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Original Article

Socio-demographic Profile of Patients Admitted in Thalassemia Care Center of Chattogram Maa Shishu-O-General Hospital

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Abstract

Background: *Thalassemia is the most common hemoglobin disorder in the world including Bangladesh. Population migration and intermarriage between different ethnic groups have had a major impact on disease epidemiology. To observe the prevalence and specturm of thalassemia as well as demographic and social factors of thalassemia patients.*

Materials and methods: *This descriptive cross-sectional study was conducted in the Thalassemia Care Center of Chattogram Maa Shishu-O-General Hospital, Chattogram from July, 2013 to June, 2014. Parents of 70 thalassemia patients aged 2-18 years interviewed with a formulated questionnaire based on social and demographic characteristics. Data were analyzed by both manually and by SPSS-18.*

Results: *Mean age of patients was 6 years (± 3.66). Near about half of patients (40%) were diagnosed at the age less than 5 years. Mean age of diagnosis was 1.6 years (± 1.53 SD). Majority of patients belonged to lower middle class (42.9%) with male predominance (62.9%). A good number of patients (22.8%) were not engaged in any educational activity. Mean annual income of family was 262000 taka/year ± 245477.35 (USD 3324.87 ± 3115.19). Mother contributed to annual income in only 4.7% families. The percentage of Hb E/β thalassemia was the highest (54.4%) followed by β thalassemia major (37.1%) and Hb E disease (4.3%). Male predominance was found in every type of thalassemia. Half of the thalassemia major patients were diagnosed during infancy and majority (60.53%) of Hb E/β thalassemia patients were diagnosed at the age less than 5 year.*

Conclusion: *A nation-wide screening program should be carried out to address the carrier status of population at risk. There may be further analysis regarding clinical diversity of thalassemia.*

Key words: Thalassemia; Socio-demographics; Pattern of thalassemia.

INTRODUCTION

Thalassemia is the most common hemoglobin disorder in the world. It comes from a Greek word "Thalas" meaning the sea and "emia" for blood. The word came into use as thalassemia was originally described in countries bordering the Mediterranean Sea[1]. It is particularly associated with people of Mediterranean, Indian subcontinent, Middle-east, Southern China as well as countries along the north coast of Africa and in the South America with highest carrier rate in Cyprus (14%) and South-east Asia[2,3]. Population migration and intermarriage between different ethnic groups has introduced thalassemia in almost every country of the world including Northern Europe where thalassemia was previously absent[4]. It has been estimated that about 1.5% of the global population are carrier of beta thalassemia with about 60,000 symptomatic individual born annually with great majority in the developing world[4,5].

In South-East Asia, the common combination of beta thalassemia with abnormal hemoglobin, Hb E/β thalassemia is the most prevalent where carrier frequency is around 50%.[5] The estimated prevalence is 16% in people from Cyprus, 1% in Thailand and 3-8% in populations from Bangladesh, China, India, Malaysia and Pakistan.[6] There are about 65,000-67,000 β thalassemia patient in India and approximately 30 million carriers of β thalassemia with a mean prevalence of 3.3%[7]. In Pakistan, an estimated 5000-9000 children with β thalassemia are born per year and the estimated carrier rate is 5-7%[8]. In Bangladesh though the exact data regarding the prevalence and spectrum of hemoglobinopathies is not known, a conservative WHO report estimates that 3% of total population (About 3.6 million people) is carrier of β thalassemia and 4% are carriers of Hb E in Bangladesh and more than two thousand thalassemic children are born every year[6,9] and the most common form of Hb disorder is Hb/β thalassemia followed by Hb E type and β thalassemia major[9,10].

This chronic disease particularly causes major social and financial burdens on patients, families and health care system[11]. Thalassemia is becoming a burden for our country. As the asymptomatic carrier is the reservoir the diseases and the disease are continues to increasing[12]. There is limited data to provide a true picture and incidence varies according to marriage practices and culture. This study was conducted to assess socio-economic and demographics profile of thalassaemic patients by which we can provide information to health authority regarding the spectrum and other related messages to take necessary steps.

MATERIALS AND METHODS

It was a descriptive cross-sectional study conducted at Chattogram Maa Shishu-O-General Hospital, Chattogram from July, 2013 to June, 2014. 70 patients aged 2-18 years registered at Thalassaemia Care Centre of Chattogram Maa Shishu-O-General Hospital, Chattogram were included in this study. Study work was approved by the Ethical Review Committee of Chattogram Maa Shishu-O-General Hospital, Chattogram. Informed written consent was obtained from any of parents or a family member of each patient. Detailed study related information was read out and explained in the local language from a printed hand out. Parents were interviewed according to a formulated questionnaire covering demographic, social and economic variables. Data were checked and analyzed manually with the help of calculator and software SPSS 18.0.

RESULTS

Among 70 patients, most of the patients were in <5 years age group followed by 5–10 years age group with male predominance (62.9%). Mean age was 6 years (± 3.66). Majority of patients were from rural background (54.9%) and were belonged to lower middle class (42.9%) followed by lower class (31.4%) (Table I). Most of the child was diagnosed as thalassemic at the age of 1–5 years group (40%) followed by 6 month–12 months (32.9%), <6 months (22.8%), 5–10 years age group (4.3%) and mean age of diagnosis was 1.6 years (± 1.53 SD) (Table I). About 22.8% were not engaged in any educational activity, 34.3% (n=24) were studied in primary education, 10% in secondary level and 32.9% were below the school age as we considered the age completed 4th years as age of beginning of school. Majority were belonged to lower middle class followed by lower class (31.4%). 5.7% family had another affected child and 7.1% had a child died previously of thalassemia (Table I).

Father was the only earning member in majority family. Mother contributed to total annual income in 5.7% family. Total annual income ranged from 24000 to 1320000 taka/year (USD 304.57 to USD 16751.27) and only in 15.7% (n=11) families it was more than 400000 taka/year (USD >5076.14). Mean annual income was 262000 taka/year ± 245477.35 (USD 3324.87 ± 3115.19) (Table I). Mother's income ranged between 16000-240000 taka/year (USD 203.05-3045.69) (Table II) and on an average 28.19 % ± 25.60% of annual income was contributed by mother (Table III).

Table I : Patient's demographics (n = 70)

Variables	Frequency	Percentage (%)
Age in Groups		
< 5 Years	38	54.3
5 – 10 Years	23	32.9
10 – 15 Years	7	10.0
> 15 Years	2	2.8
Gender		
Male	44	62.9
Female	26	37.1
Locality		
Rural	38	54.3
Urban	32	45.7
Age of Diagnosis		
< 6 Months	16	22.8
6 – 12 Months	23	32.9
1 – 5 Years	28	40.0
5 – 10 Years	3	4.3
Level of Education		
Not Reached at School Age	23	32.9
Nil	16	22.8
Primary	24	34.3
Secondary	7	10.0
Socio-economic Status		
Lower Class	22	31.4
Lower Middle Class	30	42.9
Upper Middle Class	15	21.4
Upper Class	3	4.3
Family History of Thalassemia		
No Sibling Affected	51	72.9
One Sib Affected	4	5.7
No Sibling	15	21.4

History of Sibling Death		
One Sib Death	5	7.1
No Death	65	92.9
Parent's employment		
Only Father	66	94.3
Both Father & Mother	4	5.7
Annual income of parent's (Taka/Year)		
< 50000	3	4.3
50000 – 100000	12	17.1
100000 – 200000	20	28.6
200000 – 300000	17	24.3
300000 – 400000	7	10.0
> 400000	11	15.7

- Age of Patients (Mean ± SD (Range): 6.06 ± 3.66 Years (1.9 – 17.0)
- Age of Diagnosis (Mean ± SD (Range): 1.60 ± 1.53 Years (0.2 – 7.0)
- Annual Income -

Mean ± SD (Range): BDT 262000.00 ± 245477.35 (BDT 24000-1320000)

: USD 3324.87 ± 3115.19 (USD 304.57-16751.27)*

* 1 dollar = 78.80 taka as per exchange rate on July, 2016

BDT = Bangladeshi taka, USD = US dollar

Table II : Contribution of mother's income to total annual income (n = 4)

No. of Patients (%)	Annual Income	Range BDT / Year (USD / Year)	Mean ± SD BDT / Year (USD / Year)
1 (25.0)	BDT < 50000		
0 (0.0)	BDT 50000–100000	BDT 16000 – 240000 (USD 203.05 – 3045.69)	BDT 139000.00 ± 95519.63 (USD 1763.96 ± 1212.18)
1 (25.0)	BDT 100000 – 200000		
2 (50.0)	BDT >200000		

- BDT / Year = Bangladeshi Taka per year
- USD / Year = US Dollar per year

The most common pattern of thalassemia was Hb E/β thalassemia (54.4%) followed by β thalassemia major (37.1%), Hb E disease (4.3%), Hb H disease (2.8%) and Hb S/δ Thalassemia (1.4%) (Table IV). Male predominance was noted in every type of thalassemia (Table IV). Most of the Hb E/β Thalassemia patients (60.53%) were diagnosed at 1 to 5 years of age and half of the β Thalassemia major patients were diagnosed at 6 month to 12 months age group (Table V).

Table III : Pattern of thalassemia (n = 70)

Variables	Frequency	Percentage (%)
Hb E/β Thalassemia	38	54.4
β Thalassemia major	26	37.1
Hb E Disease	3	4.3
Hb H Disease	2	2.8
Hb S/δ Thalassemia	1	1.4

Table IV : Distribution of different type of thalassemia according to sex (n = 70)

Variables	Male (n = 44) No (%)	Female (n = 26) No (%)
Hb E/β Thalassemia (n=38)	25 (65.79)	13 (34.21)
β Thalassemia Major (n=26)	15 (57.69)	11 (42.31)
Hb E Disease (n=3)	2 (66.67)	1 (33.33)
Hb H Disease (n=2)	1 (50.00)	1 (50.00)
Hb S/δ Thalassemia (n=1)	1 (100.00)	0 (0.00)

Table V : Distribution of different type of thalassemia according to age of diagnosis (n = 70)

	< 6 Months		6 – 12 Months		1 – 5 Years		5 – 10 Years	
	No	%	No	%	No	%	No	%
Hb E/β Thalassemia (n=38)	5	13.16	8	21.05	23	60.53	2	5.26
β Thalassemia Major (n=26)	10	38.46	13	50.0	3	11.54	0	0.0
Hb E Disease (n=3)	1	33.33	1	33.33	0	0.0	1	33.33
Hb H Disease (n=2)	0	0.0	1	50.0	1	50.0	0	0.0
Hb S/δ Thalassemia (n=1)	0	0.0	0	0.0	1	100.0	0	0.0

DISCUSSION

Unlike some other studies where common age group was <10 years, we found, most of our patients (54.3%) were in <5 years age group with male preponderance (62.9%) and mean age was 6 years (± 3.66)[13,14]. Male preponderance was also reported by other studies[14,15,16]. Similar to Bandyapahyay B et al we found only 2.8% patients were beyond 15 years[17]. In most cases, thalassemia was diagnosed at <5 years. This findings is consistent with to Mallik S et al, Riewpaiboon A et al[14,18]. Mean age of diagnosis of thalassemia of our patients was 1.6 years (± 1.53). But in Thailand and Iran the average age of diagnosis of thalassemia was 9.52 years and 4 years respectively[18,19]. This may be due to clinical diversity and type of thalassemia.

In Iran 44% patients had family history of thalassemia but we had only 5.7% patients with another thalassemic sib[19]. This may be due to that in Iran the study was carried out nationwide involving a large group of population but we conducted the study in Thalassemia Care Center of one hospital where only small group of patients of the locality are registered and this study was conducted over one year only. Disease burden might be doubled or more of those family having another thalassemic sib that is really difficult for them to continue full treatment of their child.

We found one third (32.9%) patients did not reach the age of beginning of school as we consider the 4th years completed age as the age of entrance of school. Another one third (34.3%) were on primary education, 10% were on secondary education. More than 75% patients had completed primary education in Kolkata (75%), Iran (78.9%) that is quite higher than our findings[14,19]. A good percentage (22.8%) of our patints were not engaged in any educational activity that is consisted with other studies conducted in our neighbor countries like Kolkata

(37%), Pakistan (66.7%), Western India (18%)[14,20,21]. We should encourage our parents to start or continue their child's education despite regular blood transfusion and other treatment related stress of a thalassemia patient.

Most of our patients (42.9%) were from lower middle socio-economic status whereas most of the patients in Kolkata, Pakiatan, Western India were from poor family[14,15,20,21]. In Pakistan, 91.7% had income <Rs 5000/month, average father's income was Rs 28512 per annum and there was <5 patients whose father's income was >Rs 6000/month[15,20]. In contrast, 28.6% of our family had annual income between 10000 to 200000 taka/year (USD 126.90 to USD 2538.07) 4.3% had <50000 taka/year (USD <634.52) and only 15.7% had income >400000 taka/year (USD >5076.14). Average annual income was 262000 taka/year ± 245477.35 (USD 3324.87 ± 3115.19). In Iran main income provided for patients and their families was the parents (78%), patient's husband/wives (8%), patients himself/herself (7%) whereas in our study in cent percent cases main income source was the father[19]. Our findings are consistent with the findings of Pakistan in where majority of the father was the only earning members of the family and most of the mothers were housewife[22]. Mother contributed to annual income only in 5.7% cases and of them in 50% family mother contributed up to 50% of annual income. No patient of our study was engaged in earning. This is because we enrolled patients belongs to pediatric age group aged 2–18 years only, none of them was married or engaged in any job.

The percentage of Hb E/β thalassemia was the highest (54.4%) followed by β thalassemia major (37.1%) and Hb E disease (4.3%). This is supported by other studies conducted in our country like Mannan A et al, Uddin MM et al implies that Hb E/β thalassemia is the most common type thalassemia in our country[16,23]. Worldwide and also in asia-pacific region Hb E/β thalassemia is one of the most frequent thalassemia[24,25]. Unlike Mannan A et al we did not find any thalassemia intermedia or Hb E trait patient that may be due to mild variety in nature and occasional need of blood transfusion of these type for which these were missed as we enrolled only those patients who had history of at least 1 year blood transfusion[16]. Similar to Mannan A et al male predominance was found in every type of thalassemia[16]. These may be due to gender inequality in care seeking behavior of parents for chronic illness that is still prevalent in our society. Similar to other studies we observed that most of the beta thalassemia major patients were diagnosed as thalassemia before 1 years of age but most of Hb E/β thalassemia patients were diagnosed at the age ranged 1 to 5 years[26,27]. This also represent clinical diversity of different type thalassemia and the earlier clinical presentation of beta thalassemia major than Hb E/β thalassemia.

LIMITATIONS

This study was conducted only in thalassemia care center of Chattogram Maa Shishu-O-General Hospital, Chattogram. The sample size was small and study period was only one year.

CONCLUSIONS

This study reveals that the most common pattern of thalassemia are Hb E β thalassaemia followed by β thalassaemia which represents an overall prevalence of thalassemias of the country. Population migration may explain the prevalence of these patterns. Earlier age of onset in majority cases reflects the severe form of thalassemia. Severe forms are widely distributed in both Hb E β thalassaemia and β thalassaemia. It is necessary to study more about the reason of clinical diversity for better management and an accurate population frequency data are needed for the control of thalassemia. We have not studied the correlation of clinical diversity with genetic mutation. There may be further analysis in genetic studies identifying the reasons of phenotypic diversity.

DISCLOSURE

All the authors declared no competing interest.

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