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Assessing Thalassemia Knowledge Among Secondary School Educators: Implications for Prevention

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Abstract
Background: *Thalassemia, a hereditary blood disorder, poses a significant health challenge globally. Early detection of carrier status and awareness about preventive measures are crucial in minimizing its prevalence. Participants' interest in knowing the severity of the disease and assessing their risk of getting the disorder may imply the health belief model as a possible means of predicting thalassemia public screening services.*
Objective of the study: *The aim of this research article isto investigate the level of thalassemia knowledge among secondary school educators and explores the potential implications for prevention strategies.*
Methods: *From January to June 2019, eight secondary schools in Dhaka hosted this cross-sectional investigation. Four hundred twenty-four teachers (424) were chosen among the eight government schools using a rigorous random sampling procedure. The respondent's level of knowledge on thalassemia was assessed using a semi-structured questionnaire with 15 questions (9 questions for general elements of thalassemia and 6 questions about carrier state, which include etiology, mode of inheritance, and clinical presentation). Descriptive statistics were the test statistics applied to the data analysis. Additionally, the questionnaire evaluated concerning preventive strategies.*
Results: *The study's findings indicate that a significant portion of secondary school teachers possess information about thalassemia; however, their understanding of the occurrence, nature, and prognosis of thalassemia is insufficient. Only6.3% of the participants demonstrated a high level of knowledge, while 20.4% had an average level, and a substantial 73.3% had a poor level of knowledge. In terms of preventive measures, 17.92% recognized the importance of prenatal diagnosis for carrier couples, and 33.33% agreed that individuals carrying thalassemia should not marry each other and 48.74% of the respondents acknowledged the necessity of premarital screening as a crucial step in preventing thalassemia in the next generation.*
Conclusion: *This research highlights the urgent need for interventions aimed at improving thalassemia awareness among secondary school educators. By addressing knowledge gaps and promoting preventive measures, educators can contribute significantly to reducing the prevalence of thalassemia.*
Keywords: *Thalassemia, Awareness, Prevention, Secondary School Educators, Carrier Status, Genetic Disorders, Hemoglobin, Education Intervention*

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I. Introduction

Thalassemia is a single-gene disorder that is passed from parent to child by what is called an autosomal recessive pattern of inheritance. An autosomal disease can affect males and females alike since the abnormality is on one of the autosomes, i.e., not the chromosome responsible for determining the sex of a child[1]. Recessive means that the child needs to inherit the defective gene from both the father and the mother to develop severe clinical conditions of thalassemia major. Individuals who inherit a defective gene from their mother and father are described as homozygotes[2]. In the case of β-thalassemia, they are described as patients with homozygous β-thalassemia or thalassemia major. In the case of β-thalassemia, individuals who inherit a normal gene from one parent and a defective gene from the other are known as heterozygotes or heterozygous for thlassaemia[3].

Thalassemia, the most common inherited gene disorder in the world, was initially described in Italians, Greeks, Spaniards, and other people of Mediterranean origin[4]. However, it is now realized that thalassemia is a common disorder with a widespread geographical distribution. It also occurs in the Middle East, India, and Southeast Asia. No population group is entirely free from the condition[5]. An estimated 7,000,000 babies are born every year with a genetic disorder or congenital anomaly, and up to 90% of births take place in low- or

middle-income nations[6]. According to a minimal estimate, more than 300,000 babies are born each year suffering from thalassemia, sickle cell anemia, or one of its variations[7].

In Bangladesh, no definite data regarding the carrier status of hereditary hemoglobin disorders exists. Several demographic studies have documented the remarkably high gene frequency of Hb-E, particularly in the eastern part of India, including Bengal, Burma, and Southeast Asia[8]. So, the interaction of Hb-E and β-Thalassemia, HbE-β-Thalassemia is the most important type of congenital hemolytic anemia in this region. In Bangladesh, one study found that 67% of the congenital hemolytic anemia cases were HbE-β-Thalassemia, which is consistent with other studies where HbE-β-Thalassemia is reported as the commonest form of Thalassemia in the neighboring and other Southeast Asian countries[9]. The high prevalence of hemoglobinopathies in a large population of Bangladesh also creates a significant burden on the health sector and is a major public health concern.Even though thalassemia is a serious health issue that causes severe physical and psychological problems in those who have it, a person with thalassemia major can still lead a normal life and enjoy a good quality of life if they use effective coping mechanisms that involve both individual and group efforts from family, society, material resources, and health services[10].

Secondary school educators play a pivotal role in shaping students' understanding of health issues, making their awareness of thalassemia carrier status crucial for effective prevention.A structured questionnaire was administered to a representative sample of secondary school teachers and we aimed to assess educators' knowledge of thalassemia toward carrier status, and the preventive measures because they could incorporate their lessons to the students through their teaching practices to make a significance awareness to the next generation regarding thalassemia.

II. Materials and Method

From January to June 2019, eight secondary academic institutions participated in a cross-sectional observational study. We included secondary school teachers from a few chosen schools in Dhaka city who voluntarily answered the questionnaire in our study. Nevertheless, teachers with thalassemia-affected family members were not allowed to participate in the study. We decided on 424 as the final sample size after sample size calculation. Systematic sampling was used to choose the necessary number of respondents.

Age and sex-related demographic traits of the respondents were examined. A semi-structured questionnaire assessed the respondents' knowledge, opinions, and carrier status concerning the significant characteristics of thalassemia, the marriage and pregnancy of carriers and couples, and prenatal screening.

Operational definitions

Thalassemia: Short stature, facial anomalies (depressed nasal bridge and bossing of the skull), delayed or missing puberty, and psycho-social issues are all characteristics of thalassemia major, a transfusion-dependent anemia that lasts a lifetime.

Knowledge: In order to lower the prevalence of thalassemia in the community, secondary school teachers must be better informed about all facets of the disease.

The respondents' scores fell into the following three groups for evaluation[11].

Level of general knowledge

The general aspect knowledge level was classified as follows:
Good: Score 9 – 7 (> 75%) were 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 degree of knowledge was divided into:
Good: 6 – 5 (> 75%) were graded as good knowledge
Average: 4 – 3 (50 – 75%) graded as average knowledge
Poor: < 3 score (< 50%) graded as poor knowledge

Overall knowledge

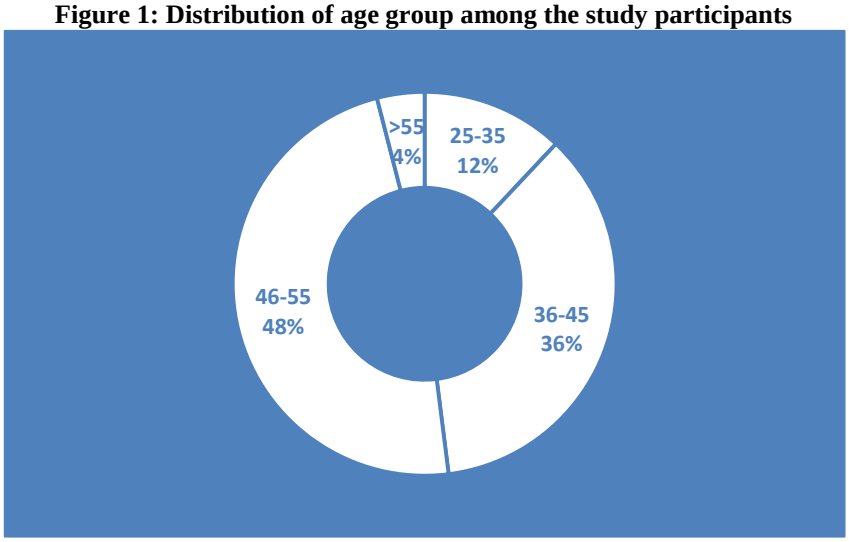
Good: 5 – 11 (> 75%) were graded as good knowledge
Average: 10 – 8 (50 – 75%) graded as average knowledge
Poor: < 7 score (< 50%) graded as poor knowledge

Data were processed and analysed using SPSS. Descriptive statistics were the statistical tests that were used to analyse the data. The analysis results were shown as tables and graphs with appropriate commentary. Ethical approval was taken from each of the institution and proper consent of the participants was noted to use their data as a research purpose study.

III. Results

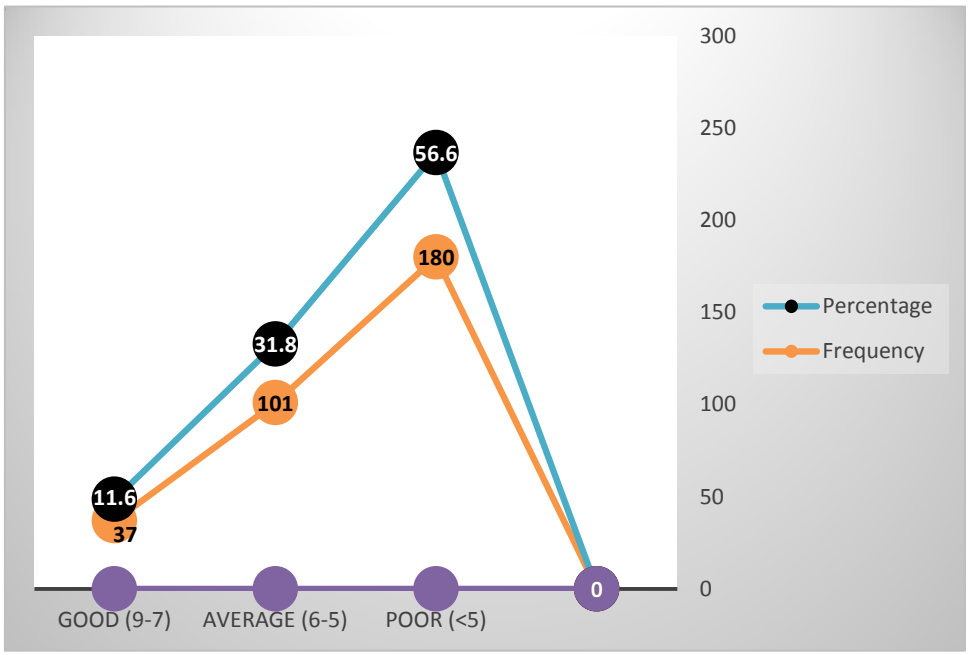
Of the 424 responders, 318 (75%) had heard of thalassemia, whereas the remaining 106 (25%) had never heard of it.Study participants ranged in age from 46 to 55 in 48% of cases, 36 to 45 in 36%, and 25 to 35

Figure 1: Distribution of age group among the study participants



in 12%. The oldest subjects (4%) were those who were above 55. The age distribution was 43.6 ± 6.4 years.With 54% of research participants being male, the male-to-female ratio was approximately 1.2:1.

Figure 2: Comparison between gender and response data among the study population



Only 11.6% of the respondents had strong knowledge about general elements of thalassemia, compared to 56.6% who had poor knowledge and 31.8% who had average knowledge.

Figure 3: Distribution of respondents by the level of knowledge about general aspects of thalassemia (n= 318)

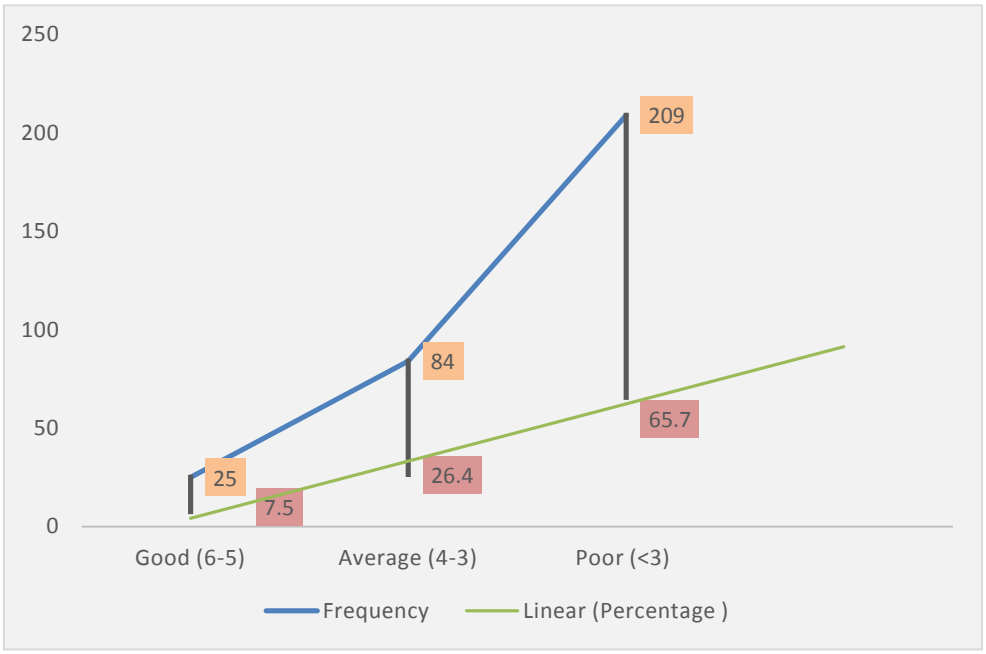
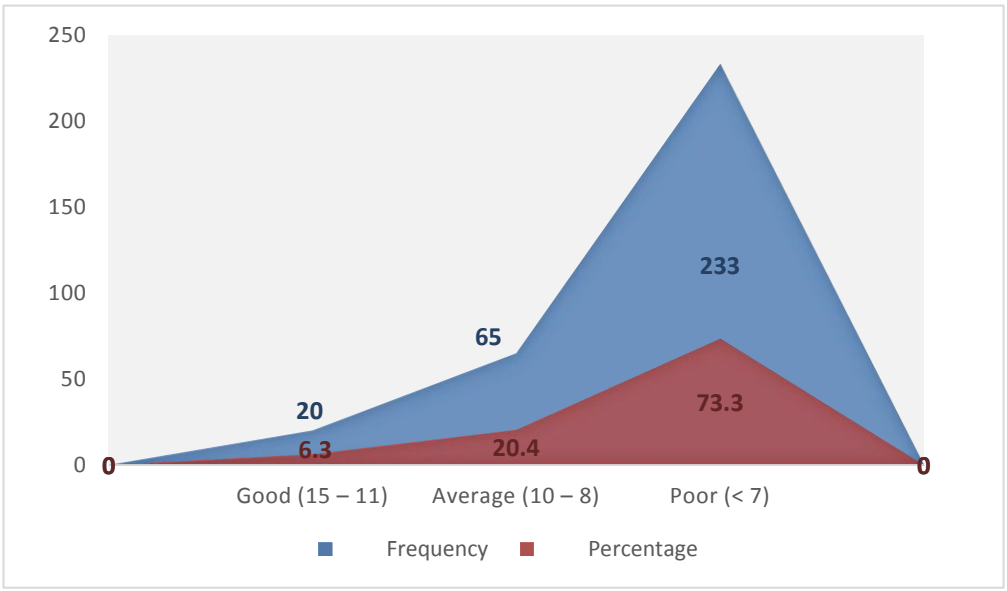


Figure 4: Distribution of respondents by the level of knowledge regarding carrier state of thalassemia(n= 318)



65.7% of those surveyed knew very little about the thalassemia carrier condition. Only 7.5% of the cases had strong knowledge and rest portion (26.4%) having an average level of understanding.

Out of all the respondents, 73.3% had poor knowledge about thalassemia, 20.4% had average idea, and only 6.3% had good knowledge.

Prenatal diagnosis of the fetus of carrier couple should be done	Marriage between carriers should be postponed	Premarital screening can reduce the incidence of the disease thalassemia
57 (17.92%)	**106 (33.33%)**	**155 (48.74%)**

Table 1: Knowledge and views of the respondents towards prevention ofthalassemia (n=318)

Of those surveyed, 17.92% were aware that prenatal testing should be done on the fetus of carrier couples; 33.33% believed that marriage between carriers should be delayed, and 48.74% believed that screening before marriage could lower the incidence of thalassemia.

Components of attitude evaluation	Frequency (%)	95 % CI
Need additional 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 submission in special school	100(31.7)	26.6-36.8
Teaching with compassionate behavior with thalassaemic children	306(97.1)	95.2-98.9

Table 2: Respondents attitude in academic environment towards thalassaemic patients (n = 318*)
***Total will not correspond to 100% for multiple responses.**

92 percent of the respondents thought that children with thalassemia needed extra care. Additionally, 98.7% and 978% of respondents, respectively, said that children who miss examinations and school due to illness should be given particular care; roughly 31.7% said that pupils with thalassemiaemia should attend special schools; and 97.1% said that teachers should be trained to be understanding with students who have thalassemia.

IV. Discussion

The findings underscore the crucial role educators' play in thalassemia prevention. A well-informed teaching community can significantly contribute to the dissemination of accurate information about the disease, its hereditary nature, and the importance of preventive measures. By integrating thalassemia education into the curriculum, educators can empower students with knowledge that may influence their choices in adulthood, including marriage and family planning.The results of this study should be compared and contrasted with those of related studies carried out both domestically and outside to conclude. We examined some research that included information about the attitudes and understanding of university students and the general public regarding thalassemia to compare and contrast our findings with those studies.

The percentage of respondents with strong thalassemia knowledge was 6.3%, average knowledge was 20.4%, and bad knowledge was 73.3%. The respondents' age or gender had no bearing on their degree of expertise. This result aligns with findings from related studies in Saudi Arabia, Egypt, and Syria on the usefulness of premarital screening in preventing hereditary blood diseases[12-14]. According to research done in Jordan, 75% of families were unaware of the illness before their first affected kid was born[15]. Likewise, inadequate awareness has also been discovered among Pakistani families residing in the UK on the possibility of carrying a gene that could lead to the birth of a kid with thalassemia[16]. As a result, the results of this study and those from other nations that were previously mentioned show that professional knowledge about carrier testing, prenatal diagnosis, and premarital screening needs to be of higher quality. Most couples in the current study (87.8%) indicated that legislation requiring thalassemia screening before marriage is necessary, suggesting that premarital screening rather than prenatal testing may be a good technique for preventing and controlling thalassemia[2,3].

An Indian study revealed that accurate carrier identification is critical in preventing beta-thalassemia. It was shown that the participants had a good impression regarding how the general public views beta-thalassemia. Social discomfort was often not a significant problem; however, accepting a life partner with the beta thalassemia trait was unacceptable among the population under study. Although prevention measures and their implications were widely accepted, research revealed that rural people were more likely to support prenatal diagnosis (98.0%) and premarital screening (80.8%)[17].

The high percentage (92.0%) of educators expressing the need for additional care for thalassemic students reflects a positive view. The overwhelmingly considerate attitudes toward absenteeism from both regular school activities (98.7%) and exams (97.8%) indicate a recognition of the unique challenges faced by thalassemic students. Educators' understanding and flexibility in accommodating the needs of these students are pivotal in ensuring equal educational opportunities.Approximately one-third of educators (31.7%) believed that thalassemic students should be enrolled in special schools.The positive response (97.1%) to teaching with compassionate behavior indicates a willingness among educators to create an empathetic and supportive learning environment. The low percentage of educators supporting prenatal diagnosis (17.92%) and advocating for postponing marriages between carriers (33.33%) reveals a potential gap in understanding the preventive aspects of thalassemia. Notably, only 48.74% believed that premarital screening could reduce the incidence of the disease.

According to a survey, 92% of Omani university students believed that premarital screening is necessary to prevent hereditary blood disorders and thought it should be done. About one-third (36%) supported passing laws and regulations to forbid marriage if premarital screening yielded positive results, and nearly half of them (53%) supported making premarital screening a mandatory process before a wedding[18].Because prenatal screening is secondary or tertiary prevention, but premarital screening is primary prevention, it is superior to prenatal screening for hereditary illnesses[19]. By lowering the number of high-risk couples, premarital screening can lessen the burden of inherited hemoglobin disorders. This is helpful in numerous nations where hemoglobinopathies are endemic to comparable degrees[20].Premarital genetic screening was made mandatory in Saudi Arabia in 2004 due to the strain β-thalassemia patients placed on the healthcare system and their quality of life [21].

But things have also altered recently in Iran. The choice of marriage has often been minimally affected, if at all, by genetic counseling. Before prenatal testing became widely available and the government allowed the termination of an affected fetus, the only alternative available in Iran was to separate and find another spouse[22]. In Saudi Arabia, the long-awaited mandate for premarital screening for hereditary hemoglobinopathies was preceded by debates in the fields of science and religion[23]. Premarital screening is the primary preventive measure in Saudi Arabia for this extremely conservative population.

This study highlights the positive attitudes of secondary school educators toward thalassemic students but also identifies areas for improvement, particularly in terms of knowledge about preventive measures. Educational interventions tailored for educators can bridge this knowledge gap, equipping them to instill preventive awareness in students from their formative years. Ultimately, a collaborative effort involving educators, health professionals, and policymakers is essential to create a comprehensive approach to thalassemia prevention within the educational system.

V. Conclusion

This research highlights the urgent need for interventions aimed at improving knowledge about thalassemia carrier status and its prevention among secondary school educators. By addressing knowledge gaps and promoting preventive measures, educators can contribute significantly to reducing the prevalence of thalassemia.

VI. Limitation of study

The samples for our study were specifically gathered from secondary schools located in urban areas, implying that caution should be exercised when attempting to generalize the findings to all secondary school teachers, as the characteristics and contexts in urban settings may differ from those in rural or suburban areas. Additionally, it is important to note that a comprehensive comparison of our study's findings with existing research was hindered by the absence of a directly relevant head-to-head article.

VII. Recommendations

By implementing following recommendations, we can enhance thalassemia knowledge among secondary school educators:

- Design and implement comprehensive educational programs specifically tailored for secondary school educators and utilize various teaching methods, such as workshops, seminars, and e-learning modules, to ensure engagement and knowledge retention.
- Advocate for the integration of thalassemia education within pre-service and in-service teacher training programs.
- Create online portals, webinars, and social media campaigns targeting secondary school educators for wider reach, flexibility, and the incorporation of multimedia resources to enhance the learning experience.

Conflict of Interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this article.

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