in populations from Bangladesh, China, India, and Malaysia and Pakistan.⁶⁻⁷

These disorders can be avoided as identification of carrier is possible using simple hematological tests.⁸ The birth of a child with thalassaemia can be prevented if 'at-risk' couples opt for prenatal diagnosis and subsequently opt for termination of an affected fetus.

Although thalassemia is a serious health problem and poses tremendous physical and psychological problems in the affected individuals, it is possible for thalassaemia major to enjoy a good life and to live a normal lifespan with good coping strategies that entail individual personal and collective efforts of family, society, material resources and health services.⁹ Lack of knowledge and understanding about thalassaemia leads to general confusions over differences between the carriers and thalassaemia major, inheritance pattern, its manifestations, survival rate, treatment available and the physical and psychological impact of the disorder in affected individual and their families. Stigma and discrimination surrounding thalassaemia rooted in misconception and erroneous beliefs. Wong found some fundamental misconceptions which include erroneous beliefs that thalassemia minor exhibit signs and symptoms of thalassemia major, a child can inherit thalassemia major even if only one parent is a carrier, and perceived all thalassemia major are severely handicapped.¹⁰ Such misconceptions clearly lead to unnecessary anxieties and may have a profound effect among carriers.¹¹ Chattopadhyay found that unawareness causes people to overlook screening tests for diseases.¹² Several studies demonstrated that public education and awareness campaigns in many countries have greatly reduced the frequency of infants born with thalassemia major.¹³⁻¹⁵

Studies on knowledge and attitude towards thalassaemia are relatively scarce. Among those, one study was conducted by Al-Kindi et al in 2012 to see knowledge and attitude of university students of Oman towards premarital screening program.¹⁶ Another study by Wahab and associates in 2011 was conducted in Malaysia to see the perception of parents and family members towards thalassaemia.¹⁷ A nationwide survey in Malaysia was conducted in 2011 aimed at determining the level of Malaysian people's awareness, perception and attitude towards thalassaemia and thalassaemia screening practices.¹⁸ In all the above studies the findings hope to provide insights into culturally congruent educational interventions to increase knowledge and cultivate positive attitudes toward prevention of thalassaemia.

The main way to combat this serious condition is prevention. Developing an effective prevention programme is difficult. Therefore requires the commitment of national health authorities, health workers, expert centers, teachers and mass media. Among them, teachers play an important role in our society. They are the builders of the nation, mentor in knowledge, responsible for values formation and the preservation of culture and molders of a future leader. Due to the large number of thalassaemic patients in Bangladesh and limited medical service resources, it is not possible to give optimal blood transfusions and iron chelating agents to the majority of patients. These masses of untreated thalassaemic patients

develop a multitude of complications. Improving this situation will require proper education of health personnel, not only the physicians but downstream to the auxiliaries working in the community. If teachers are made aware about thalassaemia, they can disseminate it to others easily.

Therefore, knowledge and attitude of school teachers towards thalassaemia should be assessed and programme should be taken to improve their knowledge and attitude for prevention of thalassaemia. But, by far, no study has yet been conducted in Bangladesh to assess the knowledge and attitude of school teachers towards thalassaemia.

This study, is therefore, designed to assess the knowledge and attitude of secondary school teachers towards thalassaemia.

Objectives of the study

To find out the level of knowledge and attitude on thalassaemia in secondary school teachers in Dhaka city.

Materials and Method

This cross-sectional observational study was carried out in 8 selected government secondary schools in Dhaka city From January 2018 to June 2018. All teachers of class (VI – X) were selected as study population. 400 teachers who were willing to respond to the study questionnaire were enrolled in the study. The participated teachers were termed as respondents in this study. Teachers who had a family member affected with thalassaemia and not willing to respond were also excluded. Demographic characteristics of the respondents were studied in terms of age and sex. Knowledge of the respondents, their opinion regarding characteristics of thalassaemia major, carrier state, marriage and pregnancy of carriers and couples, prenatal screening were evaluated using a semi structured questionnaire.

Operational definitions

Thalassaemia:

Thalassaemia major is a life-long transfusion-dependent anemia with short stature, facial abnormalities (depressed nasal bridge and bossing of the skull), delayed or absent puberty and psycho-social problems.

Knowledge: In this study, knowledge meant for perception of the secondary school teachers on different aspects of the disease, thalassaemia, needed to reduce the incidence of thalassaemia in the community.

Attitude: Attitude is the reflection of one's mind as the way it views a problem. It may be positive, may be negative. In this study attitude meant for views or feelings of the teachers regarding improvement of educational and national facilities of the children with thalassemia.

Data collection:

Data were collected using a semi-structured questionnaire (research instrument) containing all the variables of interest.

Out of 24 Govt high school in Dhaka city 1st 16 were boys' and last 8 were girls' school. Out of 24 schools, 8 (33%) schools (4 boys and 4 girls) were selected using random table. From these 8 schools 400 teachers, 50 teachers from each school were taken. After introduction random selection of 10 teachers from each class by lottery method, face to face interview was conducted using semi-structured pretested questionnaires. The questionnaire comprised questions divided into 4 parts. Firstly, respondents were asked if they had ever heard of thalassaemia. Only those who answered 'yes' were asked further questions. Secondly, respondents' knowledge about thalassaemia were evaluated across several domains: 1) general knowledge about thalassaemia and 2) knowledge about thalassaemia carrier state. For each correct response, a score of '1' (one) and for each wrong answer or non-response a score of '0' (zero) was assigned. There were altogether 15 questions (9 questions for general knowledge and 6 for carrier-state about thalassaemia) and therefore the score of the respondents ranged from 0 – 15. The scores attained by the respondents were evaluated in 3 categories as follows.

Level of general knowledge:

The 9 variables on general aspect of thalassaemia were- nature of disease, tools of diagnosis, major clinical feature, and requirement of regular transfusion, food habit, and life span of thalassaemia major, growth, mental and psychological development of the child which together constitute a score of 9. The level of knowledge on general aspect was categorized as:

Good: Score 9 – 7 (> 75%) graded as good knowledge

Average: Score 6 – 5 (75 – 50%) graded as average knowledge

Poor: Score < 5 (< 50%) graded as poor knowledge

Level of knowledge about carrier state:

The 6 variables on carrier state of thalassaemia were – whether thalassaemia carrier later develop thalassaemia major, options of future child of carrier parents, marriage which carries more chance when both parents are carriers, life span of thalassaemia carrier, and necessity of thalassaemia carrier blood testing, inhibition of consanguineous marriage.

The knowledge level was categorized as:

Good: 6 – 5 (> 75%) graded as good knowledge

Average: 4 – 3 (50 – 75%) graded as average knowledge

Poor: < 3 score (< 50%) graded as poor knowledge

Overall knowledge:

Combining the knowledge scores obtained on general aspect and carrier state of thalassaemia comprised overall knowledge (the highest obtainable score was 15) and were categorised as follows:

Good: 15 – 11 (> 75%) graded as good knowledge

Average: 10 – 8 (50 – 75%) graded as average knowledge

Poor: < 7 score (< 50%) graded as poor knowledge

The third part of the questionnaire assessed preventive strategy towards thalassaemia, where participants were asked for their views on premarital screening, marriage between individuals who are both carriers, pregnancy of carrier couples and termination of pregnancies affected with thalassaemia.

The fourth part of the questionnaire assessed views and feelings of the teachers (attitude) for thalassaemic students. Here, their views are assessed in 2 different environments. In academic environment, their attitude were evaluated by asking 5 questions (necessity of extra care at school, special consideration for not being present or attend exam, teaching with sympathetic behaviour, requirement of special school). As a responsible citizen, their views are assessed by asking 5 questions (requirement of personal society, special policy from government, opportunity of having blood/ medication at cheaper rate). Every question was explained to them prior to interview by the investigator herself.

Statistical analysis: Using computer software SPSS (Statistical Package for Social Sciences) data were processed and analysed. Statistical tests used to analyse the data were descriptive statistics. Analysed data were presented in the form of tables and graphs with due interpretation.

Results

Out of 400 respondents, 315 (78.8%) were heard about thalassaemia (Fig 1)

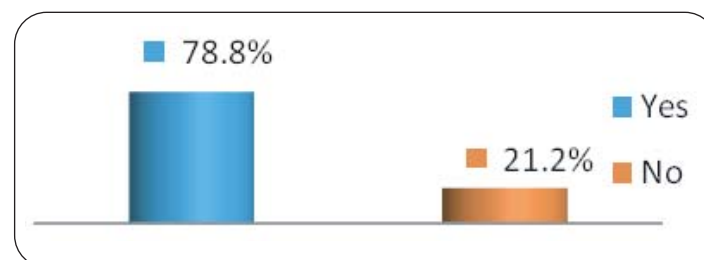


Fig 1: Distribution of respondents by ever hearing of thalassaemia (n= 400)

Among the study subjects 47% were 46-55 years old, 38.8% were 36-45 years, and 13.2% were 25-35 years. The subjects over 55 years were the least (1%) The mean age was 42.6 ± 6.4 years. (Fig 2)

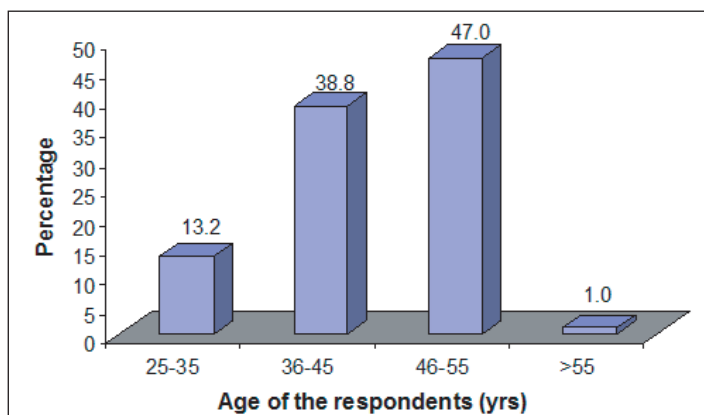


Figure 2: Distribution of respondents by age (n=400)

More than half of the study subjects were male (54%) giving a male to female ratio of roughly 1.2 (Fig 3)

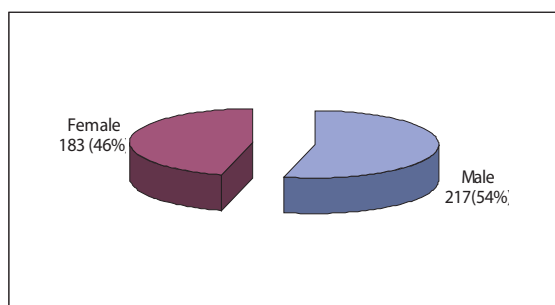


Figure 3: Distribution of respondents by Sex (n=400)

Majority of the respondents (56.2%) had poor level of knowledge on general aspects of thalassaemia, 32.7% had average knowledge, where as only 11.1% had good knowledge. (Table I)

Table I : Distribution of respondents by the level of knowledge about general aspects of thalassaemia (n= 315)

Level of knowledge (score)	Frequency	Percentage
Good (9 – 7)	35	11.1
Average (6 – 5)	103	32.7
Poor (< 5)	177	56.2

In our study 66.1% of the respondents had poor knowledge about the carrier state of thalassaemia. Average level of knowledge was found in 26.3% of the cases and only 7.6% had good knowledge. (Table II)

Table II: Distribution of respondents by the level of knowledge regarding carrier state of thalassaemia(n= 315)

Level of knowledge (score)	Frequency	Percentage
Good (6 – 5)	24	7.6
Average (4 – 3)	83	26.3
Poor (< 3)	208	66.1

Among the respondents, 73.9% had poor level of knowledge, 20% had average knowledge, and only 6.1% had good knowledge about thalassaemia (Table III)

Table III: Distribution of respondents by overall knowledge about thalassaemia (n=315)

Overall knowledge (score)	Frequency	Percentage
Good:(15 – 11)	19	6.1
Average:(10 – 8)	63	20.0
Poor: (< 7)	233	73.9

Among the respondents, 16.5% knew that prenatal diagnosis of the fetus of the carrier couples should be done; 24.4% knew that marriage between carriers should be postponed and 32.3% knew that premarital screening can reduce the incidence of thalassaemia. (Table IV)

Table IV: Knowledge of the respondents towards prevention of thalassaemia (n=315)

Views regarding prevention of thalassaemia	Frequency	Percentage
Prenatal diagnosis of the fetus of carrier couple should be done	52	16.5
Marriage between carriers should be postponed	77	24.4
Premarital screening can reduce the incidence of the disease thalassaemia	102	32.3

Among the respondents, 92% believed that thalassaemic children need extra care, 97% and 98% respectively believed that absentees from school and exams due to their ailments should get special consideration; about 31% had an opinion that thalassaemic patients require special schools and 91% thought that they should be taught the thalassaemic students with sympathy (Table V)

Table V: Respondents attitude in academic environment towards thalassaemic patients (n = 315*)

Components of attitude evaluation	Frequency (%)	95 % CI
Need extra care	292(92.0)	89.7-94.3
Considerate to absentee from school	311(98.7)	97.4-99.9
Considerate to absentee from Exam	308(97.8)	96.2-99.4
Need special school	100(31.7)	26.6-36.8
Teaching with compassionate behavior with thalassaemic children	306(97.1)	95.2-98.9

* multiple responses.

Among the respondents 55.2% felt the necessity of a thalassaemia society and 87% felt the necessity of a national policy. Provision of free blood was advocated by 96% and provision of free medication was advocated by 100% respondents. (Table VI)

Table VI: Respondents attitude as a responsible citizen towards thalassaemia

Social and national policy-related attitude	Frequency (%)	95 % CI evaluation
Necessity of Thalassaemia society	174(55.2)	49.71-60.69
National policy for thalassaemia patients	275(87.3)	83.62-90.98
Opportunity of free blood	305(96.8)	94.86-98.74
Opportunity of free medication	315(100.0)	

Discussion

The present study was conducted to assess the perception of the secondary school teachers about thalassaemia. To arrive at a conclusion the findings of the present study should be compared and contrasted with those of similar studies conducted at home and abroad. But using all the available means of literature search, no head-to-head article was found. However, several studies were found which incorporated the knowledge and attitude of the university students and general public about the disease thalassaemia and we used these articles to compare and contrast our findings with those studies.

The results of the present study clearly showed that majority of the secondary school teachers are aware of the disease thalassaemia, but their knowledge was poor about its various aspects including prevention. Only 6% of the respondents had a good level of knowledge, 20% average and 74% poor level of knowledge. The level of knowledge was not influenced by age or gender of the respondents. This finding is consistent to what was reported in similar studies conducted on the role of premarital screening to prevent genetic blood disorders in Egypt, Saudi Arabia, and Syria.¹⁹⁻²¹ This could be due to the participants' lack of ability to appreciate the seriousness of the genetic blood disorders and its huge impact on the emotional and financial status of the affected families.

A study conducted in Jordan demonstrated that 75% of families have not heard about the disease before having their first affected child.²² Similarly, insufficient knowledge also have been found in UK based Pakistani families about the risk of carrying a gene that may result in the birth of a thalassaemic child.²³ Thus, the findings of the present study and those of other countries presented above indicate that there is a need to improve the quality of information disseminated by professionals about carrier testing, prenatal diagnosis and premarital screening. Premarital screening instead of prenatal test may be a good strategy in prevention and control of thalassaemia as was evident in Pakistan as majority (87.8%) of the couples in the existing study suggested a need for legislation for mandatory thalassaemia screening before marriage.⁴

A study conducted in India demonstrated that correct knowledge of carriers is a very important criteria for the

prevention of Beta thalassaemia. Participants were found to carry a positive attitude towards the public perception of Beta thalassaemia. In general, social discomfort was not a serious issue, but acceptance of life partner with Beta thalassaemia trait was unacceptable among population studied. The acceptability for prevention strategies and its implication was high but rural people was found to be more inclined towards premarital screening (80.8%) and prenatal diagnosis (98.0%).²²

In terms of attitude, only 1 in 6 teachers thought the necessity of prenatal diagnosis of the fetus of the carrier couples and only 1 in 4 agreed that thalassaemia carriers should not marry each other. About one-third were in favour of premarital screening of public for the prevention of thalassaemia to next generation. However, majority of them had a positive attitude towards creating an academic environment, where they can learn and receive a caring attitude from their teachers which they deserve as a right for their compromised state. Most of the teachers were of the opinion to establish separate schools for them, though no such school has yet been established in our country. The teachers, in general, were in favour of establishing a Thalassaemia Society and formulating a National Policy-legislation so that the thalassaemic children can have free medical services (including free medication and free blood). Similar attitudes are found among literate people all over the world. Most of the Omani university student (92%), as revealed by a survey, though it is important to carry out premarital screening to prevent genetic blood disorder and agreed to do it. Around half of them (53%) favored having premarital screening as an obligatory procedure before marriage and about one-third (36%) favored making laws and regulation to prevent marriage in case of positive results.²³

Premarital screening for genetic diseases is superior to prenatal screening since the former is primary prevention while the latter is secondary or tertiary prevention.²⁴ Premarital screening can potentially reduce the burden of inherited hemoglobin diseases by the number of high-risk marriages. This was proven to be beneficial in many countries with similar endemicity levels of hemoglobinopathies.²⁵⁻²⁶ Because of the burden on the healthcare system and effect on the quality of life in patients with β -thalassaemia, premarital genetic screening was mandated in Saudi Arabia in 2004.²⁷

However, the situation in Iran has also recently changed. Genetic counseling has generally had little or no impact on the choice of spouse. Separating and finding another spouse was the only option in Iran before prenatal testing generally available and abortion of an affected fetus was permitted by the government.²⁸ On the other hand, once pregnancy has occurred, the couple will almost invariably seek prenatal diagnosis.²⁹ This can be achieved before 13 weeks using chorionic villus biopsy.

Mandating the premarital screening for inherited hemoglobinopathies was long awaited in Saudi Arabia and was preceded by religious and scientific debate.³⁰ In this highly conservative population, premarital screening in Saudi Arabia is the main preventive tool. In our country premarital screening for genetic disorders is limited in some tertiary level hospitals. But mass population is unaware of the service, for lack of social mobilization. Government of Bangladesh must have to formulate policies what services it will provide to thalassaemia children what services it will provide to reduce the incidence of thalassaemia in the country.

Limitation of study

The following limitations of the study deserve mention:

1. We collected our sample from the schools situated in the urban areas and such findings cannot be generalized to all secondary school teachers.
2. Head-to-head article was not found to compare the findings of the present study with those of others.

Conclusion

From the findings of the study, it can be concluded that majority of the secondary school teachers have poor level of knowledge about thalassaemia. However, majority of them showed positive attitude towards creation of academically and nationally friendly environment for the thalassaemic patients.

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