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Clinico Demographic Profile of Beta Thalassemia Major Patients in a Government Tertiary Care Centre

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ABSTRACT

Background and Objectives: Thalassemia is autosomal recessive single gene disorder. About 200 million people globally are affected by thalassemia, with half of these cases having the severe form of the disease that is beta thalassemia major. 1-3 So, this study was taken up to know the clinico demographic profile of beta thalassemia patients in a government tertiary care centre in south india.
Methods: The present cross sectional observational study was carried out from August 2022 to January 2025. Among 100 children aged 6 months to 18 years with confirmed beta thalassemia major patients in the Department of Pediatrics, Gulbarga Institute Of Medical Sciences, Kalaburagi. Details related to socio demographic profile and clinical profile of the patient were taken. Statistical data was analysed by IBM SPSS 25.0 version software and statistical significance for all analyses was set at $P<0.05$.
Results: In the study, 63.0% children were not taking iron chelators and 37.0% children were taking iron chelators. In our study, the mean pre transfusion Hb% level was 6.36 gm/dl, 11.0% children have undergone splenectomy, Thalassemia facies were present in 74.0% children and hepatomegaly was present in 29.0% children.
Interpretation & Conclusion: In our study, the mean pre transfusion Hb% level was 6.36 gm/dl, Thalassemia facies were present in 74.0% children and hepatomegaly was present in 29.0% children. This shows inadequate transfusion received by the study participants.

Keywords*: Iron chelators; Thalassemia major; clinical profile.*

INTRODUCTION

Thalassemia is autosomal recessive single gene disorder. About 200 million people globally are affected by thalassemia, with half of these cases having the severe form of the disease that is beta thalassemia major. [1-3]

Beta thalassemia is a hereditary hemoglobinopathy characterized by the defects in the beta globin chain of haemoglobin. Homozygous and compound heterozygous forms have an imbalance in the production of alpha and non alpha globin chains, which results in ineffective erythropoiesis and decreased production of normal haemoglobin A. [4]

Southeast Asia is a known hotspot for thalassemia. In India, For about 12000 infants born every year have major form of the disease {10% of global burden} and half of these patients die before reaching adulthood. [5]
So, this study was taken up to know the clinico demographic profile of beta thalassemia patients in a government tertiary care centre in south india.

METHODOLOGY:

This cross sectional observational study was conducted from August 2022 to January 2025 among 100 confirmed cases of

beta thalassemia major children attending department of Paediatrics, Gulbarga institute of Medical sciences, Kalaburagi in the age group of 6months to 18years. The study was conducted after obtaining the ethics committee approval from Institutional Ethics committee. Informed consent was obtained from all eligible participants after explaining the objectives and nature of this study in their own language.

A detailed history taking, examination and relevant investigations was done. Details such as age, sex, place of residence (rural or urban), caste, per capita monthly income, socio economic status (classified based on modified B G Prasad classification)[6], pre transfusion haemoglobin level (gm/dl), number of blood transfusion received last year, splenectomy status, history of intake of iron chelators , duration since receiving iron chelators were taken. On examination, we looked for presence/ absence of thalassemia facies. Spleen size and liver size were measured.

Statistical data was analyzed by using statistical package for social sciences (SPSS, version 20.0). If p value is <0.05, it is considered as statistically significant.

RESULTS:

Table 1: Age and gender wise distribution of children

	Males		**Females**		**Total**	
Age in years	**Number**	**Percentage**	**Number**	**Percentage**	**Number**	**Percentage**
0.5—5 years	20	33.9	16	39.0	36	36.0
5.1—18.0 years	39	66.1	25	60.9	64	64.0
Total	59	100.0	41	100.0	100	100.0
Mean ± SD	7.57 ± 4.48		8.05 ± 5.05		7.77 ± 4.68	

Table 1 shows that, 36 (36.0%) children were belonging to the age group of 0.5—5 years, 64(64.0%) children were belonging to the age group of 5.1—18.0 years. Minimum age of children in the study was 1.5 years and maximum age was 17.25 years. The mean age of male children was 7.57 years, and the mean age of female children was 8.05 years. Mean age of all children was 7.77 years. In the study, Male children were 59 (59.0%) and female children were 41 (41.0%).
In the study, 65 (65.0%) children were residing in rural area and 35 (35.0%) children were residing in urban area.

In the present study, 91 (91.0%) children were belonging to Hindu Religion and 9 (9.0%) children were belonging to Muslim. Among Hindu religion, 51 (51.0%) children were belonging to SC/ST (scheduled caste/scheduled tribe), followed by 34 (34.0%) children were belonging to OBC category.

Table 2: Socio-economic status wise distribution of children

Socio economic status Classification	**Number of children**	**Percentage (%)**
Upper Class	0	0.0
Upper Middle Class	4	4.0
Middle Class	23	23.0
Lower Middle Class	61	61.0
Lower Class	12	12.0
Total	100	100.0

Table 2 shows, Socio-economic status wise distribution of children (As per modified B G Prasad classification). Majority of children, 61 (61.0%) were belonging to Lower middle class, followed by 23 (23.0%) children were belonging to middle class, 12 (12.0%) children were belonging to lower class, 4 (4.0%) children were belonging to upper middle class and none of the children were belonging to upper class.

Table 3: Blood transfusion frequency in the previous year

Blood transfusion frequency	**Number of children**	**Percentage**
10—12	40	40.0
13—14	25	25.0
15—16	32	32.0
≥ 17	3	3.0
Total	100	100.0

Out of 100 Beta thalassemia major in children; 40 (40.0%) children had the frequency of blood transfusion 10 to 12 times in the previous year, followed by 32 (32.0%) children had the frequency of blood transfusion 15 to 16 times and 25 (25.0%) children had the frequency of blood transfusion 13 to 14 times in the previous year.

Table 4: Taking iron chelators and duration of chelation therapy.

Taking iron chelators	**Duration of chelation therapy(in years)**	**Number of children**	**Percentage (%)**

No (N=63)	**---**	**63**	**63.0**
Yes (N=37)	**< 5**	**24**	**24.0**
	5—9	**11**	**11.0**
	≥ 10	**2**	**2.0**
Total	**---**	**100**	**100.0**
Mean ± SD	**3.91 ± 2.76**	**----**	**--**

Out of 100 Beta thalassemia major children; 63 (63.0%) children were not taking iron chelators and 37 (37.0%) children were taking iron chelators.

Among the children taking chelation therapy; majority of children that is 24 (64.9%) children were taking chelators since less than 5 years, followed by 11 (29.7%) children were taking chelators since 5 to 9 years. The mean duration of taking iron chelators was 3.91 years.

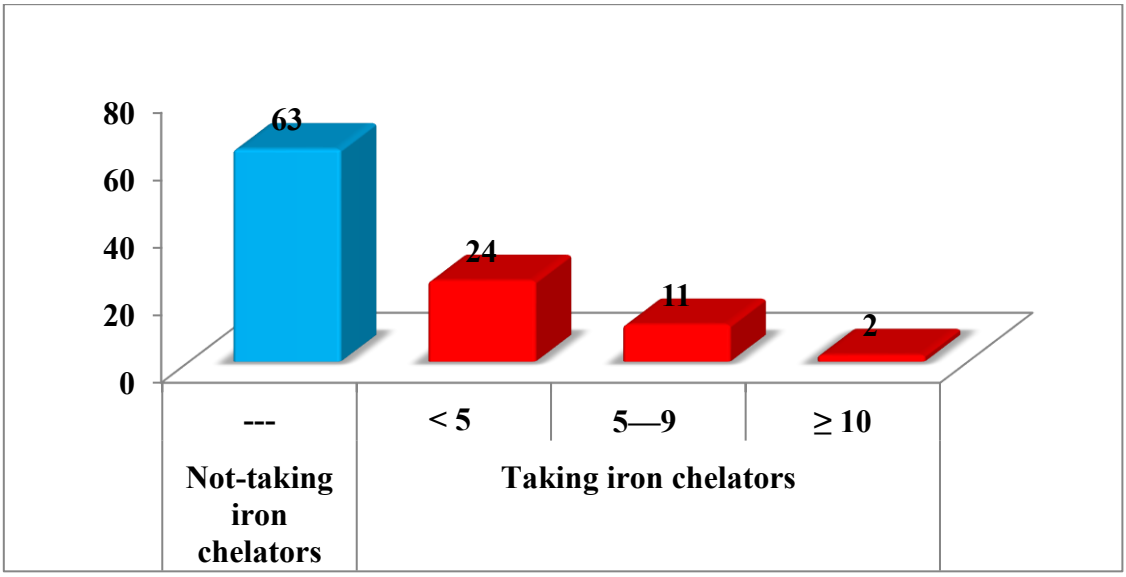

Figure 1: Taking iron chelators and duration of chelation therapy

Table 5: Thalassemia related Characteristics in the study

Characteristics		**Number of children**	**Percentage**	**Mean ± SD**
Pre transfusion Hb% level (in gm/dl)	**< 5**	12	12.0	6.36 ± 1.38
	5—10	88	88.0	
Undergone splenectomy	**Yes**	11	11.0	----
	No	89	89.0	
Thalassemia Facies	**Present**	74	74.0	------
	Absent	26	26.0	
Hepatomegaly	**Present**	29	29.0	---
	Absent	71	71.0	

Table 5 shows, In the study 12 (12.0%) children had pre transfusion Hb% level <5gm/dl and 88 (88.0%) children had pre transfusion Hb% level between 5—10gm/dl. The mean pre transfusion Hb% level was 6.36 gm/dl. In the study, 11 (11.0%) children have undergone splenectomy and Thalassemia facies were present in 74 (74.0%) children. Hepatomegaly was present in 29 (29.0%) children.

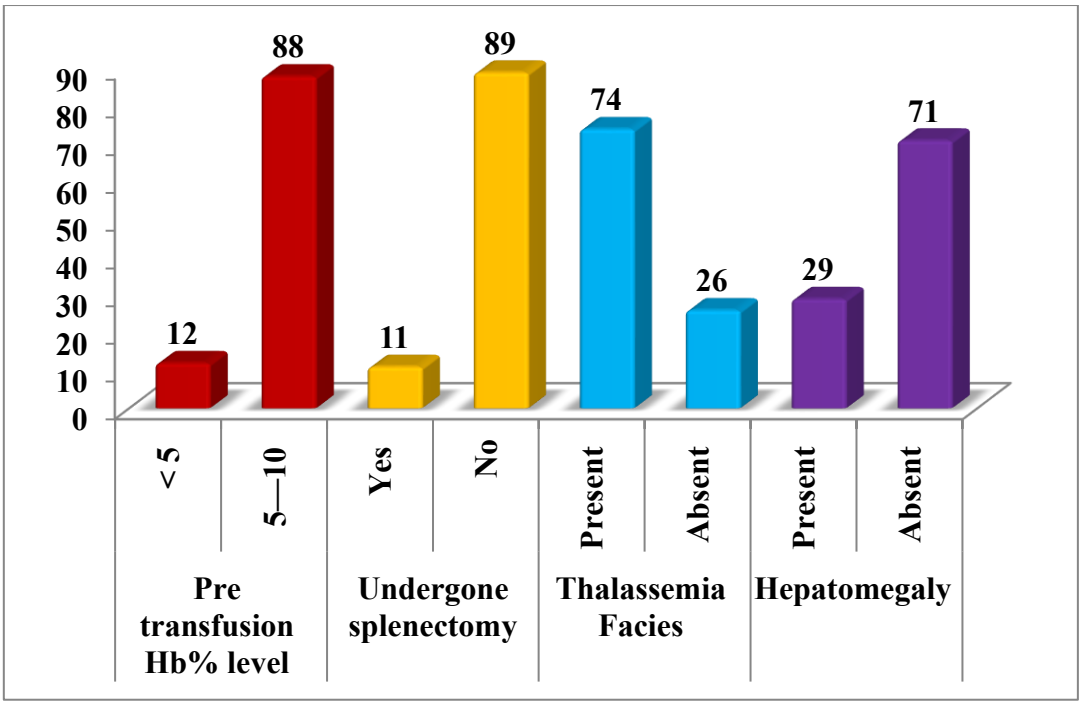

Figure 2: Thalassemia related Characteristics wise distribution of children

DISCUSSION:

Thalassemia is autosomal recessive single gene disorder. About 200 million people globally are affected by thalassemia, with half of these cases having the severe form of the disease that is beta thalassemia major. [1-3]

Southeast Asia is a known hotspot for thalassemia. In India, For about 12000 infants born every year have major form of the disease {10% of global burden} and half of these patients die before reaching adulthood. [5]

So, this study was taken up to know the clinico demographic profile of beta thalassemia patients in a government tertiary care centre in south india.

The sample size in the present study is comparable to the other studies like Mirhosseini et al,[7] Upadhye et al,[8] and Fahim et al.[9] except for study conducted by Bijit Biswas et al,[5] where the sample size was larger compared to our study.

Socio demographic profile of the participants in the study

In our study, about 36.0% children were belonging to the age group of 0.5—5 years and 64.0% children were belonging to the age group of 15.1-18.0 years.

Minimum age of children in the study was 1.5 years and maximum age was 17.25 years.

The mean age of male children was 7.57 years, and the mean age of female children was 8.05 years. Mean age of all children was 7.77 years.

In our study, Male children were 59.0% and female children were 41.0%.

The study conducted by Mirhosseini et al,[7] had participants aged 8-18 years. The mean age in the study was 13.5 years and this study included 56.4 % boys and 43.6 % girls. In a study conducted by Sheikh et al.[10] age range of the patients of thalassemia major was 2 to 16 years with mean age of 7.88 years.

In a study conducted by Bijit Biswas et al,[5] Most of the study participants (37.2%) were aged between 11 and 12 years (range, 5–12 years). The mean age in the study was 8.0 years. There was almost equal representation of both sexes that is 54.0% were males and 46.0% were females.

In our study, 65.0% children were residing in rural area and 35.0% children were residing in urban area and majority (51.0%) of the children were belonging to SC/ST (scheduled caste/scheduled tribe). In a study conducted by Bijit Biswas et al, [5] 51.1% children were residing in rural area and 40.7% children were residing in urban area.

In our study, Majority of children, 61.0% were belonging to Lower middle class, followed by 23.0% children were belonging to middle class. Similar observations were seen in a study conducted by Bijit Biswas et al, [5] where 48.8% were belonging to lower middle class followed by 24.1% were belonging to middle class.

Characteristics of the participants related to thalassemia
In our study, 63.0% children were not taking iron chelators and 37.0% children were taking iron chelators. The mean duration of taking iron chelators was 3.91 years. In the study conducted by Bijit Biswas et al, [5] 93.3% children were on iron chelators. The mean duration of taking iron chelators was 35.6 months.

In our study, the mean pre transfusion Hb% level was 6.36 gm/dl, 11.0% children have undergone splenectomy, Thalassemia facies were present in 74.0% children and hepatomegaly was present in 29.0% children. In the study conducted by Mirhosseini et al, [7] the mean pre transfusion Hb% level was 9.5 gm/dl. Similar observations to our study was seen in the study conducted by Pemde et al,[11] 9.73% children have undergone splenectomy and hepatomegaly was present in 30.57%. Where as in the study conducted by Bijit Biswas et al, [5] mean pre transfusion Hb% level was 5.51 gm/dl, 25.3% children have undergone splenectomy and Thalassemia facies were present in 55.5%.

CONCLUSION:
In our study, about 36.0% children were belonging to the age group of 0.5—5 years and 64.0% children were belonging to the age group of 15.1-18.0 years, Male children were 59.0% and female children were 41.0%. Mean age of all children was 7.77 years. In the study, 63.0% children were not taking iron chelators and only 37.0% children were taking iron chelators, which shows there is need of iron chelators to be made available free of cost to all the thalassemia major patients and also proper advice and counselling should be given regarding the same.

In our study, the mean pre transfusion Hb% level was 6.36 gm/dl, 11.0% children have undergone splenectomy, Thalassemia facies were present in 74.0% children and hepatomegaly was present in 29.0% children. This shows inadequate transfusion received by the study participants, so in order to overcome this there is a need for parental counselling regarding the practice of adequate transfusion. In order to take care of these children there should be a separate thalassemia day care units with a dedicated social worker or counseller, There is a need for periodic counselling and monitering of this children to prevent any associated complications as well as to address any challenges facing by them and also to educate them about the government schemes and facilities available for them so that they can easily utilize them.

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