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MATERNAL KNOWLEDGE AND ATTITUDINAL INSIGHTS ON CHILDHOOD THALASSAEMIA – A HOSPITAL BASED STUDY

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ABSTRACT

Background: Thalassaemia major is a lifelong condition and parents' beliefs and knowledge influence everyday management and prevention. To manage this condition effectively, addressing the knowledge gaps of the parents and their perception towards thalassaemia is very crucial. **Objective:** To assess the extent of parental knowledge and their perceptions regarding thalassemia. **Materials and Method**: In a cross- sectional survey of 52 mothers of thalassaemic children admitted topaediatric department of a tertiary medical college hospital, a validated questionnaire was used to document knowledge of inheritance, screening, treatment, and prevention as well as social and ethical issues. **Results:** Knowledge gaps were considerable,3.8% had known that thalassaemia exists prior to having their first affected child; 53.8% did not know that the disease is hereditary; another 86.5% did not know that positive family history increases risk; and only 36.5% knew about consanguinity relevance. Despite 84.6% identifying transfusion as a mode of treatment, only 3.8% were aware that bone marrow transplantation is one of the treatment modalities; 86.5% accepted the necessity for regular transfers (and) more than half believed this would be necessary for life. Preventive literacy was poor—80.8% did not know about prenatal diagnosis and only 23.1% had heard of premarital screening, while 73.1% were not able to name any preventable method. Attitude wise, 65.4% were against carrier inter-marriage; 82.7% were in favor of premarital screening for the general population; 48.1% agreed with termination when a fetus is thalassaemia major and 76.9% supported the necessity for legislation of premarital screening to prevent affected births. Financial and emotional distress were reported by many (80.8% and 67.3%, respectively), and over half (55.8%) felt that their child's education was involved in some way or other with the condition. **Conclusion:** These findings underlie the importance for culturally appropriate counselling, available screening pathways and practical support in improving care giving and minimizing avoidable complications.

Keywords: Thalassaemia; Parental knowledge; Maternal attitudes; Premarital screening; Prenatal diagnosis.

INTRODUCTION

Thalassaemia, an inherited blood disorder, is the most common haemoglobinopathies worldwide[1]. Previously its distribution was more prevalent in certain regions such as the South East Asia, Indian subcontinent, Mediterranean and Middle East but cases are increasing in other areas, including North America and Northern Europe, primarily due to migration [2,3].

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The estimated prevalence of thalassaemia varied both across nations and within national borders. Among 23 population-based studies that reported on clinically significant forms of thalassaemia, prevalence estimates per 100,000 individuals varied widely. For combined alpha and beta thalassaemia, rates ranged from 0.2 in Spain to 27.2 in Greece. For alpha thalassaemia alone, prevalence ranged from 0.03 in Spain to 4.5 in Malaysia. In the case of βeta-thalassaemia, estimates ranged from 0.2 in Spain to between 35.7 and 49.6 in Iraq [4]. In India, βeta-thalassaemia was reported to be between 0.94% to 13.20%[5]. Indonesia sees the birth of roughly 2500 babies with thalassaemia major every year [6]. In Bangladesh, the prevalence rate of Beta-thalassaemia train and Hemoglobin E (Hb E) trait are 4.1% and 6.1% respectively possessing a greater threat to future generation [7]. In Bangladesh, Hb E-β thalassemia is the most common haemoglobinopathy among anaemic children, accounting for 68.5% of cases, followed by β-thalassemia major (31%) and Hb E disease (0.5%) among the admitted patients in Thalassemia center of Dhaka Sishu Hospital [8]. HbE Trait was 21.6% while Thalassemia Major, Thalassemia Minor, HbE Disease, and HbE with β-Thalassemia were 1.7%, 4.2%, 1.7% and 4.2% respectively [9].

Thalassaemia is a serious inherited blood disorder that makes it difficult for the body to produce enough healthy haemoglobin, often leading to a lifelong struggle with chronic anaemia[10]. For many families, managing this condition is not just a medical challenge – it is a continuous journey filled with complex decisions and emotional resilience [11]. Management of this condition usually requires periodic blood transfusions along with iron chelation therapy to control excess iron accumulation [12]. In more advanced cases, options like stem cell transplantation and gene therapies may offer hope for curative solution [13]. Yet, each path comes with its own set of challenges, making support, awareness and access to care all the more critical. While these medical advances have improved outcomes, they also bring emotional, physical and financial challenges – particularly in low and middle income countries (LMICs), where access to specialized care can be scarce [13,14].

In these settings prevention is not only important but also vital to reduce patient burden [15]. Public health strategies like premarital screening, genetic counselling and community education have shown real promise in reducing the burden of the disease [16]. However, the effectiveness of these efforts often hinges on the awareness and attitudes of parents, who are central to both caregiving and prevention. Their understanding of thalassaemia, from treatment to early intervention, plays a crucial role in shaping how the disease is managed at both the family and community levels [17]. Therefore, this study aimed to investigate the parental knowledge gaps and perceptions regarding thalassemia, the barriers confronted by the parents for caring for their thalassaemic children and their attitude to prenatal screening and prenatal diagnosis.

The current study seeks to explore the depth of parental knowledge and their attitudes toward thalassemia, prenatal screening and diagnosis and practical barriers faced by the parents of thalassaemic children in Bangladesh.

MATERIALS AND METHOD

Study design
A cross-sectional study

Study Population
Mothers of children diagnosed with thalassaemia admitted in department of Paediatrics of Gonoshasthaya Samaj Vittik Medical College.

Sampling Method
Convenient sampling of mothers of thalassaemia patients attending a tertiary healthcare centre.

Data Collection Tool
A pre-tested, semi-structured questionnaire divided into two sections:
Knowledge - covering awareness of disease transmission, screening, treatment, and prevention.
Attitude - exploring perceptions on social, ethical, and emotional aspects.

Data Collection
Data were collected from the mothers of thalassaemia patients from 1stFebruary to 31st July, 2023, with face-to-face interview by trained healthcare personnel using the structured questionnaire.

Inclusion Criteria
- Mothers of confirmed thalassaemia patients.
- Willing to participate and provide data

Exclusion Criteria
- Mothers who were not directly involved in the care of the child.
- Inability to communicate due to illness or language barrier.

Data Analysis
Data were analyzed by using SPSS version 25.0. Descriptive statistics (frequencies, percentages,means) were used to summarize the data.

Ethical Considerations
Informed consent was obtained from all participants. Confidentiality and anonymity of responses were ensured. Ethical approval was obtained from the appropriate institutional review board.

RESULTS

A total of 52 mothers of thalassaemic children took part in our study. Mean age of the children during the interview was 7.48 years. Majority of mothers were from rural areas (53.8%). Four participants (7.7%) received no formal education and 13 (25%) had passed secondary level.

Table 1 shows knowledge of the participants regarding thalassaemia. Only 3.8% mothers heard about thalassaemia before their first child was born with thalassaemia. Majority (53.8%) did not know that thalassaemia is an inherited disorder. Most (86.5%) of them were unaware that a positive family history is a risk factor for thalassaemia. Only 19 (36.5%) of our participants could mention the role of consanguinity in developing thalassaemia. Of the total participants, 84.6%mothers considered blood transfusion as a treatment option whereas only 2 (3.8%) knew about bone marrow transplantation. Although most of the participants (86.5%) knew that individuals with thalassaemia major require regular blood transfusion but only 50% understood that blood transfusion need to be sustained throughout a patient's lifetime. Nearly all mothers (90.4%) had no knowledge of the Hepatitis B vaccine.

Table 1: Participants' responses on knowledge on thalassaemia.

SL No.	Knowledge questions	Answer	No	%
1	Did you know about thalassaemia before first child?	No	2	3.8
		Yes	50	96.2
2	What kind of disease is thalassaemia?	Do not know	28	53.8
		An inherited disorder	24	46.2
3	Do you know the risk factor of thalassaemia?	Do not know	45	86.5
		Family history	7	13.5
4	Do you know the role of consanguinity in thalassaemia?	Yes	19	36.5
		No role	14	26.9
		Do not know	19	36.5
5	What are the treatment options of thalassaemia?	Don't know	6	11.5
		Blood transfusion	44	84.6
		Blood transfussion& BMT	2	3.8
6	Do you know that blood should be transfused regularly	Yes	45	86.5
		No	7	13.5
7	How long should blood transfusion be continued?	Life long	26	50.0
		Do not know/ Incorrect answer	26	50.0
8	Do you know about prenatal diagnosis?	Yes	10	19.2
		No	42	80.8
9	Do you know about premarital screening?	Yes	12	23.1
		No	40	76.9
10	What is the importance of premarital screening?	Preventive measure to control thalassaemia	12	23.1
		Not Applicable	40	76.9
11	Do you know about investigations needed to prevent complication?	Yes	32	61.5
		No	20	38.5
12	Do you know about additional medications including chelation therapy?	Yes	26	50.0
		No	26	50.0
13	Do you know about side effects of regular blood transfusion?	Don't know	15	28.8
		Allergic reaction	28	53.8
		Disease transmission	4	7.7
		Iron overload	5	9.6
14	How can we prevent thalassaemia?	Don't know	38	73.1
		Genetic counselling	4	7.7
		Premarital screening	10	19.2
15	Do you know what food you should give to your child?	Yes	36	69.2
		No	16	30.8

Prenatal diagnosis was unfamiliar to 80.8% of the participants. Of the participants, 12 (23.1%) mothers heard about premarital screening and all 12 of them knew that premarital screening is an important measure to prevent thalassaemia. Majority (61.5%) of the mothers were aware about the investigations needed to prevent complications of thalassaemia and 50% knew about different medications including iron chelators needed for thalassaemia treatment. About one fourth (28.8%) participants were not aware of the side effects of blood transfusion. A large majority (73.1%) of mothers could not identify any preventive measures for thalassaemia.

The attitude of the mothers regarding thalassaemia are shown in Table 2. According to 34 (65.4%) participants, marriage between two thalassaemic carriers should be avoided. A total of 25 (48.1%) believed that couples who are carriers should not plan to have children but majority (82.7%) felt that premarital screening is necessary for general public. Although only 25 (48.1%) parents held the view that a pregnancy ought to be terminated if the fetus is affected by thalassaemia major, majority (76.9%) felt the necessity for legislation of premarital screening. Half (48.1%) of our parents do not consider their thalassemic children as a family burden, but 80.8% agreed that treatment of thalassaemia caused extra family expenditure and raising a child with this chronic disorder had caused emotional turmoil to 67.3% parents. A majority (73.1%) of mothers disclosed the disease of the child to family and society and 55.8% agreed that thalassaemia has hampered education of their child.

Table 2: Attitude of participants regarding thalassaemia major

SL No.	Questions	Responses		
		Agreed	Uncertain	Disagreed
1	Two thalassaemia carriers should get married	8 (15.4%)	10 (19.2%)	34 (65.2%)
2	Carrier couple should have children	11 (21.2%)	16 (30.8%)	26 (48.1%)
3	Premarital screening is necessary for general public	43 (82.7%)	4 (7.7%)	5 (9.6%)
4	Termination of pregnancy should be done due to thalassaemia major of the fetus	25 (48.1%)	10 (19.2%)	17 (32.7%)
5	We need legislation for premarital screening	40 (76.9%)	6 (11.5%)	6 (11.5%)
6	A child with thalassaemia is a burden	19 (36.5%)	8 (15.4%)	25 (48.1%)
7	Thalassaemia causes extra family expenditure	42 (80.8%)	4 (7.7%)	6 (11.5%)
8	Raising a thalassaemic child causes emotional turmoil	35 (67.3%)	5 (9.6%)	12 (23.1%)
9	Child's education is hampered due to thalassaemia	29 (55.8%)	3 (5.8%)	20 (38.5%)
10	Disclosure of the disease of the child to family and society	38 (73.1%)	5 (9.6%)	9 (17.3%)

DISCUSSION

Thalassaemia is an inherited autosomal recessive condition in which the production of α- or β-globin chains of hemoglobin is either diminished or completely lacking, leading to defects in their amount or functionality. This study aimed to evaluate the level of awareness about thalassemia major among parents of children affected by the disorder. Our study involved 52 mothers of children diagnosed with β-thalassemia. Of our participants,53.8% belonged from rural areas and only 25% passed beyond secondary level. Similar result were found by other studies [18-26] except two studies done in Malaysia and Andhra Pradesh of India where education level of general people was higher[27,28].

Only 3.8% of our participant mothers had heard about thalassaemia before the birth of their first child affected by the disorder which is comparable to studies done in Bangladesh and India [17,24] although it was slightly higher in Pakistan [23]. The majority (53.8%) were unaware that thalassaemia is a hereditary disorder and it was equivalent to studies done by Kumar et al [27] and Barua et al [20]. In most of the studies, this percentage of ignorance was higher [17,19,23]. Only one study found that 76.9% of their participants could recognize the genetic nature of the disease [24]. Among our participants, 36.5% were able to identify consanguinity as a contributing factor in the development of thalassaemia comparable to findings of other researchers [19,23,25,26,29]. As a result, most participants (86.5%) did not know that having a positive family history increases the risk of thalassaemia.

Only 3.8% were aware of bone marrow transplantation as a potential treatment option similar to findings of a study done in Patiala, India [21]. Authors from two other studies found that almost one fourth of their participants were familiar with bone marrow transplantation as a cure option[20,23]. Duration of regular blood transfusion was unknown to half (50%) of our mothers in contrast of the findings in Karnataka where all of the participants were well aware of life long blood transfusion[24]. Regular blood transfusion poses risk of disease transmission but almost all mothers (90.4%) were unaware of the Hepatitis B vaccine in our study as only 7.7% participants knew about the risk. One study from India showed that 51.9% of their parents knew about optional vaccines[27]. Our participants (9.6%) showed poorer knowledge on iron over load in comparison to other studies where awareness ranged from 33.9 to 68.7% [21,23,24].

Prenatal diagnosis was unfamiliar to 80.8% of the participants consistent with the findings of others[17,18,20,23,25,27] except one study from India where 49.5% parents knew about this method[24]. Of the participants, 12 (23.1%) mothers were familiar with premarital screening as an important measure to prevent thalassaemia resembling the findings of other authors[24,29]. While almost three-quarters of the mothers (73.1%) could not identify any measures to prevent thalassaemia, Barua et al. documented a comparatively lower percentage of 55.7%[20]. The majority of mothers (61.5%) were aware of the investigations required to prevent thalassaemia complications, a proportion higher than that reported by previous authors[27]. Half of the participants knew about medications, including iron chelators, needed for thalassaemia management, consistent with earlier findings[21,27]. Awareness of appropriate food habits was reported by 69.2% of mothers, comparable to results from another research[23].

When the participants' attitudes toward thalassaemia were evaluated, they demonstrated a generally less favorable attitude. Approximately 65.4% of our participants believed that carrier couples should avoid marriage, a proportion notably lower than that reported in previous studies[22,24]. Dhanwadkar et al observed that all of their participants (100%) felt that individuals who are carriers should not marry and unanimously agreed that carrier couples should not have children [24]. On the contrary only half of our parents agreed that couples in which both partners are carriers should avoid having children. This underscores the strong social expectation of having children after marriage in our country. Begum et al, in her study, showed that 91% of parents believed carrier couple should bear children only after undergoing prenatal diagnosis[22]. The majority of participants (82.7%) perceived premarital screening as necessary for the general population consistent with findings of other authors[22,25]. Only 25 parents (48.1%) felt that a pregnancy should be terminated if the fetus is diagnosed with thalassaemia major. This viewpoint differed across studies[17,19,20,22,24]. The variation may reflect prevailing religious objections to therapeutic abortion, although further research is needed to clarify this. Most participants (76.9%) supported the need for legislation mandating premarital screening. Baqar et al. likewise highlighted the significance of implementing premarital screening programs[30]. Nearly half of our parents (48.1%) did not perceive their thalassaemic children as a burden to the family. However, 80.8% acknowledged that managing thalassaemia resulted in additional financial strain, and 67.3% reported experiencing emotional distress while raising a child with this chronic condition. This is similar to other study[27]. Among the mothers, 73.1% reported disclosing their child's condition to family and society, while 55.8% acknowledged that thalassaemia had negatively affected their child's education. These findings are also comparable to findings of other authors[27].

CONCLUSION

The results of this hospital-based study show significant gaps in women's knowledge about thalassaemia (genetic inheritance patterns, long-term treatment needs, risks from blood transfusion, and prevention techniques). However, many women reported they would support interventions at the population level (e.g., premarital screening) and would be willing to consider legislative approaches to reduce the impact of this disease if the information is clear and reliable. Women also expressed both support for screening and concerns about reproductive choices (e.g., termination of pregnancy). This demonstrates the need for empathetic, culturally and religiously sensitive counselling and accurate risk communication. Families experience higher levels of stress due to financial burdens, emotional strain, and interruption of children's education. Knowledge-based interventions alone will not suffice to address these issues adequately; thus, education on thalassaemia will require practical solutions including; affordable transfusions and chelation, vaccination, etc.

LIMITATIONS

This study took place in just one hospital, so what we found might not apply everywhere else. As it is a cross sectional study, we cannot be certain if things have changed over time or if one thing causes another.When people answered questions, they might not have shared everything honestly, especially about sensitive issues like terminations or disclosure.We only looked at the mothers' views as only mothers were present during interview in inpatient department, which means we missed out on input from fathers and other caregivers that could provide a fuller picture.Measurement constraints: The survey mainly asked basic questions, which means we did not have the chance to use established scales or explore things more deeply.

RECOMMENDATIONS

Community anchored education: Deploy culturally tailored, plain language sessions through local health workers to explain inheritance, lifelong transfusion, chelation, and vaccination. Integrated screening and counselling: Expand premarital and prenatal screening access with genetic counselling that respects religious and ethical preferences and clarifies options beyond termination. Strengthen transfusion safety and preventive care: Standardize guidance on Hepatitis B vaccination, infection risk, and iron overload monitoring, with clear schedules families can follow. Reduce caregiving burden: Offer financial assistance pathways, peer support groups, and school accommodations to mitigate economic and educational impacts. Broaden future research: Include fathers and diverse regions, use validated KAP instruments, and evaluate intervention effectiveness on knowledge, screening uptake, and psychosocial outcomes.

CONFLICT OF INTEREST

There is no conflict of interest

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