

# Health seeking behavior of $\beta$ -thalassemia major children and its attributes: An epidemiological study in Eastern India

Bijit Biswas<sup>1</sup>, Narendra Nath Naskar<sup>2</sup>, Keya Basu<sup>3</sup>, Aparajita Dasgupta<sup>4</sup>, Rivu Basu<sup>5</sup>, Bobby Paul<sup>4</sup>

<sup>1</sup>Department of Community and Family Medicine, All India Institute of Medical Sciences, Patna, Bihar, <sup>2</sup>Department of Public Health Administration, All India Institute of Hygiene and Public Health, Kolkata, West Bengal, <sup>3</sup>Department of Pathology, Calcutta National Medical College and Hospital, Kolkata, <sup>4</sup>Department of Preventive and Social Medicine, All India Institute of Hygiene and Public Health, Kolkata, West Bengal, <sup>5</sup>Department of Community Medicine, R.G.Kar Medical College and Hospital, Kolkata, West Bengal, India

## ABSTRACT

**Background:** Health seeking behaviour (HSB) of thalassaemic children is one of the rarely explored entity. **Aim:** To explore HSB of  $\beta$ -Thalassemia Major ( $\beta$ -TM) children and its attributes. **Materials and Methods:** It was a cross-sectional design, observational study, conducted among 328  $\beta$ -TM children and their caregivers attending a tertiary care health facility of Kolkata; West Bengal situated in Eastern India in between May 2016 and April 2017 with a structured schedule. The data were analyzed using SPSS 16.0 version. **Results:** At the disease onset, 79.6% of them consulted an allopathic doctor. In multivariable logistic regression model, those who were residing in urban area [adjusted odds ratio, AOR: 3.2 (1.2-8.7)], Hindu by religion [AOR: 3.0 (1.2-7.4)], had educated parents [AOR: 3.2 (1.1-9.2)], no family history of the disease [AOR: 3.6 (1.5-8.5)], belonged to higher socio-economic status (Class II, III and IV) [AOR: 2.9 (1.2-6.8)] and had caregiver with satisfactory knowledge related to the disease ( $\geq 4$ ) [AOR: 12.2 (5.1-29.6)] were significantly more likely to seek healthcare from an allopathic doctor at onset of the disease. When we consider their HSB till date, 61.0% continued to consult allopathic doctors only. The multivariable determinants of satisfactory HSB till date were place of residence [AOR: 2.7 (1.4-5.2)], caste [AOR: 3.3 (1.6-6.7)], religion [AOR: 3.4 (1.7-6.9)], family history of the disease [AOR: 2.3 (1.2-4.6)] and caregiver's knowledge related to the disease [AOR: 5.3 (3.1-9.2)]. **Conclusions:** HSB of the study participants were significantly associated with their caregiver's knowledge regarding the disease, parents' educational level, socio-economic status, caste, religion and family history of the disease.

**Keywords:** Caregiver, children, health seeking behavior, knowledge, thalassemia

## Introduction

Thalassemia is an autosomal recessive single gene disorder with half a lakh new cases registered annually with the

severe form of the disease (i.e.  $\beta$ -TM) affecting 200 million people globally. The condition is becoming a global public health concern as it is spreading its roots to the parts of the world which were not previously considered as endemic for thalassemia mostly due to high population movement.<sup>[1-3]</sup> Southeast Asia is a well-known hotspot for thalassemia.<sup>[2,4]</sup> In India, nearly twelve thousand infants born each year with the major form of the disease (10% of global burden) with half of these patients die before reaching adulthood. A large

**Address for correspondence:** Dr. Bijit Biswas, Department of Community and Family Medicine, All India Institute of Medical Sciences, Phulwarisharif, Patna, Bihar - 801507, India. E-mail: drbijitbiswas@gmail.com

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proportion of these early deaths are likely to be contributed due to inappropriate HSB.<sup>[5-7]</sup>

HSB has been defined as any set of activities undertaken by individuals who perceive themselves to have a health issue or to be ill to find an appropriate remedy. HSB is preceded by a decision-making process that is further governed by individuals and/or household behavior, expectations and community norms as well as provider-related characteristics and functioning.<sup>[8-10]</sup> As per existing literature on the predictors of HSB for childhood illnesses are found to be age, sex, ethnicity, parents' educational level, socioeconomic status, distance from the health facility, caregivers knowledge related to the disease and caregiver's perception regarding the severity of his/her child's illness etc.<sup>[11-22]</sup> Thalassemia is a chronic disease with no known non-allopathic management. At disease onset/initiation, seeking care from a non-allopathic provider is not at all warranted as it not only delays the timely relevant management of the child but also lays an additional unnecessary financial burden on his/her caregiver. After being diagnosed as thalassemic, seeking treatment from a non-allopathic provider in addition to allopathic care exposes the child to undue risks (i.e. infection due to unhygienic herbal remedies). It also reveals his/her caregiver to excessive mental (due to long unnecessary treatment) and financial stress (due to costs incurred in fees, travel, etc.).

To our knowledge, there had been no prior evidence on the HSB of thalassemic children and the associated factors which are vital in terms of their therapeutic efficacy and survival. With this background, the study was designed to explore HSB of  $\beta$ -TM children and its attributes. The findings of the research will help in the identification of factors determining HSB of thalassemic children and formulating interventions to assure quality care right from primary level and protect their caregivers from unnecessary healthcare costs.

## Materials and Methods

The study was a cross-sectional, hospital-based, analytical observational study, conducted in thalassemia day care unit of Calcutta National Medical College and Hospital of West Bengal, situated in the eastern part of India, from May 2016-April 2017. In the study, 328  $\beta$ -TM children and their accompanying caregivers participated. The data were collected with a structured schedule by principal investigator himself, consisted of socio-demographic (age, sex, place of residence, caste, religion, parents educational level), socio-economic (per capita monthly family income), family history of the disease, caregivers' social discrimination status, travel time to current tertiary care health facility and HSB (at the onset of the illness and till date). Notably, the study was conducted only on known  $\beta$ -TM children. These children were diagnosed as having  $\beta$ -TM by the medical officer in charge of the thalassemia unit using diagnostic criteria as a patient with haemoglobin less than 7gm% with haemoglobin F  $\geq 70\%$  and haemoglobin A  $< 30\%$  on haemoglobin electrophoresis at the time of diagnosis. After being diagnosed, these  $\beta$ -TM children

attend thalassemia unit outdoor to get assessed by the concerned medical officer in charge for the need of blood transfusion (by Hb measurement and clinical examination) and other therapeutic interventions (i.e. iron chelators, vaccinations etc.). Mostly these visits are follow-up visits for treatment.

$\beta$ -TM children who had at least received one blood transfusion in the previous year and attended thalassemia day care unit along with a caregiver during the study period and consented to participate were included in the research. On the other hand, those who were critically ill were excluded. Here 'critically ill' means thalassemic children who are bedridden and urgently requires medical intervention to survive. One day in a week was allocated for data collection. On an average thalassemia unit, the outpatient department serves 15-20  $\beta$ -TM patients on a single day. Every second patient attending the outpatient department was approached for the study by the principal investigator. Notably, the principal investigator of the study was a junior resident doctor then. An interview took on an average of 15-20 minutes. On average, eight patients and their caregivers could be interviewed on a single day. Before each interview study participants were enquired regarding if they were interviewed before, to prevent duplication. Total 41 days in 1 year were available for data collection (excluding public holidays) by this method 328 parents could be interviewed in the stipulated study period.

Some operational definitions used in the study were as following:

### Health seeking behavior (HSB)

To explore HSB at disease onset, the caregivers were asked: "Where did you first go when the child first presented with symptoms?". Those who reported it to be a government hospital/nursing home/private allopathic consultant were considered as having satisfactory HSB at disease onset. To assess their HSB till date, they were asked: "Have you ever visited the following for the treatment of the patient?" The options were Ojha/Tantrik, quack, spiritual leader and any other (specify). If they say yes to any of the above options. Then they were also asked regarding the number of visits and number of days under treatment to that concerned healthcare provider. Those who have reported it to be 'no' were considered as having satisfactory HSB till date.

### Caregiver

In the present study, any adult relative who accompanied the thalassemic child during a visit to the thalassemia outdoor of the hospital and currently living with and taking care of the patient was considered as a caregiver.

### Caregivers' knowledge regarding the disease

It was calculated by the addition of scores they received for each knowledge item where a higher score indicated a higher level of knowledge regarding the disease. The minimum and maximum achievable score were 0 and 7, respectively. Notably, the minimum and maximum attained score was the same as

possible scores. Those who had more than equal to 4 (median achieved score) score were considered having satisfactory knowledge while those who scored less than four were marked as having unsatisfactory knowledge regarding the disease. Details described in Table 1.

Data were analyzed using IBM SPSS (Chicago, USA) (version 16). Bivariate and multivariable logistic regression tests were done to find out any relationship between HSB (at disease onset and till date) and its various attributes. The minimum acceptable confidence level was  $\alpha = 0.95$  for all statistics, and the maximum acceptable significance level was  $P < 0.05$ .

Ethical clearance of the Institutional Ethics Committees of All India Institute of Hygiene and Public Health and Calcutta National Medical College and Hospital, Kolkata were taken before conducting the research. Informed written consent of each of the study participant was taken before their participation. During data collection, their confidentiality was assured.

### Results

Most of the study subjects were aged between 11 and 12 years (37.2%) with range (5-12 years). There was almost equal representation of both the sexes. Majority of the caregivers interviewed were mothers (75.0%) with a mean age of 29.8 years, and the rest being mostly fathers (23.8%) with a mean age of 34.8 years and followed by grandparents (1.2%) of the thalassemic children. Most of the fathers and mothers of the study participants were educated up to primary and above (58.6% and 59.8%, respectively) whereas 70 (21.3%) of the fathers and 70 (21.6%) of the mothers were illiterate. Majority of the study participants presented with the symptoms of thalassemia within the first year of their lives (67.4%) with the mean age at symptoms of 14.9 months. Most of the thalassemic children were diagnosed as thalassemic within the first year of their lives (56.5%) with a mean age at diagnosis of 20.2 months. Notably, the median travelling time to the current tertiary care health facility was 120 minutes/2hours with an interquartile range of 60-180 minutes (range: 30-300 minutes) [Table 2].

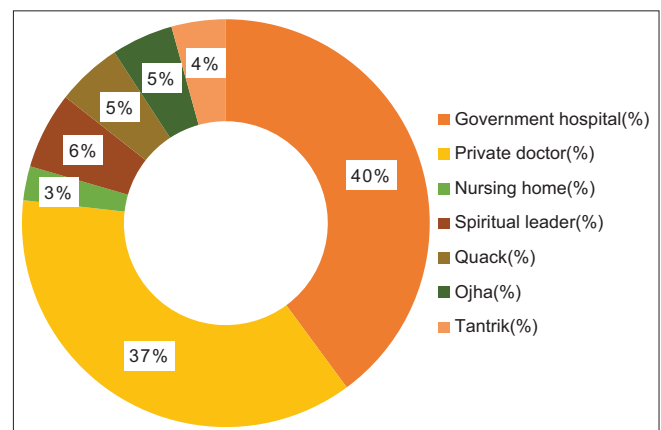
HSB of the study participants at disease onset is depicted in Figure 1. Majority of the caregivers of the study participants (79.6%) preferred to consult an allopathic doctor when their child first presented with symptoms of the disease while 20.4% preferred non-allopathic healthcare provider. However, while considering their HSB till date, 61.0% of the caregivers preferred allopathic doctors only for their child's treatment, while 39% also preferred non-allopathic healthcare provider for their child's treatment [Figure 2].

Those who had also consulted non-allopathic healthcare providers for their child's treatment till date ( $n = 128$ ), 39.8% consulted spiritual leader followed by Ojha/Tantrik (38.2%), others (18.7%) and quack (13.2%), respectively [Table 3].

**Table 1: Distribution of the study participants according to their knowledge regarding the disease:  $n=328$**

Variable	Frequency	Percentage	Score
Do you know how this disease is caused?			
Yes	189	57.6	
No	139	42.4	
Cause of thalassemia as specified by the caregiver:			
Correct knowledge (Genetic)	156	47.6	1
Incorrect knowledge (Destiny/Contact with other thalassemic)	33	10.0	0
Don't know	139	42.4	0
Have you ever heard about premarital counselling?			
Yes	172	52.4	1
No	156	47.6	0
Have you ever heard about antenatal screening?			
Yes	167	50.9	1
No	161	49.1	0
Do you know about the treatment of thalassemia?			
Yes	303	92.4	
No	25	7.6	
Treatment modalities as specified by the caregiver*:			
Only blood transfusion	54	16.5	1
Only iron chelation	0	0.0	1
Both blood transfusion and iron chelation	249	75.9	2
Splenectomy	63	19.2	1
Bone marrow transplantation	9	2.7	1
Don't know	25	7.6	0

\*multiple responses



**Figure 1: Doughnut diagram showing the distribution of study participants according to their health-seeking behavior at the onset of the disease:  $n = 328$**

At the disease onset, 79.6% of them consulted an allopathic doctor. In multivariable logistic regression model, those who were residing in urban area [adjusted odds ratio, AOR: 3.2 (1.2-8.7)], Hindu by religion [AOR: 3.0 (1.2-7.4)], had educated parents [AOR: 3.2 (1.1-9.2)], no family history of the disease [AOR: 3.6 (1.5-8.5)], belonged to higher

socio-economic status (Class II, III, and IV) [AOR: 2.9 (1.2-6.8)] and had caregiver with satisfactory knowledge related to the disease ( $\geq 4$ ) [AOR: 12.2 (5.1-29.6)] were significantly more

likely to seek healthcare from an allopathic doctor at onset of the disease. The model was adjusted with patients age, sex, caste, caregiver's social discrimination status, and travelling time to the current tertiary healthcare facility. When we consider their HSB till date, 61.0% continued to consult allopathic doctors only. The multivariable determinants of satisfactory HSB till date were place of residence [AOR: 2.7 (1.4-5.2)], caste [AOR: 3.3 (1.6-6.7)], religion [AOR: 3.4 (1.7-6.9)], family history of the disease [AOR: 2.3 (1.2-4.6)] and caregiver's knowledge related to the disease [AOR: 5.3 (3.1-9.2)] adjusted with patients age, sex, parents' educational level, socio-economic status and caregiver's social discrimination status and travelling time to current tertiary healthcare facility. The two multivariable models of satisfactory HSB explained 45.9% (at disease onset) and 33.3% (till date) of its variability with predictive accuracy rate (PAR) of 86.0% and 75.0%, respectively [Table 4].

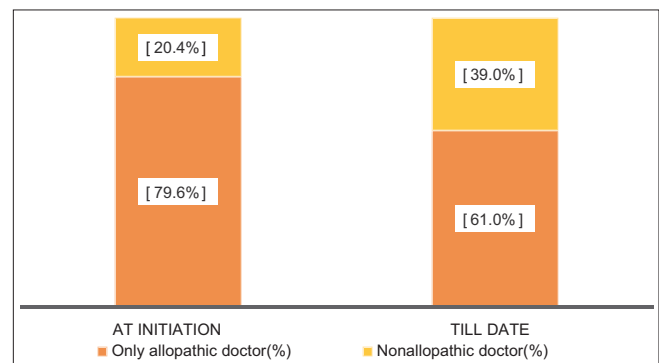
**Table 2: Background characteristics of the study participants: n=328**

Variables	n (%) / Mean $\pm$ SD
Age in completed years:	8.0 $\pm$ 2.3
Sex:	
Male	177(54.0)
Female	151(46.0)
Place of residence:	
Urban	91(27.7)
Rural	237(72.3)
Religion:	
Hindu	197(60.1)
Muslim	129(39.3)
Christian	2(0.6)
Caste:	
Other	172(52.4)
OBC*	45(13.7)
SC†	109(33.2)
ST‡	2(0.7)
The educational level of the father: (completed years of schooling)	
Illiterate (0)	70(21.3)
Below primary (0-4)	66(20.1)
Primary (5-7)	76(23.2)
Middle (8-9)	74(22.6)
Secondary and above ( $\geq 10$ )	42(12.8)
The educational level of the mother: (completed years of schooling)	
Illiterate (0)	71(21.6)
Below primary (0-4)	61(18.6)
Primary (5-7)	84(25.6)
Middle (8-9)	68(20.7)
Secondary and above ( $\geq 10$ )	44(13.5)
Per capita monthly family income in USD:	22.9 $\pm$ 12.3
Socio-economic status: §	
Class II (43.8-87.6) USD	21(6.4)
Class III (26.3-43.7) USD	79(24.1)
Class IV (13.1-26.2) USD	160(48.8)
Class V (<13.1) USD	68(20.7)
Family history of thalassemia: (Yes)	67(20.4)
Caregiver knowledge score regarding the disease:	3.4 $\pm$ 1.5
The caregiver who had faced social discrimination for being a caregiver of a thalassemic child: (Yes)	137(41.8)
Travelling time to the tertiary health care facility in minutes:	137.5 $\pm$ 78.7

\*other backward class, †scheduled caste, ‡scheduled tribe, §according to modified B.G Prasad scale October 2015

## Discussion

It was a cross-sectional, hospital-based, observational study, aimed to assess the HSB of  $\beta$ -TM children and also to determine the explanatory and contextual factors affecting it. Majority of the caregivers' of the study participants (79.6%) preferred to go to an allopathic doctor when their child presented with symptoms of the disease, while 20.4% preferred non-allopathic healthcare providers. This dropped to 61.0% when we estimated their HSB till date, which was entirely unwanted as thalassemia has no known non-allopathic management. This indicates not only their doubt in allopath but also their secret wishes to seek help from other sources which usually suggested by their friends and relatives. Seeking treatment from a non-allopathic healthcare provider must have resulted in an unnecessary financial



**Figure 2:** Bar chart showing health-seeking behavior of the study participants at the initiation of the disease and till date: n = 328

**Table 3: Distribution of the study participants according to their health-seeking behavior till date other than an allopathic doctor: n=328\***

Treatment modalities	Yes Frequency (%)	Number of visits	Median (IQR <sup>†</sup> ), Range	Number of days under treatment	Median (IQR <sup>†</sup> ), Range
Ojha/Tantrik	49(14.9)	3.0(2.5-6.0), 1.0-96.0	90.0(30.0-180.0), 6.0-840.0		
Quack	17(5.2)	12.0(3.5-30.0), 2.0-52.0	360.0(60.0-900.0), 15.0-1080.0		
Spiritual leader	51(15.5)	11.0(3.0-18.0), 1.0-240.0	120.0(30.0-720.0), 21.0-2520.0		
Others <sup>‡</sup>	24(7.3)	18.0(12.0-24.0), 6.0-36.0	630.0(337.5-772.5), 180.0-1080.0		
Not applicable	200(61.0)	-	-		

\*multiple responses, †interquartile range, ‡others include Homeopathic and Ayurvedic doctors



**Table 4: Univariate and multivariable logistic regression analysis showing predictors of health-seeking behavior at the initiation of the disease and till the date of the study subjects: n=328**

Variables	Satisfactory health seeking behaviour (Consulted Allopathic Doctor Only)					
	At Initiation: Yes= 261(79.6%)			Till Date: Yes= 200(61.0%)		
	N(%) / Mean (SD)	OR <sup>§</sup> (95%CI <sup>  </sup> )	AOR <sup>¶</sup> (95%CI <sup>  </sup> )	N(%) / Mean (SD)	OR <sup>§</sup> (95%CI <sup>  </sup> )	AOR <sup>¶</sup> (95%CI <sup>  </sup> )
Age in completed years: (increasing)	8.0(2.3)	0.9(0.9–1.1)	0.9(0.7–1.0)	8.1(2.2)	1.0(0.9–1.1)	1.0(0.9–1.1)
Sex:						
Male	143(80.8)	1.2(0.7–2.0)	1.9(0.9–3.9)	103(58.2)	0.8(0.5–1.2)	1.2(0.7–2.0)
Female	118(78.1)	Ref.	Ref.	97(64.2)	Ref.	Ref.
Place of residence:						
Urban	84(92.3)	4.1(1.8–9.3)	3.2(1.2–8.7)	72(79.1)	3.2(1.8–5.6)	2.7(1.4–5.2)
Rural	177(74.7)	Ref.	Ref.	128(54.0)	Ref.	Ref.
Caste:						
Other/OBC*	174(80.2)	1.2(0.6–1.9)	2.5(0.9–6.5)	139(64.1)	1.4(0.9–2.3)	3.3(1.6–6.7)
SC†/ST‡	87(78.4)	Ref.	Ref.	61(55.0)	Ref.	Ref.
Religion:						
Hindu	168(85.3)	2.4(1.4–4.1)	3.0(1.2–7.4)	132(67.0)	1.9(1.2–2.9)	3.4(1.7–6.9)
Others	93(71.0)	Ref.	Ref.	68(51.9)	Ref.	Ref.
The educational level of parents:						
Educated	237(82.0)	2.8(1.4–5.8)	3.2(1.1–9.2)	181(62.6%)	1.7(0.9–3.4)	2.0(0.9–4.6)
Illiterate	24(61.5)	Ref.	Ref.	19(48.7%)	Ref.	Ref.
Family history of thalassemia:						
No	221(84.7)	3.7(2.1–6.7)	3.6(1.5–8.5)	172(65.9)	2.7(1.5–4.7)	2.3(1.2–4.6)
Yes	40(59.7)	Ref.	Ref.	28(41.8)	Ref.	Ref.
Socio-economic status:						
Class II, III, and IV	219(84.2)	3.3(1.8–5.9)	2.9(1.2–6.8)	166(63.8)	1.8(1.0–3.0)	1.2(0.6–2.4)
Class V	42(61.8)	Ref.	Ref.	34(50.0)	Ref.	Ref.
Caregivers Knowledge:						
Satisfactory	165(95.4)	12.7(5.8–27.6)	12.2(5.1–29.6)	137(79.2)	5.6(3.4–9.0)	5.3(3.1–9.2)
Not Satisfactory	96(61.9)	Ref.	Ref.	63(40.6)	Ref.	Ref.
Caregiver faced discrimination:						
No	163(85.3)	2.3(1.3–4.0)	1.5(0.7–3.2)	127(66.5)	1.7(1.1–2.7)	1.0(0.6–1.8)
Yes	98(71.5)	Ref.	Ref.	73(53.3)	Ref.	Ref.
Travelling time to the tertiary health care facility:						
<2 hours	119(86.2)	2.1(1.2–3.8)	1.2(0.6–2.5)	93(67.4)	1.6(1.0–2.5)	1.0(0.6–1.8)
≥2 hours	142(74.7)	Ref.	Ref.	107(56.3)	Ref.	Ref.

\*other backward class, †scheduled caste, ‡scheduled tribe, §odds ratio, ||confidence interval, ¶adjusted odds ratio.

burden and mental trauma to the caregiver and subjected his/her child to unnecessary sufferings. This can be avoided by the counselling of the parents/caregivers during their visit to the hospital. In the present study, the place of residence emerged as a significant predictor of HSB of the study subjects both at disease onset and till date. This was in concurrence with the findings of Wambui *et al.*<sup>[14]</sup> and Mitiku *et al.*<sup>[19]</sup> It may be because rural settings itself presents many challenges, such as he/she needs to travel long distances to seek health care for the disease. These rural dwelling caregivers prefer local traditional health provider mainly due to accessibility issues, especially at disease onset as mostly they were unaware of their child's disease. This was supported by the findings of Burtscher *et al.*<sup>[16]</sup> which reported easy accessibility of traditional health practitioners compared to allopathic health facilities and its influence on HSB. Similarly, travel time to the current facility emerged as a significant predictor of HSB. As we could not able to measure the distance of the current healthcare facility from the patient's residence, travel time to the current health facility may act as a proxy indicator for it

as the distance from healthcare facility is a well-known predictor of HSB.<sup>[11,12,14,20,21]</sup>

Caregivers knowledge regarding the disease and parents' educational status emerged as a significant predictor of satisfactory HSB. A knowledgeable and educated caregiver is more likely to seek timely, relevant management for his/her child. So, it was an obvious finding. It was supported by the results of Simienuh *et al.*<sup>[15]</sup>, Mitiku *et al.*<sup>[19]</sup>, and Thandar *et al.*<sup>[21]</sup> which reported caregiver's knowledge regarding disease as a significant influence of his/her HSB for his/her ward. Whereas, Kanté *et al.*<sup>[12]</sup>, Mishra *et al.*<sup>[13]</sup>, and Wambui *et al.*<sup>[14]</sup> reported caregivers' educational level as a predictor of their HSB for their child which was concurrent with our finding. Similarly, religion and caste emerged as significant predictors of satisfactory HSB. This was in concordance with the results of Mishra *et al.*<sup>[13]</sup> but discordant with the findings of Anarfi *et al.*<sup>[22]</sup> which reported that HSB does not vary with religious affiliations of the respondent. On the other hand, Patil *et al.*<sup>[18]</sup> reported

caste as a vital associate of HSB, which was concurrent with our results. It may be because people of some religions and castes still rely on local traditional healer for ailments. Meanwhile, Muslim population preponderance in our study compared to the country's demographic norms also supports our findings.<sup>[23]</sup> Caregivers who were facing social discrimination were less likely to seek only allopathic care for his child. It may be because he/she wants his/her child to be cured early to get rid of discrimination he/she needs to face for his child's illness.

Those who had a family history of the disease were less likely to seek healthcare only from an allopathic doctor. As per health belief model (HBM) a person's health behavior has two major influencers: The degree to which the person perceives the disease (negative outcome) as threatening and the degree to which the health behaviour is believed to be effective in reducing the risk of a negative health outcome.<sup>[8-10]</sup> Those who had a family history of the disease are more likely to have a severe form of the disease. Thus, they also seek healthcare from informal providers in addition to allopathic care in the hope to get cured. Thalassemia treatment is long and complicated. As of now except blood transfusion, iron chelation, splenectomy and supportive care, there is no curative service for thalassemia through most public health facilities are being provided in the country. Iron overload related complications further complicate the treatment. Some may argue that stem cell transplantation, gene therapy as an alternative treatment option but these are expensive procedures which are unaffordable to many.<sup>[1,24-31]</sup> Thus, these caregivers are left with no option to seek healthcare from informal providers, too, in addition to allopathic care in the hope of getting their child cured.

Socioeconomic status is a well-known determinant of HSB.<sup>[17,20]</sup> In the present study, those who belonged higher socioeconomic status are more likely to seek healthcare from only allopathic healthcare providers both at the onset of the disease and till date. This may be because those who belong to a higher socioeconomic class are likely to be more educated and bear better knowledge regarding the disease. On the other hand, though public health facilities are free in West Bengal, one who is residing in a rural, remote area has to travel long distances (which requires money and time) to seek tertiary healthcare for his children. Besides, if he is a daily wage worker, he has to lose one day wage too to seek healthcare for his/her child. Thus, the findings of such kind are entirely justified.

In strengths, as per the author's knowledge, it was the first study of its kind which investigated HSB of  $\beta$ -TM children both at disease onset and till date. It further used multivariable logistic regression analysis to find out the strength of the association between HSB and its various attributes. This will help in prioritising and designing meticulous interventions to address this issue.

As for limitations of the study, all data were self-reported, and hence, there may be under, or over-reporting (recall bias) and chances of social desirability bias cannot be overlooked. There

may be specific other factors (i.e. cultural norms, perception of the severity of the child's illness, distance from tertiary care health facility) influencing HSB which we did not examine.

## Conclusion

HSB of the study participants was significantly associated with their caregiver's knowledge regarding the disease, parents' educational level, socio-economic status, caste, religion and family history of the disease. Caregiver's knowledge regarding the disease was the strongest associate of HSB both at disease onset and till date. Thus, awareness regarding the disease should be raised among vulnerable groups to improve their HSB and to protect them from unnecessary healthcare costs.

## Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form the patient (s) has/have given his/her/their consent for his/her/their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

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## Conflicts of interest

There are no conflicts of interest.

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