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"The Parental Perspective of Thalassemia in Bangladesh: Challenges for Prevention and Management of Thalassemia"

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Abstract **Original Research Article**

***Introduction*:** Thalassemia is a genetic blood disorder characterized by abnormal hemoglobin production, poses significant challenges for families worldwide. In Bangladesh, where the prevalence of thalassemia is notable, parents face unique hurdles in both preventing and managing this condition. ***Aim of the study*:** The aim of this study is to explore the parental perspective of thalassemia in Bangladesh, focusing on the challenges faced in the prevention and management of the disease. ***Methods*:** This was a cross section study conducted in the Department of Paediatrics of M Abdur Rahim Medical College, Dinajpur, Bangladesh during the period from January 2023 to December 2023. ***Result*:** Among the total of 320 caregivers, 46.9% were father, while 53.1% were mother respectively. Minority 14.1% of marriages were consanguineous, while the majority (85.9%) was not. The majority (82.8%) of respondents had one thalassemic child, while 17.2% had two or more thalassemic children. Before the diagnosis of thalassemia in their child, 90.9% of respondents had not heard about thalassemia. All respondents (100%) reported not undergoing thalassemia screening before marriage. The median age at diagnosis of thalassemia among the participants was 1.32 years. Beta thalassemia was diagnosed in 30.6% of the participants, while 68.8% had E-beta thalassemia. The majority 65.9% of respondents correctly identified thalassemia as a genetic disease, while 22.5% provided an incorrect response. ***Conclusion*:** Thalassemia presents significant challenges for affected individuals and their families in Bangladesh, ranging from limited access to diagnostic services and blood transfusions to social stigma and financial burdens.

Keywords: Thalassemia, Thalassemia Prevention, Beta Thalassemia, E-Beta Thalassemia, Thalassemia Trait.

INTRODUCTION

Thalassemia is a genetic blood disorder characterized by abnormal hemoglobin production, poses significant challenges for families worldwide [1]. In Bangladesh, where the prevalence of thalassemia is notable, parents face unique hurdles in both preventing and managing this condition [2]. From limited awareness to financial constraints and emotional distress, the journey of parents navigating thalassemia spans a spectrum of difficulties [3, 4]. Bangladesh classified as a developing nation is home to over 174 million individuals with approximately 70% of its populace dwelling in rural regions lacking adequate resources for diagnosing and treating hemoglobin disorders [5]. The primary focus of all thalassemia prevention programs is the detection of carriers and educating them about the disease and its consequences. Common strategies include mandatory premarital screening, offering prenatal diagnosis, and providing the option of therapeutic termination of pregnancy. Countries such as Cyprus, Greece, Iran, and Italy have achieved significant success in reducing the birth prevalence of thalassemia by implementing these measures [6]. While screening services and prenatal diagnosis with therapeutic termination are available in Bangladesh, their effectiveness and acceptability in this context remain uncertain. Effective community participation is crucial, particularly in developing countries like Bangladesh, where overall health awareness among the general population is low. Therefore, engaging parents or caregivers of

thalassemia children at the community level could play a pivotal role in raising mass awareness. Parents or caregivers play a crucial role in managing chronic diseases like thalassemia [7]. Many parents in Bangladesh may lack awareness about thalassemia, its inheritance patterns, and the importance of genetic testing before marriage. This lack of awareness can result in marriages between carriers of the thalassemia gene, increasing the risk of having children with the disease. There may be social stigma attached to thalassemia, leading to discrimination against individuals affected by the disease and their families. This stigma can exacerbate the challenges faced by parents in managing thalassemia [8]. Managing thalassemia can impose a significant financial burden on families in Bangladesh. Costs associated with regular blood transfusions, iron chelation therapy, medications, and frequent medical check-ups can strain family finances, particularly for those with limited resources. Access to specialized healthcare services and facilities for thalassemia management may be limited in certain areas of Bangladesh. Parents may struggle to find appropriate medical care and support for their children with thalassemia, particularly in rural or underserved regions [9]. Coping with the emotional toll of having a child with thalassemia can be overwhelming for parents. Witnessing their child undergoes frequent medical procedures, dealing with the uncertainty of the disease, and managing the associated stress can take a significant toll on parental well-being [10]. For parents who already have a child with thalassemia, making decisions about family planning can be complex. They may grapple with concerns about the risk of having another affected child and the emotional implications of such decisions [11, 12]. The parental journey in preventing the transmission of thalassemia to their offspring and managing the disease in affected children is fraught with complexities stemming from socioeconomic, cultural, and healthcare-related factors [13]. In Bangladesh, where access to quality healthcare is unequal and out-of-pocket healthcare expenditures are common, the economic impact of thalassemia can be devastating for families already grappling with poverty and socioeconomic disparities. The financial constraints faced by parents may impede their ability to provide comprehensive care for their children with thalassemia, leading to suboptimal treatment outcomes and exacerbating health disparities within the population [14]. Additionally, the indirect costs associated with caregiving, such as lost wages due to parental caregiving responsibilities and transportation expenses for medical appointments, further compound the financial challenges faced by affected families. Beyond the tangible financial costs, the emotional toll of raising a child with thalassemia cannot be overstated [15].

Objective

The objective of this study was to investigate the challenges faced by parents in the prevention and management of thalassemia, with a particular emphasis on understanding the socio-economic, cultural, and healthcare-related factors influencing their experiences in Bangladesh.

METHODOLOGY & MATERIALS

This was a cross section study conducted in the Department of Paediatrics of M Abdur Rahim Medical College, Dinajpur, Bangladesh during the period from January 2023 to December 2023. Participants eligible for inclusion criteria in the analysis were comprised of parents or caregivers of children diagnosed with thalassemia in Bangladesh. Inclusion criteria encompass individuals who had direct involvement in the care and management of a child with thalassemia, including but not limited to biological parents, adoptive parents, or legal guardians. Participants of any age, gender, or socioeconomic background will be considered for inclusion. Additionally, thalassemia patients of any age group and disease severity were included in the medical records review. Exclusion criteria will apply to individuals without direct caregiving responsibilities for a child with thalassemia, such as extended family members or healthcare professionals not directly involved in caregiving.

Data Collection:

The study involves interviewing parents or caregivers of children diagnosed with thalassemia to gain a deeper understanding of their experiences, the challenges they face, and their support requirements. These interviews were conducted using semi-structured interview guides and audio-recorded for analysis.

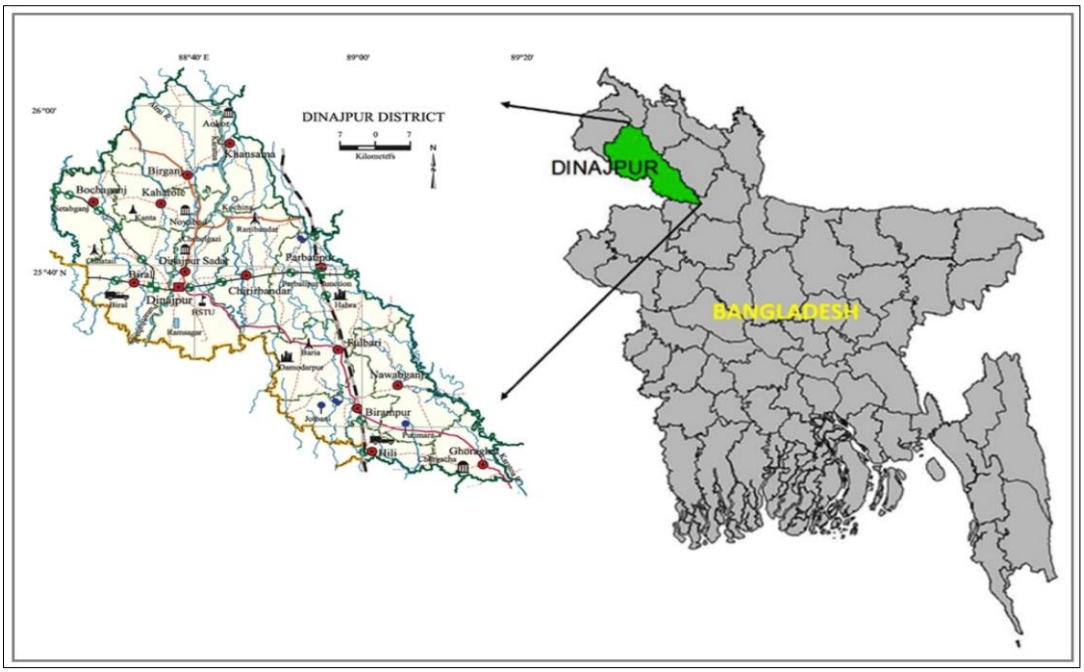

Figure 1: Data Collection in Dinajpur, Bangladesh (N = 320)

In our research endeavor, we meticulously gathered data from 320 participants hailing from Dinajpur District, Bangladesh, enriching our study's depth and scope with regional insights.

Ethical Consideration:

Prior to commencement of the study, the respective authority was approved the research protocol. All the patients included in this study were informed about the nature, risks and benefits of the study. Confidentiality was maintained. Proper permission was taken from the department and institution concerned for the study.

Statistical Analysis of Data:

After collection of data, all data were compiled in a master table first. Data was processed and analyzed using SPSS (22) for windows software. Qualitative data presented on categorical scale was expressed as frequency and corresponding percentage. Quantitative data was presented as mean and standard deviation (SD).

RESULT

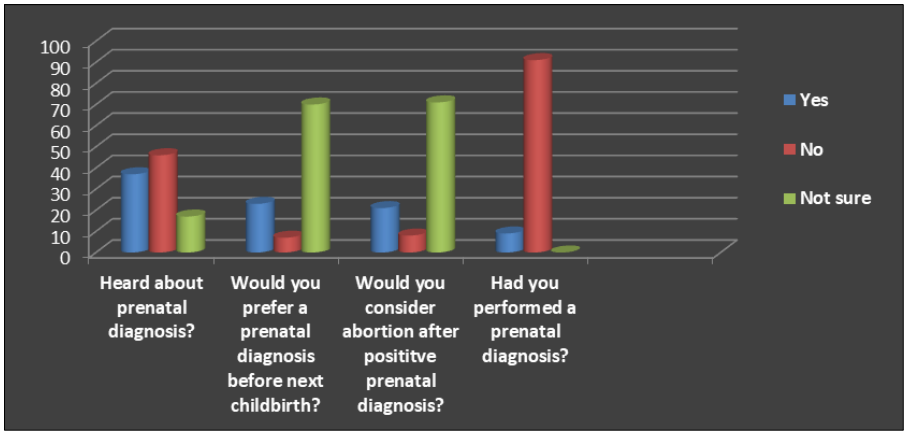

Figure 2: Knowledge, Attitude, and Practice of Prenatal Diagnosis in Bangladesh (N = 320)

Figure 2 represents responses regarding knowledge, preferences, and actions related to prenatal diagnosis among the 320 surveyed population. Majority 37% of respondents reported that they have heard about prenatal diagnosis, 46% stated that they have not heard about it and 17% were unsure respectively. 23% of respondents expressed a preference for undergoing prenatal diagnosis before their next childbirth, 7% indicated that they would not prefer it, 70% were not sure. 21% of respondents stated that they would consider abortion if prenatal diagnosis results were

positive, 8% mentioned that they would not consider abortion and 71% were unsure respectively.

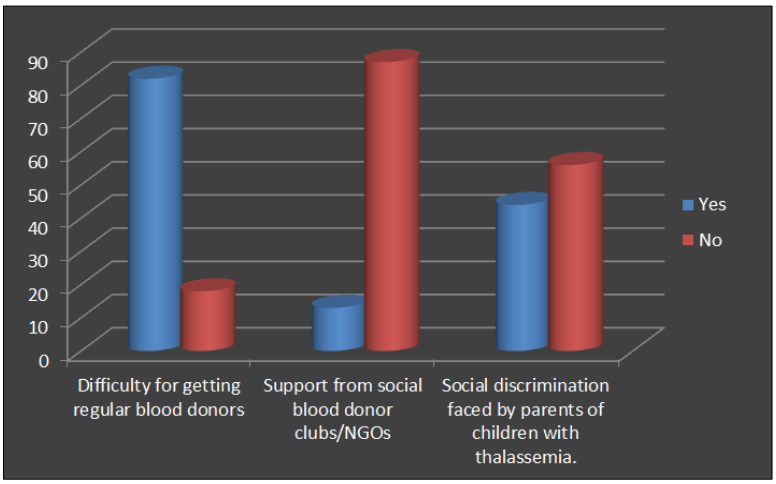

Figure 3: Challenges Encountered by Parents of Thalassemic Children (N = 320)

Figure 3 represents the responses regarding difficulties in obtaining regular blood donors, support from social blood donor clubs/NGOs, and social discrimination faced by parents of children with thalassemia. The majority 82% of respondents reported facing difficulty in obtaining regular blood donors, 18% indicated that they did not face difficulty in this aspect respectively. 13% of respondents stated that they received support from social blood donor clubs/NGOs, 87% reported not receiving support from such organizations. 44% of respondents reported facing social discrimination as parents of children with thalassemia, 56% stated that they did not face social discrimination in this regard.

Table 1: Participant Characteristics of Parents/Caregivers (N = 320)

Variable		**n**	**%**
Caregiver (total 320)	Father	150	46.9
	Mother	170	53.1
Consanguineous marriage	Yes	45	14.1
	No	275	85.9
Father's education	No formal education	46	14.4
	Primary	82	25.6
	Secondary	67	20.9
	Graduate	125	39.1
Mother's education	No formal education	58	18.1
	Primary	112	35.0
	Secondary	57	17.8
	Graduate	93	29.1
Monthly family income*	Upper	18	5.6
	Upper middle	31	9.7
	Middle	76	23.8
	Lower middle	87	27.2
	Lower	108	33.8
No. of children	1 child	69	21.6
	≥2 child	251	78.4
No. of thalassaemic children	1 child	265	82.8
	≥2 child	55	17.2
Heard about thalassemia before the diagnosis in child	No	291	90.9
	Yes	29	9.1
Screening of thalassemia before marriage	No	320	100
	Yes	0	0

Table 1 outlines the characteristics of parents/caregivers participating in the study, which involved a total of 320 individuals. Among the caregivers, 46.9% were father, while 53.1% were mother respectively. Minority 14.1% of marriages were consanguineous, while the majority (85.9%) was not.

Regarding fathers' education, the distribution was as follows: 14.4% had no formal education, 25.6% had primary education, 20.9% had secondary education, and 39.1% were graduates. For mothers' education, the breakdown was: 18.1% had no formal education, 35.0% had primary education, 17.8% had secondary education, and 29.1% were graduates. The distribution of monthly family income was as follows: 5.6% were in the upper income bracket, 9.7% were in the upper middle, 23.8% were in the middle, 27.2% were in the lower middle, and 33.8% were in the lower income bracket. 21.6% of respondents had one child, while 78.4% had two or more children. The majority (82.8%) of respondents had one thalassemic child, while 17.2% had two or more thalassemic children. Before the diagnosis of thalassemia in their child, 90.9% of respondents had not heard about thalassemia. All respondents (100%) reported not undergoing thalassemia screening before marriage.

Table 2: Profile of Children with Thalassemia Requiring Regular Blood Transfusion (N = 320)

Variable		n	%
Gender	Girl	153	47.8
	Boy	167	52.2
Median age at diagnosis (years)		1.32	
Type of thalassemia	Beta thalassemia	98	30.6
	E-beta thalassemia	220	68.8
	Others (thalassemia traits)	2	0.6
Frequency of blood transfusion per month	1	235	73.4
	2	85	26.6

Table 2 outlines the profile of children diagnosed with thalassemia who require regular blood transfusions, with a total of 320 participants. Among the participants, 47.8% were girls, while 52.2% were boys. The median age at diagnosis of thalassemia among the participants was 1.32 years. Beta thalassemia was diagnosed in 30.6% of the participants, while 68.8% had E-beta thalassemia. Only 0.6% had other types of thalassemia. The distribution of blood transfusions per month was as follows: 73.4% of participants received one transfusion per month, 26.6% received two transfusions per month respectively.

Table 3: Understanding of Thalassemia (Accurate, Inaccurate, and Unsure)

Question (Correct Answer)	Responses	n	%
I. Thalassemia is a genetic disease (Yes)	Correct	211	65.9
	Incorrect	72	22.5
	Unsure	37	11.6
II. Thalassemia is a contagious disease (NO)	Correct	292	91.3
	Incorrect	5	1.6
	Unsure	23	7.2
III. Thalassemia could be transmitted through blood transfusion from a person with thalassemia (No)	Correct	267	83.4
	Incorrect	2	0.6
	Unsure	51	15.9
IV. Marriage between two carriers can lead to a child with thalassemia major (Yes)	Correct	277	86.6
	Incorrect	5	1.6
	Unsure	38	11.9
V. Thalassemia carriers are as healthy as normal people (Yes)	Correct	179	55.9
	Incorrect	54	16.9
	Unsure	87	27.2
VI. Thalassemia is a preventable disease (Yes)	Correct	164	51.3
	Incorrect	71	22.2
	Unsure	85	26.6
VII. Thalassemia is a completely curable disease (No)	Correct	211	65.9
	Incorrect	43	13.4
	Unsure	66	20.6
VIII. What is the most important complication of thalassemia? (iron overload)	Correct	152	47.5
	Incorrect	8	2.5
	Unsure	160	50.0
IX. Thalassemia can be identified by blood test (Yes)	Correct	240	75.0
	Incorrect	15	4.7
	Unsure	65	20.3

Table 3 presents the understanding of thalassemia among the 320 respondents, categorized into correct, incorrect, and unsure responses, along with the respective frequencies and percentages. The majority 65.9% of respondents correctly identified thalassemia as a genetic disease, while 22.5% provided an incorrect response, and 11.6% were unsure. The majority 91.3% of respondents correctly identified thalassemia as not contagious, while 1.6% provided an incorrect response, and 7.2% were unsure. Then 83.4% of respondents correctly identified that thalassemia cannot be transmitted through blood transfusion, while 0.6% provided an incorrect response, and 15.9% were unsure. 86.6% of respondents correctly identified that marriage between carriers can lead to thalassemia major, while 1.6% provided an incorrect response, and 11.9% were unsure. 55.9% of respondents correctly identified that thalassemia carriers are not as healthy as normal people, while 16.9% provided an incorrect response, and 27.2% were unsure. 51.3% of respondents correctly identified thalassemia as preventable, while 22.2% provided an incorrect response, and 26.6% were unsure. 65.9% of respondents correctly identified that thalassemia is not completely curable, while 13.4% provided an incorrect response, and 20.6% were unsure. 47.5% of respondents correctly identified iron overload as the most important complication of thalassemia, while 2.5% provided an incorrect response, and 50.0% were unsure. And 75.0% of respondents correctly identified that thalassemia can be identified by a blood test, while 4.7% provided an incorrect response, and 20.3% were unsure.

DISCUSSION

This essay delves into the parental perspective of thalassemia in Bangladesh, shedding light on the multifaceted challenges they encounter in preventing the transmission of the disease and ensuring optimal care for affected children. By exploring the socioeconomic, cultural, and healthcare-related factors influencing parental experiences, we gain insights into the complexities surrounding thalassemia management in this context. Through an examination of these challenges, we aim to underscore the urgent need for comprehensive strategies that address not only medical aspects but also the psychosocial and economic dimensions of thalassemia care. By understanding the perspectives of parents grappling with thalassemia, policymakers, healthcare professionals, and community stakeholders can collaborate more effectively to implement holistic interventions that alleviate the burden faced by affected families in Bangladesh.

In Bangladesh, a country with a significant burden of thalassemia, the impact of this condition reverberates deeply within families, particularly from the perspective of parents [5]. This comprehensive analysis aims to delve into the multifaceted challenges faced by parents in Bangladesh, providing a nuanced understanding of their experiences and the implications for thalassemia prevention and management strategies. Bangladesh grapples with a high prevalence of thalassemia, making it a significant public health concern in the country. According to estimates, approximately 7% of the Bangladeshi population carries the gene for β-thalassemia, with a considerable number of individuals affected by the disease [16]. The geographical distribution of thalassemia cases is widespread, with notable concentrations observed in both urban and rural areas [7-11].

This prevalence underscores the urgent need for robust prevention and management efforts to mitigate the impact of thalassemia on individuals, families, and the healthcare system at large. One of the primary challenges in combating thalassemia in Bangladesh is the lack of widespread awareness among the population, particularly regarding the genetic nature of the disease and its transmission patterns. Parents, often unaware of their carrier status, may inadvertently pass on the thalassemia gene to their offspring, perpetuating the cycle of the disease within families [3]. The absence of comprehensive genetic counseling services and premarital screening programs further exacerbates this issue, leaving many couples uninformed about the risks associated with thalassemia inheritance [17, 18].

Once a child is diagnosed with thalassemia, parents are confronted with a myriad of challenges, chief among them being the substantial financial burden associated with disease management [6]. The lifelong requirement for regular blood transfusions, iron chelation therapy, medications, and specialized healthcare services places a significant strain on family finances, particularly for those with limited resources. In Bangladesh, diagnostic tests for conditions like thalassemia are not universally available, and even where they are accessible, they often come at a considerable cost that many individuals and families cannot afford. In Bangladesh, antenatal diagnosis facilities are not widely accessible or available, limiting the options for expectant parents should seeking to identify and manage genetic conditions like thalassemia before childbirth. Parents are confronted with a myriad of emotions, ranging from fear and anxiety about their child's health and future prospects to feelings of guilt and self-blame for transmitting the disease [19]. Our study revealed several key challenges faced by parents in the prevention and management of thalassemia. One notable finding was the difficulty in obtaining regular blood donors, reported by a significant proportion of parents. This aligns with previous research indicating the scarcity of voluntary blood donations in Bangladesh [20]. Limited access to safe blood transfusions can compromise the quality of life and health outcomes for thalassemic children, highlighting the urgent need for strategies to improve blood donation rates and ensure

adequate supply. Witnessing their child undergoes frequent medical procedures, experiencing the uncertainty of thalassemia-related complications, and grappling with the long-term implications of the disease can take a profound psychological toll on parents [21, 22].

Furthermore, our study highlighted the lack of support from social blood donor clubs/NGOs, with a majority of parents reporting no assistance in this regard. This contrasts with findings from other countries where organized blood donation drives and support groups have played a crucial role in meeting the transfusion needs of thalassemic patients [23]. The absence of such support mechanisms in Bangladesh underscores the need for community-based initiatives to mobilize resources and raise awareness about thalassemia. Social discrimination emerged as another significant challenge faced by parents of thalassemic children in our study. This finding echoes the stigma associated with thalassemia reported in other cultural contexts [24]. Discrimination can exacerbate the emotional and psychological burden on families already grappling with the complexities of managing a chronic illness. Addressing societal misconceptions and fostering inclusivity through education and advocacy efforts are crucial steps towards mitigating the impact of social stigma on affected families [25].

Comparing our findings with those of similar studies conducted in other countries reveals both commonalities and unique challenges in thalassemia care. For instance, a study in India highlighted the financial strain faced by families due to the high cost of treatment and frequent blood transfusions [26]. Similarly parents in our study reported financial challenges, reflecting the economic burden of managing thalassemia in resource-constrained settings. This underscores the need for government intervention to subsidize treatment costs and improve access to healthcare services for thalassemic patients. On the other hand, studies from countries with established thalassemia prevention programs, such as Cyprus and Iran, have reported higher levels of awareness and proactive measures among parents [27, 28]. These countries have implemented comprehensive screening and genetic counseling services, resulting in a significant reduction in thalassemia prevalence. By contrast, our study revealed gaps in knowledge and preventive practices among parents in Bangladesh, indicating the need for targeted interventions to enhance awareness and promote premarital screening.

Moreover, the cultural and socio-demographic context of thalassemia care varies across different regions, influencing parental attitudes and behaviors. For instance, studies in the Middle East have highlighted the importance of family support and religious beliefs in coping with thalassemia [29]. In contrast, our study found limited family support and societal acceptance, reflecting cultural differences in the perception of chronic illnesses.

Limitations & Recommendations

The study's reliance on a specific geographic area or healthcare facility may introduce sampling bias, limiting the generalizability of findings to the broader population of Bangladesh. One of the primary limitations in thalassemia management is the inadequate availability of voluntary blood donors. Reliance on family members or paid donors may introduce risks of infection or incompatible blood transfusions. Longitudinal studies would provide a more comprehensive understanding of the challenges faced by parents over time. Efforts should be made to expand access to affordable diagnostic services for thalassemia screening and prenatal diagnosis across Bangladesh, particularly in rural and underserved areas. Public health campaigns should be implemented to raise awareness about thalassemia, its inheritance patterns, and the importance of genetic counseling and premarital screening to prevent the transmission of the disease. The government should allocate resources to subsidize the cost of diagnostic tests and treatment for thalassemia patients, ensuring affordability and accessibility for all socio-economic groups. Further research is needed to explore the socio-cultural factors influencing thalassemia care in Bangladesh and to identify innovative strategies for improving prevention, diagnosis, and management. Collaboration between government agencies, healthcare providers, NGOs, and international partners is essential to address the multifaceted challenges of thalassemia effectively.

CONCLUSION

Thalassemia presents significant challenges for affected individuals and their families in Bangladesh, ranging from limited access to diagnostic services and blood transfusions to social stigma and financial burdens. Despite the efforts of healthcare providers and policymakers, the management of thalassemia remains complex and multifaceted. Our study sheds light on the experiences and perspectives of parents and caregivers of thalassemic children, highlighting the need for targeted interventions to address the unique challenges they face. From the scarcity of affordable diagnostic, screening tests and the shortage of safe blood donors, our findings underscore the urgent need for comprehensive strategies to improve thalassemia prevention, diagnosis, and management. Public awareness campaigns, capacity building for healthcare providers and community-based support programs can play a crucial role in enhancing access to quality care and support for thalassemia patients and their families.

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Conflicts of Interest: There are no conflicts of interest.

Ethical Approval: The study was approved by the Institutional Ethics Committee.

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