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Mothers' perception and attitude regarding thalassemia among children in Bangladesh

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Abstract:
Thalassemia, a prevalent genetic disorder in Bangladesh, poses a heavy burden on families and the healthcare system. This thesis examines the perceptions and attitudes of mothers towards thalassemia in children, aiming to understand their knowledge of the disease, coping mechanisms, and interactions with healthcare providers. The study aimed to evaluate the maternal understanding and attitudes concerning thalassemia in children in Bangladesh. A cross-sectional study was conducted with 112 mothers from the pediatric ward and outpatient department at Sher-e-Bangla Medical College Hospital, Barisal. A convenience sampling method was employed to select participants. Data were gathered using a structured questionnaire divided into three sections and analyzed using SPSS version 25. Descriptive statistics (frequency, percentage) and inferential statistics (t-test, ANOVA, Correlation) were applied for analysis. The average age of participants was 27 years (SD=5.822). The total mean perception (30.33±10.647) and attitude (18.80±5.451) levels were moderate and high among this study's respondents, respectively. There was a significant negative correlation between participants' age and their perception of thalassemia (r= -0.203, p=0.032). Statistically significant relationships were also found between participants' religion and perception (F=10.106, p=0.000), occupation level and perception (F=4.224, p=0.007), and residential area and perception (t=-2.442, p=0.016). The findings revealed a strong association between sociodemographic factors and mothers' perceptions and attitudes about thalassemia. Raising awareness through educational campaigns and prevention programs could help control thalassemia. Educated mothers are better equipped to provide care, improving health outcomes for children with thalassemia.

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INTRODUCTION

Thalassemia, a hereditary blood disorder, disrupts hemoglobin synthesis due to genetic mutations affecting globin chain production, leading to dysfunctional oxygen transport and chronic anemia (Sadiq et al., 2024). Clinical manifestations range from mild, asymptomatic cases to severe forms necessitating lifelong blood transfusions and complex medical care (Musa Meah et al., 2021). Beyond individual health complications, the disorder imposes substantial emotional, financial, and societal burdens, particularly in low-resource settings where healthcare infrastructure may be inadequate (Esoh et al., 2021).

Globally, thalassemia is among the most prevalent congenital disorders, with approximately 5% of the population carrying alpha or beta-globin gene variants. While many carriers remain asymptomatic, the disease's genetic heterogeneity contributes to significant morbidity in affected individuals (Goh et al., 2020). Southeast Asia bears a disproportionate burden, with carrier rates spanning 1–30% across countries such as Vietnam, Cambodia, and Laos, driven by population

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genetics and consanguineous marriages (Goh et al., 2020). This regional disparity underscores the need for localized interventions tailored to sociocultural contexts.

In Bangladesh, β-thalassemia (β-thal) and Hemoglobin E/β-thalassemia (Hb E/β-thal) are the predominant subtypes, affecting an estimated 10% of the population as carriers (Pervin et al., 2021). These figures highlight a critical public health challenge, as untreated severe cases result in growth failure, organ damage, and premature mortality. Despite the availability of diagnostic tools and preventive measures, awareness gaps persist, limiting access to early intervention and exacerbating the disease burden (Hossain et al., 2022).

Socioeconomic barriers further complicate thalassemia management in Bangladesh. Poverty restricts access to costly treatments like regular transfusions and chelation therapy, while the cultural stigma surrounding genetic disorders discourages families from seeking care. Additionally, misconceptions rooted in religious or traditional beliefs often delay diagnosis, perpetuating cycles of transmission (Hossain et al., 2022). Addressing these challenges requires multifaceted strategies that bridge healthcare disparities and cultural sensitivities.

Prevention remains a cornerstone of reducing thalassemia incidence, with premarital screening programs proving effective in identifying carrier couples and informing reproductive decisions (Wahidiyat et al., 2022). Genetic counseling and prenatal diagnosis also play pivotal roles, enabling informed choices about pregnancy outcomes and early treatment planning. In Mediterranean countries, such initiatives have significantly curtailed β-thalassemia births (Kattamis et al., 2022), demonstrating the potential for adaptation in similar sociocultural landscapes.

However, implementing these strategies in Bangladesh necessitates culturally sensitive adaptations. Religious doctrines, gender norms, and familial decision-making dynamics must be navigated to ensure program acceptance. For instance, premarital screening may face resistance due to fears of marital discord or social ostracism, requiring community engagement and trust-building efforts (Hossain et al., 2022). Collaborative partnerships with religious leaders and local influencers could enhance program legitimacy and uptake (Song et al., 2024).

Mothers, as primary caregivers, are central to managing thalassemia in children, yet their perspectives remain underexplored in Bangladesh. Despite limited health literacy or financial resources, they often shoulder responsibilities for treatment adherence, dietary management, and psychosocial support (Yousuf et al., 2022). Understanding their knowledge gaps, attitudes, and coping mechanisms is vital for designing targeted educational programs that empower families and improve disease outcomes (Mardhiyah et al., 2025).

Culturally adapted interventions must prioritize maternal education, addressing myths about disease causation and emphasizing the value of early screening (Xu et al., 2021). Community-based workshops, peer support networks, and mobile health campaigns could bridge awareness gaps, particularly in rural areas with limited access to specialized care (Obeagu, 2025). Integrating these efforts with national health policies and leveraging existing maternal-child health platforms may enhance scalability.

Mitigating Bangladesh's thalassemia burden demands a holistic approach combining preventive measures, equitable healthcare access, and community empowerment. By centering mothers' voices and addressing systemic barriers, policymakers can foster sustainable solutions that reduce disease prevalence and alleviate the suffering of affected families (Al-Worafi, 2024). Future research should focus on evaluating culturally tailored interventions and quantifying their impact on maternal practices and child health outcomes.

METHOD

This study employed a cross-sectional design to assess the perception and attitude of mothers regarding thalassemia among children in Bangladesh. The research was conducted over 12 months, from July 2023 to June 2024, at Sher-e-Bangla Medical College Hospital (SBMCH) in Barishal. The participants were mothers from both the pediatric ward and outdoor facilities of the hospital, selected using a convenience sampling technique. The sample size was determined through G*Power analysis, with a medium effect size of 0.30, a significance level of 0.05, and a power of 0.80, which yielded an initial sample size of 84. To account for a potential 10% attrition rate, the final sample size

was adjusted to 112 participants. Inclusion criteria required mothers to consent and be available for interviews during data collection.

A structured questionnaire was developed for data collection, informed by an extensive literature review. The questionnaire was divided into three parts: sociodemographic information, mothers' perceptions, and attitudes toward thalassemia. The sociodemographic section included 11 items covering the mother's age, education level, occupation, family income, residential area, and number of children. The perception section contained 15 items assessing maternal knowledge of thalassemia, rated on a 5-point Likert scale ranging from "strongly agree" to "strongly disagree." The attitude section consisted of 7 items measuring maternal attitudes, also rated on a 5-point Likert scale, with scores ranging from "highly positive" to "very negative." Higher scores indicated better perception and a more positive attitude toward thalassemia management and prevention.

Data was collected through face-to-face interviews at SBMCH, and ethical considerations were strictly followed. Approval was obtained from the Institutional Review Board (IRB) of SBMCH, and the hospital administration granted permission. Participation was voluntary, and written and verbal consent was obtained from all participants. Confidentiality and anonymity were ensured, with all collected data stored securely and destroyed upon the study's completion. The data was analyzed using SPSS version 25, with descriptive statistics like frequency, percentage, mean, and standard deviation used to describe sociodemographic characteristics. Inferential statistics such as t-tests, ANOVA, and Pearson correlation were employed to explore the relationships between sociodemographic factors and maternal perception and attitudes regarding thalassemia in children.

RESULT

The sociodemographic data of 112 participants, as shown in Table 1, highlights that the average age of the mothers ranged from 18 to 51 years, with a mean of 27 years (SD ±6.295). A significant majority (88.4%) of participants were Muslim, with smaller proportions identifying as Hindu (9.8%) and Christian (1.8%). Most mothers had school-level education (65.2%), while fewer had attended college (21.4%) or university (13.4%). The overwhelming majority (82.1%) of mothers were homemakers, with only a small percentage working in government (4.5%) or private (9.8%) sectors. Regarding fathers' education, over half (57.1%) had schooling, while 31.3% had university-level education. Fathers were primarily businessmen (46.4%) or employed in private service (29.5%).

The average monthly family income was 25,535.71 BDT (SD ±18,634.91), and most participants lived in rural areas (69.6%). Most participants came from joint families (52.7%) rather than nuclear families (47.3%), with an average of nearly two children (mean 1.99, SD ±0.935) and about five family members (mean 5.16, SD ±1.938) per household. In terms of sources of information about thalassemia, the dominant source was healthcare providers (83.9%), followed by social media (9.8%) and family or friends (6.3%).

Table 1. Distribution of sociodemographic characteristics of the participants (n=112)

Variables	Categories	Frequency (n)	Percent (%)	Mean±SD
Age (years)		Range (18-51) years		27±6.295
Religion	Muslim	99	88.4%	
	Hindu	11	9.8%	
	Christian	2	1.8%	
Mothers' Educational qualification	School	73	65.2%	
	College	24	21.4%	
	University	15	13.4	
Mothers' Occupation	Govt. Service	5	4.5%	
	Private Service	11	9.8%	
	Worker	4	3.6%	
	Housewife	92	82.1%	
Fathers' Educational qualification	School	64	57.1%	
	College	13	11.6%	
	University	35	31.3	

Volume 05, Number 02 (June 2025)
e-ISSN: 2798-5067
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Variables	Categories	Frequency (n)	Percent (%)	Mean±SD
Father's occupation	Govt. Service	8	7.1%	
	Private Service	33	29.5%	
	Worker	19	17%	
	Businessman	52	46.4%	
Monthly family income range (7000-90000) in Bangladeshi Taka				25535.71±18634.913
Residential area	Rural	78	69.6%	
	Urban	34	30.4%	
Type of Family	Nuclear	53	47.3%	
	Joint family	59	52.7%	
Number of children (1-5) per person				1.99±.935
Number of family members (3-13) per person				5.16±1.938
Source of information	Family/friends	7	6.3%	
	Health care provider	94	83.9%	
	Social media	11	9.8%	

Table 2 presents the participants' perception and attitude toward thalassemia, showing that the average total score for perception was 30.33 (SD ±10.647) with a mean score of 2.022 (SD ±0.709) on a scale likely based on a Likert-type measure. This suggests that the overall level of maternal perception regarding thalassemia was moderate. Similarly, the total mean score for attitude was 18.80 (SD ±5.451), with a mean score of 2.685 (SD ±0.779), indicating a generally positive attitude towards thalassemia, though with room for improvement.

Table 2. Participants' distribution according to their perception and attitude mean score about thalassemia (n=112)

Variables	Total Mean±SD score	The mean of the total Mean±SD score
Perception regarding thalassemia	30.33±10.647	2.022±0.709
Attitude regarding thalassemia	18.80±5.451	2.685±0.779

Table 3 presents the relationship between sociodemographic characteristics and participants' perceptions and attitudes toward thalassemia. The analysis shows a significant negative correlation between age and perception ($r = -0.203$, $p = 0.032$), indicating that as the age of the participants increased, their perception of thalassemia decreased. However, no significant correlation was found between age and attitude. Religion was significantly associated with perception ($F = 10.106$, $p < 0.001$), with Christian participants having a higher perception score than Muslim and Hindu participants. No significant association was found between religion and attitude.

Mothers' occupation was significantly associated with perception ($F = 4.224$, $p = 0.007$), where private service workers had the highest perception scores compared to other groups. However, no significant differences were observed in attitude scores. Interestingly, no significant associations between educational qualifications, fathers' occupation, and income with either perception or attitude were found. However, participants from urban areas had significantly higher perception scores ($t = -2.442$, $p = 0.016$) than those from rural areas, but no significant difference was observed in their attitude.

Regarding the source of information, no significant relationships were observed with perception or attitude, indicating that whether participants received information from family, healthcare providers, or social media, it did not significantly influence their perception or attitude toward thalassemia.

Volume 05, Number 02 (June 2025)
e-ISSN: 2798-5067
p-ISSN: 2798-5059

Table 3. Relationship between sociodemographic characteristics, perception, and attitude regarding thalassemia among participants.

Variables	Categories	Perception			Attitude		
		Mean±SD	t/F/r	Sig (p)	Mean±SD	t/F/r	Sig (p)
Age (years)	Range (18-51) years		-0.203*	0.032		-0.087	0.360
Religion	Muslim	30.21±9.972a	10.106	0.000	18.58±5.498	0.750	0.475
	Hindu	26±9.327b		c>a>b	20.45±4.39		
	Christian	60±.00c			21±9.899		
Mothers' Educational qualification	School	29.16±10.424	1.97	0.144	18.38±4.827	0.645	0.527
	College	34.08±12.233			19.75±7.415		
	University	30±7.919			19.33±4.761		
Mothers' Occupation	Govt. Service	29.2±7.596a	4.224	0.007	15.8±3.564	1.892	0.135
	Private Service	40.18±12.576b		b>c>a>d	22±6.372		
	Worker	35±18.221c			27.75±2.872		
	Housewife	29.01±9.638d			18.63±5.398		
Fathers' Educational qualification	School	30.08±11.069	1.056	0.351	18.41±5.827	0.621	0.540
	College	23±9.420			18.46±3.573		
	University	32±10.233			19.66±5.335		
Father's occupation	Govt. Service	32.38±5.975	1.654	0.181	21±5.155	1.328	0.269
	Private Service	32.55±12.07			19.61±5.494		
	Worker	26±7.172			17.11±6.822		
	Businessman	30.19±11.019			18.58±4.832		
Monthly family income range (7000-90000) in Bangladeshi Taka			-0.050	0.602		0.067	0.481
Residential area	Rural	28.74±9.511	-2.442	0.016	18.35±5.093	-1.350	0.180
	Urban	33.97±12.273			19.85±6.145		
Type of Family	Nuclear	29.6±8.242	-0.697	0.487	17.92±5.990	-1.63	0.106
	Joint family	30.98±12.455			19.59±4.832		
Number of children (1-5) per person			0.023	0.813		-0.099	0.298
Number of family members (3-13) per person			0.050	0.599		0.045	0.639
Source of information	Family/friends	28.86±7.669	0.142	0.868	19.15±4.145	1.246	0.292
	Health care provider	30.56±10.794			16.92±3.950		
	Social media	29.27±11.671			19.89±3.332		

DISCUSSION

The current study tried to investigate the mothers' perception and attitude about thalassemia among children and any possible association between these levels and the participants' sociodemographic profile.

The current study revealed that participants had a moderate level of perception about thalassemia, as evidenced by the total mean perception score of 30.33 (±10.647) out of a possible 60. This suggests that while the participants had some awareness of thalassemia, there is still room for improvement in their overall knowledge. A similar trend of poor knowledge was observed in a population-based study in Bangladesh (Alam et al., 2022), underscoring the need for increased educational efforts in these regions.

Regarding attitude toward thalassemia, the current study demonstrated a good attitude level among participants, with a mean score of 18.80 (±5.451) out of a possible 28. This finding indicates a positive outlook and awareness regarding thalassemia, crucial for preventive behaviors and support for affected individuals. This positive attitude aligns with the findings of Alam et al. (2022), who also reported a high attitude level in their Bangladeshi-based study. Furthermore, an Indonesian study by Wahidiyat et al. (2021) found that although participants had poor knowledge about thalassemia, they still exhibited a good attitude towards the condition, reflecting the importance of fostering positive attitudes even when knowledge levels were lacking. These results suggest that while knowledge about thalassemia may vary across regions, attitudes towards the condition are more favorable, which can be critical in promoting health-seeking behavior and preventive practices.

Volume 05, Number 02 (June 2025)
e-ISSN: 2798-5067
p-ISSN: 2798-5059

Efforts should be directed toward improving knowledge through education and awareness campaigns while maintaining and enhancing positive attitudes toward thalassemia care and prevention (Badagabettu et al., 2022).

The current study explored the relationship between sociodemographic characteristics and participants' perceptions of thalassemia, uncovering several significant findings that contribute to understanding how these factors influence awareness and knowledge of the disease. A noteworthy negative correlation was identified between participants' age and their perception of thalassemia (r= -.203*, p=.032). This finding indicates that younger mothers were more knowledgeable about thalassemia than older mothers. Younger individuals often have greater access to education, health campaigns, and digital resources, which enhance their understanding of genetic disorders like thalassemia. This aligns with Wahidiyat et al. (2021), who also found age to be a significant factor in thalassemia knowledge, emphasizing the importance of age-related access to health information.

Religious beliefs can profoundly influence health-related attitudes and behaviors, including perceptions of disease causality, genetic testing, and medical interventions. This suggests that in communities where religious beliefs play a central role, health education programs must be culturally sensitive, integrating religious perspectives to improve awareness and management of thalassemia. This need for culturally tailored interventions highlights the broader challenge of promoting health literacy in diverse populations (Abd Rashid & Yusof, 2025).

The study also revealed a significant relationship between mothers' occupation levels and their perception of thalassemia (F=4.224, p=.007). Mothers in higher occupational categories demonstrated better awareness of the disease than those in lower occupational roles. Occupation often serves as a proxy for socioeconomic status, which is closely linked to access to healthcare resources and information. This finding mirrors other studies, including those by Wahidiyat et al. (2021), which also found significant associations between occupational status and health literacy. These results underscore the role of socioeconomic factors in shaping health knowledge and the potential disparities in access to health education.

In addition, a significant relationship was found between residential areas and perception of thalassemia (t=-2.442, p=.016). Mothers living in urban areas showed a better understanding of the disease than those in rural areas. Urban settings often provide greater access to healthcare services, educational campaigns, and information, making it easier for residents to become aware of genetic diseases (Angastiniotis, 2024). Interestingly, the study found no significant relationship between mothers' education level and their perception of thalassemia, challenging the common assumption that higher education directly correlates with better health knowledge. Similarly, fathers' education levels did not significantly influence mothers' understanding of thalassemia, indicating that education alone may not drive health awareness in this context (Chowdhury et al., 2020).

Additionally, the study found no significant relationship between fathers' occupation and mothers' perceptions, indicating that economic stability or occupational status does not necessarily lead to better awareness of thalassemia. This is consistent with Wahidiyat et al. (2021), suggesting that health education needs to be tailored beyond occupational categories. Lastly, no significant correlation was found between family income and perceptions of thalassemia, challenging the notion that higher income automatically improves health knowledge. This finding underscores the importance of targeted health education programs to raise disease awareness, particularly in lower-income populations. Despite these results, other studies by Hossain et al. (2021) found income to be a significant factor, reflecting the complexity of socioeconomic influences on health awareness.

Regarding the relationship between various sociodemographic characteristics and mothers' attitudes toward thalassemia in Bangladesh, no significant relationships were found between participants' age, religion, education levels, occupation, income, residential area, family structure, or other demographic variables. These findings challenge the assumption that sociodemographic factors decisively shape health-related attitudes. Surprisingly, the study revealed no significant relationship between mothers' age and attitudes toward thalassemia. Age is often considered a key factor influencing perceptions due to differences in life experiences, but it did not significantly impact how mothers viewed and managed thalassemia. This result contrasts with studies like Wahidiyat et al. (2021), which identified age as an influential factor in attitudes towards thalassemia. The discrepancy suggests the influence of other cultural or contextual factors not captured in this study.

Volume 05, Number 02 (June 2025)
e-ISSN: 2798-5067
p-ISSN: 2798-5059

Similarly, the study found that religion did not significantly impact attitudes toward thalassemia, even though religious beliefs often shape health-related behaviors and medical decision-making. Religious beliefs had little influence on health attitudes in this context. It may suggest that, in this population, cultural or socioeconomic factors hold more sway over health attitudes than religious practices. One of the most striking findings was the lack of a significant relationship between the education levels of both mothers and fathers and their attitudes toward thalassemia. Education is generally viewed as a key determinant of health awareness and behavior. However, the study suggests that formal education alone may not be enough to shape positive attitudes toward thalassemia. Instead, other factors, such as cultural norms, health literacy, and access to targeted health education, may play more prominent roles. This finding is consistent with Wahidiyat et al. (2021) and highlights the importance of designing culturally tailored health education programs that address specific gaps in knowledge and attitudes.

The study also found no significant correlation between either mothers' or fathers' occupations and their attitudes toward thalassemia. Occupation is often linked to socioeconomic status and access to healthcare resources, but these findings suggest that occupation alone does not influence health perceptions in this population. Another unexpected result was the lack of a significant relationship between family income and attitudes toward thalassemia. Income is typically associated with better access to healthcare services and information, but the findings suggest that financial stability alone may not improve attitudes toward genetic disorders like thalassemia. Financial resources must be paired with effective health communication strategies to enhance awareness and change attitudes (Morse & Sawh, 2021).

The study also found no significant relationship between residential areas and attitudes toward thalassemia. Urban and rural areas often differ in access to healthcare facilities and information. However, the lack of significance may indicate that health education about thalassemia is uniformly lacking across both settings. Additionally, family structure and the number of family members did not significantly impact attitudes, suggesting that family dynamics do not play a central role in shaping health perceptions (Wangi et al., 2025). Sociodemographic factors alone are insufficient to explain attitudes towards thalassemia. The lack of significant relationships between these variables and health attitudes underscores the need for targeted, culturally appropriate health education interventions (Aydinok et al., 2024). Broader factors like health literacy, cultural beliefs, and healthcare access are likely more influential. Future research should explore these further to improve health awareness of genetic diseases like thalassemia.

CONCLUSION

This cross-sectional study has provided valuable insights into the perception and attitudes of mothers regarding thalassemia in children at Sher-e-Bangla Medical College Hospital, Bangladesh. The findings reveal a moderate level of perception among the participants, with a mean perception score of 30.33 out of 60. At the same time, attitudes toward thalassemia were generally positive, with a mean score of 18.80 out of 28. This suggests that although mothers demonstrate some awareness and positive attitudes toward the condition, there is room for improving their knowledge, particularly about preventing and managing thalassemia.

Several sociodemographic factors significantly influenced perception. Younger mothers and those from urban areas had higher perception scores, indicating that younger age and access to more resources, such as education and health services, likely contribute to better understanding. Interestingly, religion also played a notable role in influencing perception, with Christian mothers scoring higher than their Muslim and Hindu counterparts, emphasizing the need for culturally sensitive health interventions.

On the other hand, attitudes were generally positive across different sociodemographic categories, indicating that even with moderate knowledge, mothers exhibited a supportive stance toward thalassemia management and care. However, the lack of significant associations between education, occupation, and income with attitude suggests that while positive attitudes are prevalent, they may not necessarily translate into comprehensive understanding or preventive behaviors without targeted health education.

Volume 05, Number 02 (June 2025)
e-ISSN: 2798-5067
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Overall, this study underscores the need for tailored health education programs to enhance thalassemia awareness among mothers, particularly in rural areas and among older mothers. Additionally, culturally and religiously sensitive approaches should be integrated into public health strategies to promote a better understanding and management of thalassemia in children. By improving both knowledge and attitudes, it will be possible to foster preventive behaviors and early interventions, ultimately reducing the burden of thalassemia in Bangladesh.

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