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SOCIODEMOGRAPHIC STATUS OF THE BANGLADESHI PARENTS AMONG THALASSEMIC CHILDREN

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ABSTRACT

Objective: In this study our main goal is to evaluate the sociodemographic status among the parents of thalassemic children. **Method:** This was a Hospital based cross sectional observational study which was conducted at Department of Pediatrics, Saheed Ziaur Rahman Medical College Hospital, Bogura, Bangladesh from November 2010 to July 2011, where total 50 parents of thalassemia children were selected by simple randomization. **Results:** During the study, most of the patients were boys, 72% and 28% were girls. 36% parents were illiterate, 56% parents were literate, 8% parents were educated and no parents were highly educated. Parent's perception about carrier state was inadequate. Only 08% of the parents had idea about consanguineous spread of thalassemia. **Conclusion:** The management of thalassaemia in a developing country like Bangladesh poses a major challenge to the health services. Because of the economic conditions, many thalassemia patients are unable to take the two-tier treatment, namely blood transfusion and iron chelation. Lack of facilities and coordination to this multi-disciplinary problem make the treatment difficult in a variety of ways.

KEYWORDS: Sociodemographic status, thalassaemia, blood transfusion and iron chelation.

INTRODUCTION

Thalassaemia is a wide spread and heterogeneous group of inherited disorder characterized by the reduction or absence of globin chains. There is defect in the synthesis of globin chains. In the ancient time it was known as Mediterranean Anemia as it was particularly prevalent among Mediterranean peoples and this geographical association was responsible for its naming.[1-2]

The thalassemias are classified according to which chain of the hemoglobin molecule is affected. In α thalassemias, production of the α globin chain is affected, while in β thalassemia production of the β globin chain is affected. The α thalassemias involve the genes HBA1 and HBA2 inherited in a Mendelian recessive fashion.[3] Globally, because of their high frequency and severity, the β thalassemias pose the most important public health problem. In addition to the transfusion-dependent form of β thalassemia major, there are milder conditions with a widely varying phenotype, the β thalassemia intermedias.[4] The latter vary in severity from being almost as severe as β thalassemia major to disorders characterized by relatively mild anaemia associated with normal growth and development without treatment. By far, the commonest form of β thalassemia intermedia is Hb E β thalassemia, which results from the co-inheritance of a β thalassemia allele from one parent and a structural haemoglobin variant, Hb E, from the other parent. Hb E, which occurs at an extremely high frequency in the eastern side of the Indian subcontinent, through Myanmar, to many countries in Southeast Asia. Results from a G→A substitution in β codon 26 which, in addition to producing abnormal haemoglobin, also activates a cryptic splice site which causes abnormal messenger RNA processing. The result is that Hb E is synthesized at a reduced rate, and therefore, behaves like a mild β thalassemia allele.[1]

In this study our main goal is to evaluate the sociodemographic status among the Bangladeshi parents of thalassemic children.

Objective

General objective

- To assess the sociodemographic status among the Bangladeshi parents of thalassemic children.

Specific objective

- To identify educational status of the parents.
- To detect role of consanguinity in disease process.

METHODOLOGY

Types of the study

- This was a Hospital based cross sectional observational study having both descriptive and analytic components.

Place and period of the Study

- This study was conducted at Department of Pediatrics, SaheedZiaur Rahman Medical College Hospital, Bogura from November 2010 to July 2011 where total 50 parents of thalassemia children were selected by simple randomization.

Inclusion Criteria

- Parents of those children who were previously diagnosed as THALASSEMIA and confirmed by Hb- Electrophoresis, done outside as the investigation facility was not available at the study place. One parent could be conducted only once.

Data Processing and Analysis

- The collected answer of the questions was analyzed and expressed in percentage of participant parents giving answers of the questions. The data and results were presented in the form of tables and diagram where applicable.

RESULTS

In table-1 shows socio demographic characteristics of the patients where total 50 parents, 16 were father and 34 were mother, their children were 36 boys and 14 girls. The following table is given below in detail:

Table-1: Socio demographic characteristics.

Characteristics	No. (50)	%
Source of information: Parents		
➢ **Father**	16	32%
➢ **Mother**	34	68%
Consanguinity		
➢ **Consanguineous**	12	24%
➢ **Non consanguineous**	38	76%
Economical status		
➢ **Insufficient**	08	16%
➢ **Slightly sufficient**	36	72%
➢ **Sufficient**	06	12%
➢ **Sufficient and save**	00	00%

In figure-1 shows thalassemic children of the parents where most of the patients were boys, 72% and 28% were girls. The following figure is given below in detail:

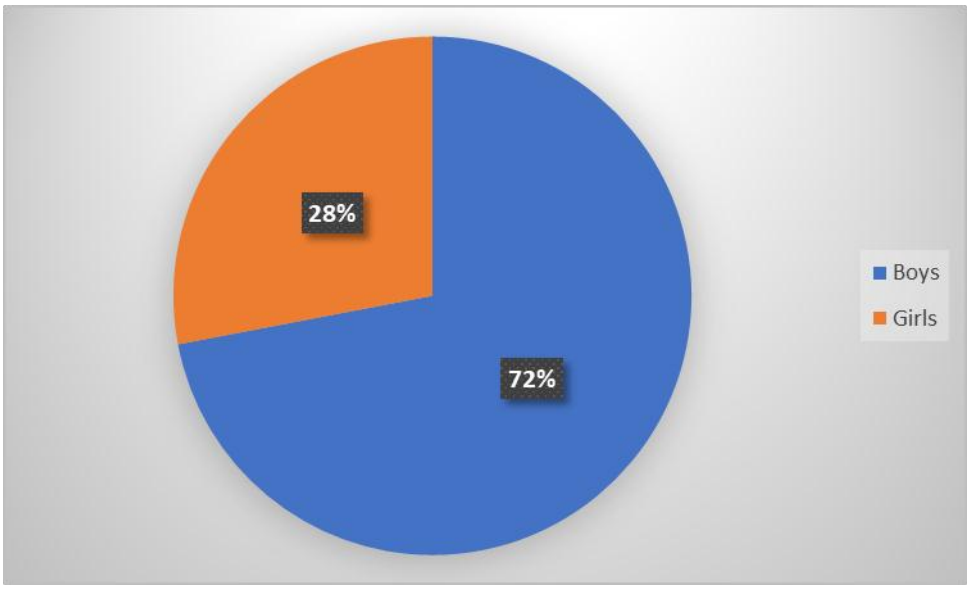

Figure-1: Thalassemic children of the parents.

In figure-2 shows educational status of the parents where 36% parents were illiterate, 56% parents were literate, 8% parents were educated and no parents were highly educated. The following figure is given below in detail:

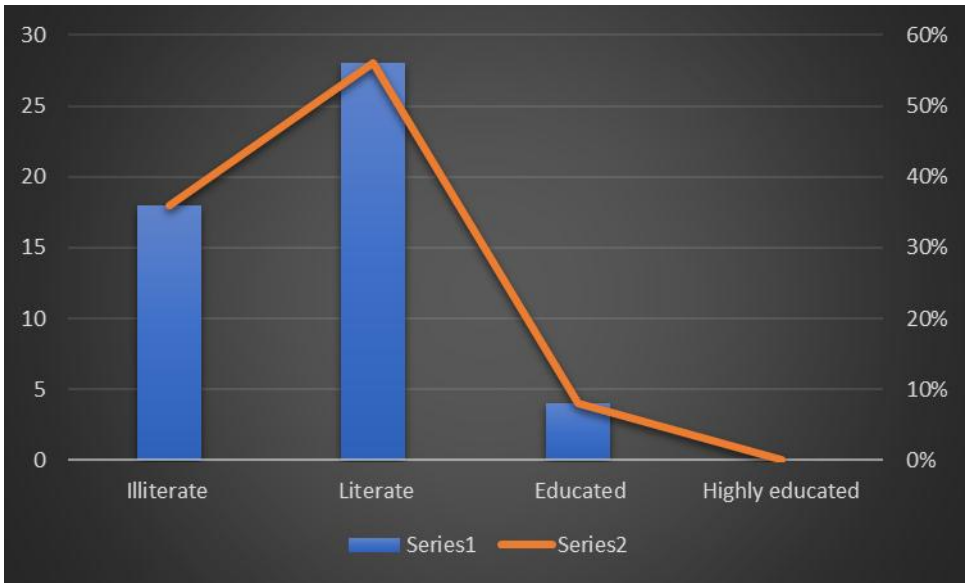

Figure-2: Educational status of the parents.

In figure-3 shows area of living Distribution. Most of the parents were from Bogra 68%, most of the sufferer children were boys 72%, economic status was mostly slightly sufficient 72%, about 36% parents were illiterate and most of the parents were non consanguineous 76%. The following figure is given below in detail:

just check, above description goes with figure??

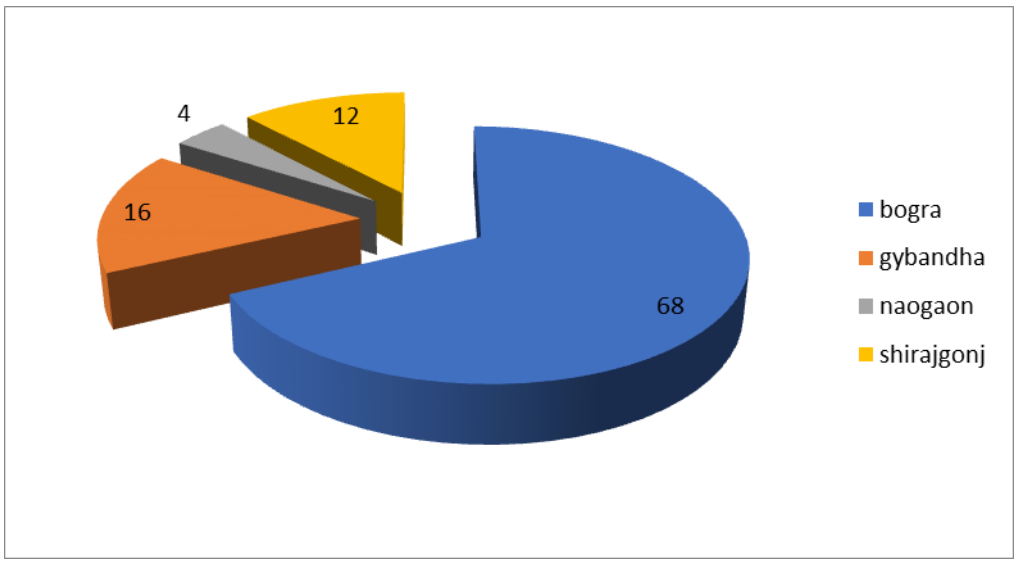

Fig 3: Area of living Distribution.

In table-2 shows role of consanguinity in disease process where parent's perception about carrier state was inadequate. Only 08% of the parents had idea about consanguineous spread of thalassemia. The following table is given below in detail:

Table-2: Role of consanguinity in disease process.

Role of consanguinity in disease process	%
Have idea	8%
No idea	92%

Table-3: Presence of consanguinity in different types of Thalassemia.

Consanguinity	No of parents	Affected beta thalassemia major children		Affected Hb E beta thalassemia major children	
		No	%	No	%
Consanguineous parents	12	04	33.3%	08	66.6%
Non-Consanguineous parents	38	10	26.3%	28	73.69%

In table-3 shows presence of consanguinity in different types of Thalassemia.

Here it was clear that incidence of Hb E Beta thalassemia more prevalent 66.6% and 73.69% in both parents group than thalassemia major.

Table-4: Relation between parental education level and Chillating therapy.

Education level of the parents	No of parents	No of the children getting Chelating therapy among different Education level	% of children getting Chillating therapy
Illiterate	18	00	00%
Literate	28	02	7.14%
Educated	04	04	100%
Highly educated	00	00	00%

Table 4 showed that chillating therapy was highly prevalent among educated parents 100%, 7.14% among literate parents and lowest among illiterate parents 00%. So, children of the educated parents were getting better treatment than the children of illiterate parents.

DISCUSSION

In this study education level of the majority of the parents were low, 36% were illiterate, 56% were only literate and 08% were educated who had academic certificate above HSC level. In contrast a study in Malaysia found that 53.3% and 39.3% participant's educational level were up to Secondary school level and University level respectively.[9] But the studies from India and Pakistan had more similarity with the present study. The study from Pakistan had shown that 66.7% of the parents were illiterate and only 2.5% were with higher education.[6] Economical statuses of the parents were bad. 72% of them had slightly sufficient monthly income, which indicate that they had no extra money to maintain the treatment cost of their thalassemic children. The present study showed most of the children of the parents attending the study were boys 72%. A journal published from Pakistan had showed that out of total 221 responders 135 (61%) were boys.[5] Another study in India also showed that proportion of male patients was higher in different institutions 72% and 68% respectively.[6] Both the findings were similar with the present study. This can be explained by the similar socio-cultural setup and gender bias that prevails in South Asian regions where parents are possibly more inclined to seek medical treatment and to spend more on their male children. The economic status of the parents of thalassemic children found in the present study revealed most of them were off slightly sufficient income family ranging Tk 3000- 7000 per month. Another study in Pakistan showed similar findings had an income < Rs 5000 / month.[7]

92% of the parents had no Idea about the consanguinity which has role in the spread of the disease and 84% of the parents had no idea about the genetic basis of the disease. A study in Malaysia showed that idea about the genetic nature of the disease and its pattern of inheritance were poor also 87.5% parents had no idea about the genetic basis of the disease.[8]

General knowledge about the disease was good among only 16% of the parents, idea regarding prevention of thalassemia was very poor, 100% of the parents had no idea about that. A study from Malaysia also revealed similar result.[9] Most of the children, 92% received blood supplied from Blood Bank reported in this study but only 08% parents had knowledge about screening of the blood to be transfused and 88% of the parents had no idea about the adverse effect of repeated transfusion. Correct knowledge about the food and drug to avoid among the parents were 44% and 36% respectively, 88% of the children were not receiving chelating therapy. Another Study in Pakistan showed that 89.2% of the parents had no idea about the screening of blood before transfusion and only 10.9% children were receiving chelating therapy.[10]

CONCLUSION

The management of thalassaemia in a developing country like Bangladesh poses a major challenge to the health services. Because of the economic conditions, many thalassemia patients are unable to take the two-tier treatment, namely blood transfusion and iron chelation. Lack of facilities and coordination to this multi-disciplinary problem make the treatment difficult in a variety of ways.

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