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Struggles and resilience: thalassemia patients navigating COVID-19 in Bangladesh

Farhin Islam[1,2], Senjuti Seemanta[1,3], Sonia Rezina[4], Afsana Mehrab[1], Enayetur Raheem[1] and Mohammad Sorowar Hossain[1,5*]

Abstract

Purpose Bangladesh is located in the thalassemia-prone region geographically. Thalassemia patients need lifetime interdisciplinary care for their well-being. In COVID-19, many patients—especially those from developing nations—faced significant difficulties receiving treatment; including irregular transfusion frequency, iron chelation interruptions, blood shortages, and unsafe blood. This study will explore the multifaceted challenges faced by thalassemia patients in Bangladesh during the COVID-19 pandemic.

Methods This cross-sectional study was an extension of an earlier investigation carried out at Bangladesh Thalassaemia Samity Hospital (BTSH). From the 365 cases of that first round, we could gather data from 156 cases in this second round. A structured questionnaire collected demographic information and thalassemia-related issues along with the impacts of COVID-19 on the patients and their families including the infection history with the virus, changes in income and/or expenditure, health status of the patient, mental health status of the mother, and difficulties in accessing healthcare services.

Results Our findings suggest significant socioeconomic and health challenges during the COVID-19 pandemic among thalassemia patients' families in Bangladesh. A substantial percentage of respondents faced income (n = 116, 74.35% experienced a decrease) and expenditure (n = 80, 51.28% experienced an increase) disruptions. Mental health challenges among mothers and difficulties in accessing healthcare services for the patients were prevalent. Among the 156 participants in our study, 35 families (22.44%) faced difficulties in managing blood or donors, 61 (39.1%) accessing services in hospitals or treatment centres, 49 (31.41%) managing regular follow-ups such as doctor visits and laboratory tests, 27 (17.42%) managing transportation for treatment purposes, and 27 (17.53%) managing money for treatment during COVID-19.

Conclusions This study will help policymakers take need-based measures for this group of highly vulnerable people during such unprecedented times.

Keywords Thalassemia, COVID-19, Pandemic, Bangladesh, Healthcare

*Correspondence:
Mohammad Sorowar Hossain
sorowar.hossain@brfbd.org
Full list of author information is available at the end of the article

Background

Thalassemia is a preventable congenital and hereditary disorder caused by defective hemoglobin in the blood resulting in hemolytic anemia in the patient [2, 6]. Thalassemia has become a health concern worldwide [30] due to its high prevalence, inadequacy of treatment facilities, imperative prevention, and lack of access to possible curative methods. An estimated 60 to 70 thousand patients in Bangladesh suffer from the severe form of thalassemia and the number of thalassemia carriers in the country is estimated to be 10–12 per cent of the total population [14, 25]. Geographically, Bangladesh is a part of the global thalassemia belt (thalassemia-prone region) [14, 21].

With adequate supportive care, thalassemia patients can lead lives similar to those of normal people, but without treatment, especially due to high poverty and resource constraints in low-income countries, children with thalassemia may die within five years of birth [23]. Monitoring and evaluation of thalassemia patients' well-being require lifelong multidisciplinary treatment involving various medical and scientific departments [11]. Patients in developing countries like Bangladesh are at risk of developing serious multiple medical complications and a significantly reduced quality of life if their complications are not well treated and managed due to the lack of universal health coverage and multidisciplinary health facilities.

The COVID-19 (Coronavirus Disease of 2019) pandemic is a global pandemic caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) that has taken a toll on more than seven million lives worldwide [32].

Although the viral infection is not associated with inherited hemoglobin disorders, patients are at increased risk of developing severe complications in the presence of comorbidity [10]. Moreover, the exceptional burden placed on the healthcare system by the pandemic could compromise the already demanding and often suboptimal treatment of people suffering from hemoglobinopathies. According to a study by the Thalassaemia International Federation (TIF), more than half of the patients worldwide faced serious challenges in accessing blood transfusion and iron chelation during COVID-19; such as interruption in frequency of transfusion, interruption in chelation, shortage of blood or medicine, unsafe blood, and all those patients were from developing countries [9]. Even patients from developed countries like Greece faced problems with the affordability of blood for transfusion and accessibility to health services (not in terms of medication and doctor visits but) in terms of systematic monitoring of complications [7].

A study from a rural setting in Bangladesh showed that the number of blood transfusions among patients under a community-based thalassemia registry was reduced to more than half during the early phase of the COVID-19 pandemic as compared to pre-COVID-19 time and the median number of transfusions per patient was reduced from four units to one unit only [13, 15]. Similar results, i.e. reduction in mean pre-transfusion hemoglobin and red cells transfused, discontinuation of investigations and monitoring of the patient, and reduction in blood supply during the lockdown, were found in a study from North India [26].

To the best of the authors' knowledge, no prior study in Bangladesh has examined the multifaceted challenges faced by thalassemia patients during the COVID-19 pandemic. This research aims to address this gap, providing valuable insights to guide policymakers in implementing need-based measures for this highly vulnerable population.

Materials and Method

Sampling

This cross-sectional study was an extension of an earlier investigation on the parental perspective of thalassemia in Bangladesh, carried out at Bangladesh Thalassaemia Samity Hospital (BTSH) [13, 15]. Participants in that study, which we call the first round, included 365 parents (fathers or mothers) of transfusion-dependent thalassemia patients who attended BTSH for follow-up care over the 2018 calendar year. Situated in Dhaka, the capital city of Bangladesh, BTSH is one of the few specialized centres for thalassemia care, with over 4,500 registered patients nationwide. Current study, which we call the second round, conveniently enrolled mothers of those 365 patients from the first round as the mothers are the primary caregivers of the thalassemia patients of Bangladesh in general.

Four of the 365 cases from the first round were duplicates. Consequently, 136 of the 361 unique cases were unreachable through phone calls in the second round because, in Bangladesh, it is usual to use many SIM (Subscriber Identity Module) cards, change contact numbers regularly, and leave old SIM cards inactive. Additionally, in the first round of the survey, several phone numbers were entered incorrectly. Thus, after two years of the first round, it was challenging to follow up on every case. Of the 225 cases we were able to contact in the second round, 168 mothers expressed interest in taking part. The mother's illness or her relocation are the main reasons for cases where the mother is not interested. Four mothers and six patients from the first round passed away in these two years. For a variety of reasons such as being busy or not understanding the local language, five cases went

incomplete. Thus, we were able to finish gathering data from only 153 mothers in the second round. The second round of cases increased to 156 after adding 3 additional cases from the pilot. The pilot cases also fulfil the inclusion criteria (Fig. 1).

Data collection

Data were collected with the help of a structured questionnaire that was divided into two parts. The first part of the questionnaire collected demographic information such as the respondent's age, education of the parents,

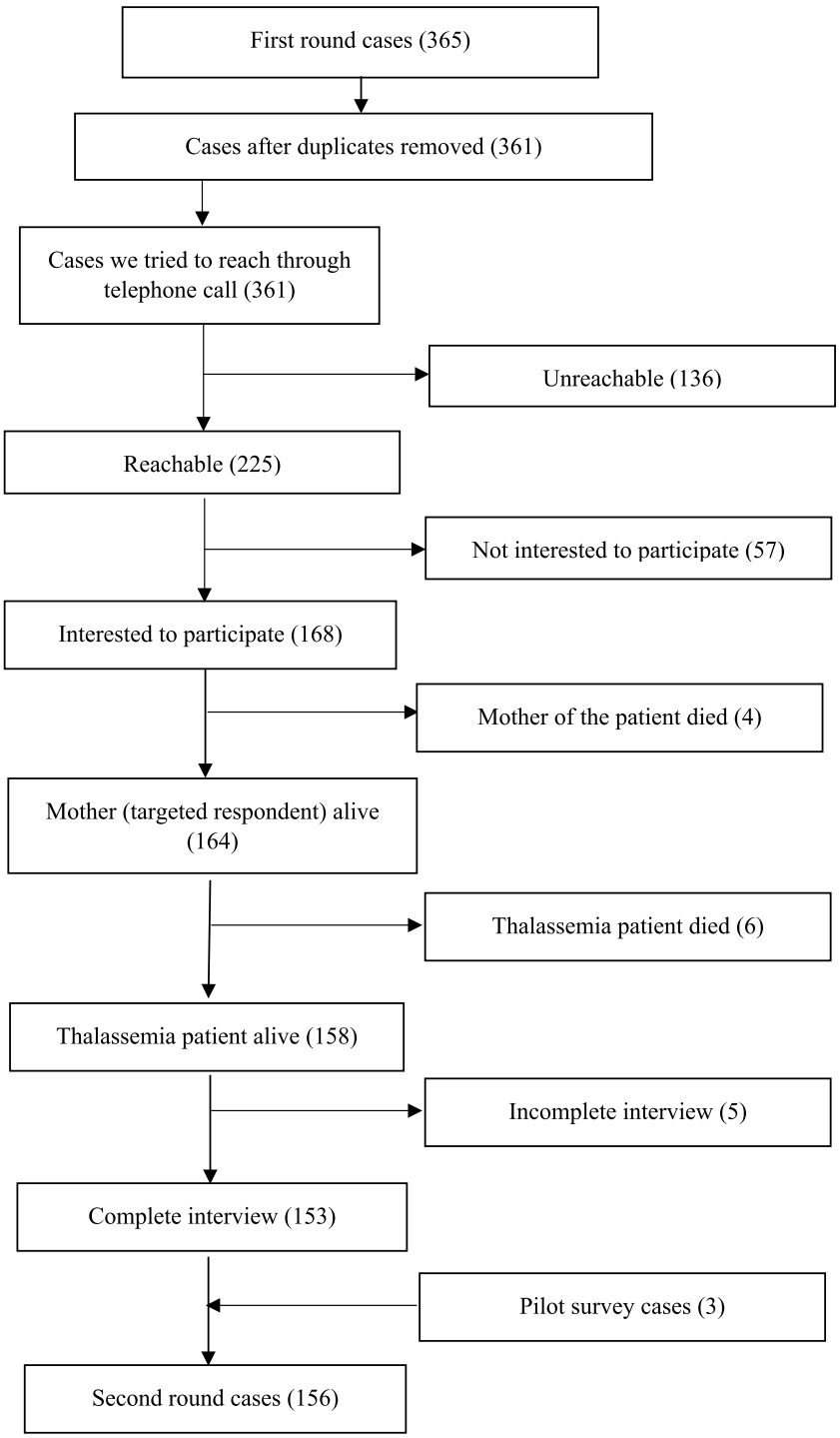

Fig. 1 Illustrative algorithm for enrollment of study participants

monthly family income, and household size with the number of children. The thalassemia-related issues in the family such as the number of years the affected child is suffering from thalassemia, transfusion frequency, and monthly treatment cost.

The second part of the questionnaire captured the multifaceted impact of COVID-19 on the patients and their families including the self-reported infection history of the thalassemia patient and their household member with the coronavirus, changes in monthly family income and/or expenditure, the self-reported health status of the patient and self-reported mental health status of the mother, difficulties in accessing healthcare services such as blood transfusion or managing blood donor, hospital service, laboratory test, doctor visit, transportation, and in managing money required for the treatment. Most of the questions in this section were assessed using Likert scale formats. Criteria defined ("no", "mild", "moderate", "severe") for the assessment of the health status of the patients were adopted from our previous study [13, 15]. To avoid complexity in the questionnaire and to minimize recall bias in measuring the mental health status of the mother, standardized instruments such as GAD-7 and PHQ-9 could not be used in this study. Therefore, we used a four-point Likert scale question ("good", "acceptable", "poor", "very poor") discretionarily to assess the self-reported mental health status. A standard five-point Likert scale on agreement ("strongly agree", "agree", "neutral", "disagree", "strongly disagree") has been used to measure all kinds of difficulties in accessing healthcare or treatment. The Likert scale for measuring the change in income and expenditure ("increased a lot", "increased moderately", "remained same", "decreased moderately", "decreased a lot") has been adopted from a previous study in Bangladesh during COVID-19 [12].

Five female, highly qualified enumerators—a biomedical engineer graduate student, a pharmacist cum academician, the wife of a patient with thalassemia who is also a lecturer at a university, a thalassemia patient cum researcher, and a medical student—collected data via telephone conversations. The survey was conducted from December 2021 to April 2022. Before the interview, verbal informed consent was obtained from all individual participants included in the study. About 20 to 30 min were spent on each interview.

Data analysis

The progress of data collecting was tracked in real time using a dedicated Google sheet. After the data were gathered, they were stored and processed by the REDCap (Research Electronic Data Capture) System. The data exported from REDCap was analysed using Stata version 13. The sociodemographic characteristics, thalassemia-related issues in the patient's family, and the socioeconomic and health impacts of COVID-19 on the thalassemia patients and their families were all investigated using descriptive statistics.

Results

The sociodemographic characteristics and the thalassemia-related issues in the family are presented in Table 1. The participant mothers of the patients are, on average, 40.38 years old (SD ± 8.89). The majority of the patients are aged 11 to 20 years (n = 85, 56.67%) and more than half of them are female (n = 79, 50.64%). The majority of thalassemia patients' mothers and fathers (n = 36, 23.08% and n = 62, 39.74% respectively) had completed the "graduate" level of education. Most patients (n = 54, 34.62%) have a family income of less than 15,000 BDT (~ US$174). Most mothers had two children (n = 81, 51.92%) and 4–5 household members (n = 100, 65.79%). Most families in this study have been dealing with thalassemia for eleven to fifteen years (n = 47, 30.13%). Every 16 to 30 days, more than half of these patients (n = 91, 59.09%) need blood transfusions regularly. Remarkably, the majority (n = 71, 46.41%) have monthly treatment costs for thalassemia falling between 5,000 and 10,000 BDT (~ US$58–116).

Among the 156 thalassemia patients recruited in our study, the majority (n = 124, 79.49%) did not have symptoms and so did not test for COVID-19 either. Other 16 patients (10.26%) had symptoms of COVID-19 but still did not go through the test. Only the remaining 16 (10.26%) patients in our study tested for COVID-19, and 7 of them got a positive report for COVID-19 while the other 9 tested negative. Thirty participants (19.48%) reported a household member (staying in close contact with the patients) testing positive for COVID-19. Most families (n = 116, 74.35%) experienced a significant decrease (43 moderately, 27.56% and 73 hugely, 46.79%) in monthly income during COVID-19. Most families (n = 80, 51.28%) saw a significant increase in monthly expenditure (51 hugely, 32.69% and 29 moderately, 18.59%) during the pandemic.

COVID-19 has posed significant challenges for patient families, with 35 families (22.44%) facing difficulties in managing blood or donors, 61 (39.1%) accessing services in hospitals or treatment centres, 49 (31.41%) managing regular follow-ups such as doctor visits and laboratory tests, 27 (17.42%) managing transportation for treatment purposes, and 27 (17.53%) managing money for treatment.. In terms of the overall health status of the thalassemia patients during COVID-19, 55 patients (35.26%) reported mild weakness, 33 (21.15%) experienced moderate weakness, and 15 (9.62%) reported severe weakness. The majority of the participating mothers of thalassemia

Table 1 Sociodemographic Characteristics and Thalassemia Issues of the Patient's Family

Variable[a]	n	%
Age of respondent/ mother of the patient (in full years), n = 156		
Mean (SD)	40.38 (8.89)	
Age of the patient (in full years), n = 150		
1–10	37	24.67
11–20	85	56.67
21–30	28	18.67
Sex of the patient, n = 156		
Male	77	49.36
Female	79	50.64
Highest education of the father, n = 156		
Illiterate	9	5.77
Primary	36	23.08
Secondary	18	11.54
Higher Secondary	31	19.87
Graduate	62	39.74
Highest education of the mother, n = 156		
Illiterate	9	5.77
Primary	45	28.85
Secondary	33	21.15
Higher Secondary	33	21.15
Graduate	36	23.08
Monthly household income (BDT), n = 156		
< 15,000	54	34.62
15,000—24,999	49	31.41
25,000—49,999	32	20.51
> = 50,000	21	13.46
Household size (number of members in the household), n = 152		
1 – 3	33	21.71
4 – 5	100	65.79
6 or more	19	12.50
Number of children in the household, n = 156		
1	32	20.51
2	81	51.92
3 or more	43	27.56
Number of years the affected child has been suffering from thalassemia, n = 156		
0–5	6	3.85
6–10	35	22.44
11–15	47	30.13
16–20	36	23.08
21–25	22	14.10
> 25	10	6.41
Transfusion frequency (The average gap between two consecutive transfusion days), n = 154		
< = 15 days	50	32.47
16 – 30 days	91	59.09
> 30 days	13	8.44
Monthly cost of treatment (BDT) related to thalassemia[b], n = 153		
< = 5,000	38	24.84
5,001–10,000	71	46.41
10,001–20,000	37	24.18
20,001–30,000	5	3.27
> 30,000	2	1.31

SD Standard Deviation, *BDT* Bangladeshi Taka

[a] Discrepancy in the total number of observations in each variable is due to the missing values where the respondent opted to skip the question

[b] Items include direct costs such as treatment and its equipment (blood transfusion, medicine, doctor visit, follow-up tests, bed charge) along with indirect costs such as transportation to the treatment facility

patients reported having poor (n = 62, 40.26%) to very poor (n = 49, 31.82%) mental health status during the pandemic (Table 2).

Discussion

This study highlights significant socioeconomic and health challenges during the COVID-19 pandemic faced by thalassemia patients' families in Bangladesh. A substantial proportion of respondents experienced income and expenditure disruptions. Mental health challenges among mothers and difficulties in accessing healthcare services for the patients were prevalent. This aligns with findings from a study conducted in a similar setting in India, where treatment, transportation, psychological tension, and expenses were the main sources of suffering for parents of children with thalassemic illnesses during the COVID-19 pandemic [3].

The disruption of healthcare services was a common issue globally, but its impact was more acute in low- and middle-income countries (LMICs). For instance, a study in North India found a drastic reduction in blood transfusion services, with patients receiving only a fraction of the pre-pandemic transfusion frequency. Worldwide, patients from developing countries have faced more pronounced challenges, including blood shortages, blood safety issues, interruptions in medication, and economic challenges, compared to patients from Western countries as a consequence of COVID-19, according to TIF [9].

In our study, the majority of the families reported spending BDT 5,000 to 10,000 per month for the treatment of the thalassemic child, substantially lower than the required BDT 10,583 to BDT 25,750 estimated for optimal care in Bangladesha [14]. The large discrepancy between the required cost and actual expenditure often leads to inadequate treatment, resulting in complications such as weakness, stunted growth, spleenomegaly, bone deformities, and even early death. It is also evident that patients who receive adequate treatment have a better quality of life [22].

The majority of the patients in our study are aged 11 to 20 years and a significant portion of patients in our

Table 2 Impact of COVID-19

Variable[a]	n	%
COVID-19 infection record of the patient (self-reported) [b], n = 156		
Tested and got positive report	7	4.49
Tested and got negative report	9	5.77
Had symptoms but did not test	16	10.26
No symptoms so did not test	124	79.49
Household member (staying in close contact) tested positive for COVID-19 (self-reported) [b], n = 154		
Yes	30	19.48
No	111	72.08
Don't know	13	8.44
Change in monthly household income during COVID-19, n = 156		
Increased a lot	5	3.21
Increased moderately	3	1.92
Remained same	32	20.51
Decreased moderately	43	27.56
Decreased a lot	73	46.79
Change in monthly household expenditure during COVID-19, n = 156		
Increased a lot	51	32.69
Increased moderately	29	18.59
Remained same	29	18.59
Decreased moderately	16	10.26
Decreased a lot	31	19.87
Difficulty in managing blood/ donor during COVID-19, n = 156		
Strongly Agree	18	11.54
Agree	17	10.90
Neutral	14	8.97
Disagree	35	22.44
Strongly Disagree	72	46.15
Difficulty in accessing services in hospitals/ treatment centres during COVID-19, n = 156		
Strongly Agree	24	15.38
Agree	37	23.72
Neutral	12	7.69
Disagree	36	23.08
Strongly Disagree	47	30.13
Difficulty in managing regular follow-up (laboratory test/ doctor visits) during COVID-19, n = 156		
Strongly Agree	17	10.90
Agree	32	20.51
Neutral	23	14.74
Disagree	35	22.44
Strongly Disagree	49	31.41
Difficulty in managing transportation for treatment purposes during COVID-19, n = 155		
Strongly Agree	14	9.03
Agree	13	8.39
Neutral	15	9.68
Disagree	41	26.45
Strongly Disagree	72	46.45
Difficulty in managing money for treatment purposes during COVID-19, n = 154		
Strongly Agree	13	8.44
Agree	14	9.09
Neutral	11	7.14

Table 2 (continued)

Variable[a]	n	%
Disagree	33	21.43
Strongly Disagree	83	53.90
Overall health status of the patient during COVID-19 (self-reported), n = 156		
No significant weakness	53	33.97
Mild weakness (weak but no problem doing daily activity)	55	35.26
Moderate weakness (could do daily activity but with difficulty)	33	21.15
Severe weakness (bedridden)	15	9.62
Overall mental health status of the mother during COVID-19 (self-reported), n = 154		
Good	9	5.84
Acceptable	34	22.08
Poor	62	40.26
Very poor	49	31.82

COVID-19 Coronavirus Disease of 2019

[a] Discrepancy in the total number of observations in each variable is due to the missing values where the respondent opted to skip the question

[b] Information on the type of tests used for diagnosis/suspicion of COVID-19 was not collected

study have been suffering from thalassemia for more than 20 years. The increasing survival of patients beyond 20 years of age, as observed in our study, underscores the growing need to address the quality of life and mental health of aging patients [27]. Disease-related complications may also increase with ageing. Adult patients are realizing at some point that adequate and regular maintenance through proper treatment can lead to better survival. But unlike their counterparts in developed countries, who achieve milestones like higher education, career, and family life [5], patients from LMICs like Bangladesh face limited opportunities due to socioeconomic constraints and systemic inadequacies. For example, a study from Malaysia revealed that thalassemia patients have a significantly lower quality of life than healthy controls [17]. COVID-19 exacerbated the situation, where disruptions in blood availability were linked to reduced health-related quality of life, as found by another study conducted in Egypt [33].

Although accessing healthcare during the critical time of the pandemic was a concern among thalassemia patients, there is no evidence of spreading the coronavirus through blood transfusion [19]. The prevalence of COVID-19 among general people nationally was 6.44% in Bangladesh as shown by a study up to October 2020 [24]. Although our study could not capture the COVID-19 prevalence rate among thalassemia patients effectively due to the low rate of screening and possible self-report bias, it reveals the fact that many patients avoided screening for COVID-19 despite having symptoms due to perceived inconvenience which seemed unnecessary to them or the lack of awareness, while the majority did not face any symptom for COVID-19 and thus did not screen. Therefore, this study underscores a significant gap in COVID-19 testing and monitoring among thalassemia patients. A study in Iran found that, while the prevalence of transfusion-dependent thalassemia was nearly identical to the general population, the prevalence of COVID-19 in non-transfusion-dependent thalassemia was considerably greater than in the general population [18]. They suggest that thalassemia patients may face higher mortality rates from COVID-19 due to comorbidities [18].

The proportion of thalassemia families having an income shock (74.4%) during COVID-19 is considerably higher than that of the general population in Bangladesh (58.9%) although the change in expenditure is similar [12]. The most conservative direct medical cost for a thalassemia patient in Bangladesh ranges from BDT (Bangladeshi Taka) 127,000 (US$ 1632) to BDT 309,000 (US$ 3960) per year [14]. Therefore, the patients must have led an insufferable time during a critical period like COVID-19 due to the further decreased income along with the high cost of maintaining the disease consequences.

While 74.35% of families experienced income reductions, only a minority (17.53%) struggled to manage treatment costs in our study. This disparity may be attributed to the subsidised care provided by institutions like BTSH and the prioritisation of treatment over other expenses. Participating patients in our study setting (BTSH) receive daycare blood transfusion services, medicines and lab tests at subsidised prices as members of the centre. Although they are not covered by any insurance scheme, the patients pay for the treatment out-of-pocket and some may receive, if available, some financial assistance

through the fund of the centre itself (i.e. poor patients' fund or Zakat fund) on a need basis. Also, patients' families might have prioritised the treatment over other expenses despite having disruptions in their income during COVID-19. Therefore, although some patients in our study faced difficulty in managing money for treatment purposes during COVID-19, the proportion is low. Nonetheless, the economic toll remains significant, warranting targeted financial support mechanisms.

Blood shortages persisted as a critical issue. A significant portion (22.44%) of patients in our study have faced difficulty in managing blood or donors during the pandemic. Our previous study found that two-thirds of thalassemia patients in Bangladesh have transfusion-dependent thalassemia [14] and 42% of these patients require one to four bags of blood per month [13, 15], yet inadequate blood bank distribution and supply shortages exacerbate their challenges. Even in normal times, thalassemia patients and their relatives often have to struggle to collect blood regularly. The Directorate General of Health Services (DGHS) listed that 116 of Bangladesh's 185 blood banks are situated in the Dhaka district, with only the remaining 69 being spread throughout other districts.[1] Moreover, about 41% of blood centres at the district level have insufficient blood supply [31]. Due to delays in getting donors and receiving blood, patients' hemoglobin decreases causing serious physical problems which also affect the quality of life of these patients. According to the most recent census [4], 68.5% of the country's population lives in rural areas where safe blood is a big concern due to inadequate screening and suboptimal processing. This issue was further magnified during COVID-19 due to donor hesitancy and mobility restrictions, as reflected in the 22.44% of participants who struggled to arrange blood or donors.

At the early phase of COVID-19, the Government imposed a general holiday aka a "relaxed lockdown" on 26 March then was extended up to 30 May 2020 [8, 28]. Restrictions including prohibited outdoor movement from 10 to 5 pm, closure of shops after 8 pm, prohibition of gatherings and restriction on public transport were there until September 2020 [1]. The lockdown can hamper the movement of patients seeking healthcare as we see in our study, 17.42% of patients faced difficulty managing transport for treatment purposes. While this proportion appears moderate, it reflects the "relaxed" nature of lockdowns in Bangladesh, compared to stricter measures elsewhere, such as India, where disruptions were more pronounced. For example, the majority of patients discontinued seeking healthcare during the lockdown due to lack of transport and even the death of two patients was reported due to the delay in blood transfusion in Maharashtra, India [20].

The difficulty in getting treatment during COVID-19 might resulted in under-treatment which was reflected in the health status of the patients. While there are 9.6% of patients in our study faced severe weakness during COVID-19, a study before COVID-19 showed no instance of severe weakness among the patients from Jamalpur's (a district in Bangladesh) community-based health registry [13, 15].

Physical adversity also affects the mental health of patients and their families, but mental health remains neglected due to the preoccupation with controlling the disease's consequences. The mental health of mothers, who act as the primary caregivers to their affected children, remains another critical concern. Caregivers of children with chronic illnesses like thalassemia often experience some level of depression, anxiety, or stress [16], which is exacerbated by the added pressures of the pandemic. Nearly 72% of the mothers in our study reported having poor to very poor mental health status during the pandemic. Similar patterns were observed in India, where parents of thalassemia patients reported heightened stress and anxiety due to disruptions in treatment and financial instability [3]. This highlights the urgent need for integrated mental health interventions tailored to caregivers of chronic disease patients, particularly in LMICs where such services are often inadequate.

Accessing healthcare services was severely impacted during the pandemic. TIF has made a timely effort to classify the level of risk affecting thalassemia patients and create patient care pathways for patients with hemoglobinopathies all over the world [10]. Addressing WHO, TIF advocated for prioritising thalassemia patients in high-risk categories during the pandemic and called the national health systems to exert extra caution against COVID-19 with adequate prevention measures in thalassemia treatment centres [29]. However, these recommendations only seemed viable in developed countries where the healthcare system is well-organised. These recommendations were not effectively implemented in resource-constrained settings in LMICs like Bangladesh. Our findings reaffirm the urgent need for context-specific interventions to mitigate the impact of future crises on vulnerable populations. Strengthening healthcare infrastructure, enhancing blood donation systems, and integrating mental health support into routine care are critical steps toward building resilience among thalassemia patients and their families.

[1] http://103.247.238.81/hsmdghs/registration/hsm_facility_show_public.php

Limitations

First, recall bias is the most significant drawback because the survey was conducted when the extreme phase of COVID-19 was settled. Second, the results of our study might not apply to all families with thalassemia in the whole country, particularly those with patients from distant locations who cannot get to the capital city for routine medical care. Third, the low number of observations resulting from the high attrition rate of first-round cases may have a substantial influence on the findings.

Conclusion

This study presents a comprehensive, context-specific, and multidimensional analysis of the challenges faced by thalassemia patients in Bangladesh, offering novel insights into an underexplored population in LMICs during an unprecedented global health crisis. It is evident that more targeted support and interventions are required for this vulnerable group of population to ensure their well-being and access to essential healthcare services during such unprecedented times. As we continue to navigate this global crisis, policymakers, healthcare professionals, and communities must collaborate effectively to safeguard the health and dignity of thalassemia patients. By addressing the specific needs highlighted in this study, we can strive towards a more inclusive and resilient healthcare system that leaves no one behind, ensuring equitable access to resources, even in the face of extraordinary challenges like the COVID-19 pandemic.

Abbreviations

BDT	Bangladeshi Taka
BTSH	Bangladesh Thalassaemia Samity Hospital
COVID-19	Coronavirus Disease of 2019
DGHS	Directorate General of Health Services
IEDCR	Institute of Epidemiology, Disease Control and Research
REDCap	Research Electronic Data Capture
SARS-CoV-2	Severe Acute Respiratory Syndrome Coronavirus 2
SD	Standard Deviation
SIM	Subscriber Identity Module
TIF	Thalassaemia International Federation
US$	United States Dollar

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Authors' contributions

Mohammad Sorowar Hossain, Farhin Islam, and Enayetur Raheem conceived the idea and designed the study. Farhin Islam, Sonia Rezina, Senjuti Seemanta, and Afsana Mehrab were involved in data generation. Farhin Islam and Enayetur Raheem analyzed data. Farhin Islam and Mohammad Sorowar Hossain prepared the first draft of the manuscript. All authors read, provided critical feedback and approved the manuscript.

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Data availability

The datasets used and/or analyzed during the current study are available from the corresponding author upon reasonable request.

Declarations

Ethics approval and consent to participate

The study protocol was approved by the institutional review board of the Biomedical Research Foundation, Bangladesh (BRF/ERB/2020/003). Informed consent was obtained from all individual participants included in the study.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

Author details

[1]Department of Emerging and Neglected Diseases, Biomedical Research Foundation, House- 22, 6Th Floor, Road- 08, Sector- 09, Uttara, Dhaka 1230, Bangladesh. [2]Bangladesh Institute of Development Studies (BIDS), Dhaka, Bangladesh. [3]M Abdur Rahim Medical College, Dinajpur, Bangladesh. [4]Uttara University, Dhaka, Bangladesh. [5]School of Environment and Life Sciences, Independent University, Bangladesh, Dhaka, Bangladesh.

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