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Original Article

Knowledge and Awareness of Parents Toward Thalassemia

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Abstract

Background: *Thalassemias are the most common heritable blood disorders that represents a major public concern. Poor awareness and lack of knowledge lead to increase number of carrier that is a silent reservoir of the disease. To observe the knowledge and awareness level of parents of thalassemic children about the disease.*

Materials and methods: *This descriptive cross-sectional study was conducted in the Thalassemia ward 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 knowledge status and awareness level of parents towards thalassemia. Data were analyzed by both manually and by SPSS-18.*

Results: *Majority of patients were from rural background (54.3%). Only 8.6% parents were consanguineous parents and majority of them completed only secondary education. 44.3% resolved it as inherited disorder. 52.9% resolved thalassemia cannot be cured. Only 24.3% regarded bone marrow transplantation as a measure of cure. More than half (55.7%) did not know how to prevent thalassemia. Only 37.1% knew about prenatal diagnosis. Carrier status of both father and mother were unknown in majority of patients (80%) and screening of sibs was not done at all in a significant number of patients (51.5%). Only 34.3% wanted to do prenatal diagnosis after conception and 65.7% parents were ready to accept therapeutic abortion if fetus would be diagnosed as thalassemia by prenatal diagnosis.*

Conclusion: *Knowledge level and awareness of parents of thalassemic child regarding the disease is unsatisfactory. To reduce disease burden an awareness program regarding the disease and its prevention covering premarital screening, acceptance of prenatal diagnosis and therapeutic abortion is essential.*

Key words: Thalassemia; Knowledge level; Awareness level.

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INTRODUCTION

Thalassemia is the most common hemoglobin disorder in the world. It has emerge as a huge public health problem worldwide[1]. 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[2,3]. Thalassemia is becoming a burden for our country. A conservative WHO report estimates that 3% of total population is carrier of β-thalassemia and 4% are carriers of Hb E disease in Bangladesh and more than two thousand thalassemic children are born every year[4,5].

The most effective approach to reduce the burden to society and the disease incidence is implementation of carrier screening program, genetic counseling, prenatal

diagnosis and selective termination of affected foetus[6]. Poor awareness, lack of information about inheritance pattern has led to an increased number of patients[7]. Some socio-cultural barrier for screening and superstition regarding inheritance also plays a great role. Still, premarital testing is not accepted in some countries for various legal and cultural factors[8]. Knowledge of parents regarding thalassemia is crucial for understanding of the disease and thereby to prevent the disease. Inadequate knowledge about thalassemia results in continue sufferings of patients in a slow and painful course ultimately leading to death[9]. The only way to prevent the disease and reduce the morbidity and mortality is by educating the general population[10]. Fortunately, awareness level is improved significantly worldwide[11,12]. Effectiveness of a prevention program can result in significant reduction of birth rate of thalassemia[13]. There have been no large epidemiological studies to provide a true picture of screening practice and awareness of parents towards future pregnancy.

Studies on knowledge and awareness regarding thalassaemia are relatively scarce in Bangladesh. This study was conducted to assess the knowlege and awareness level of parents of thalassemia patients by which we can provide valuable message to national planning and health policy and also to non-governmental organization to take necessary steps with more emphasis on improvement of public awareness and thereby prevention of the disease

MATERIALS AND METHODS

It was a descriptive cross-sectional study conducted at the Thalassemia ward of Chattogram Maa Shishu-O-General Hospital, Chattogram from July 2013 to June 2014. Parents of 70 thalassaemia patients aged 2-18 years attending Thalassaemia Care Centre of Chattogram Maa Shishu-O-General Hospital, Chattogram were included in this study. After approval from 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 asking about inheritance pattern, preventive measure, prenatal diagnosis, screening of family member, acceptance of therapeutic abortion etc. Data were recorded and analyzed manually with the help of calculator and software SPSS 18.0.

RESULTS

Majority of patients (54.3%) were from rural background. Only 8.6% parents were non-consanguine. Most of the parents (fathers =51.5%, mothers =48.6%) were up to secondary level education. 10% fathers and 20% mothers did not go to school ever. Only 21.4% fathers10% mothers were graduate and above (Table I).

Table I : Parent's demographics (n = 70).

Variables	Frequency	Percentage (%)
Locality		
Rural	38	54.3
Urban	32	45.7
Consanguineous parents		
Yes	6	8.6
No	64	91.4
Parent's education (Father)		
Nil	7	10.0
Primary	2	2.8
Secondary	36	51.5
Higher Secondary / College	10	14.3
Graduate & Above	15	21.4
Parent's education (Mother)		
Nil	14	20.0
Primary	8	11.4
Secondary	34	48.6
Higher Secondary / College	7	10.0
Graduate & Above	7	10.0

Only 44.3% resolved thalassemia as inherited disorder and 21.4% did not have any knowledge though they have thalassemic child. 52.9% considered that thalassemia cannot be cured and 24.3% regarded bone marrow transplantation as a measure of cure. Only 44.3% have knowledge that thalassemia can be prevented and more than half parents (55.7%) did not know how to prevent thalassemia. Only 37.1% knew about prenatal diagnosis. (Table II) So knowledge of parents regarding thalassemia disease was quite low though they had a thalassemic child.

Table II : Knowledge of parent's regarding thalassemia (n = 70).

Knowledge	Number	Percentage (%)
Thalassemia is a:		
Inherited Disease	31	44.3
Blood Disease	24	34.3
Does Not Know	15	21.4
It can be cured:		
Yes	19	27.1
No	37	52.9
Does Not Know	14	20.0
How can it be cured:		
By bone marrow transplantation	17	24.3
By blood transfusion	2	2.8
Does Not Know	51	72.9
It can be prevented:		
Yes	31	44.3
No	15	21.4
Does Not Know	24	34.3
How can it be prevented:		
Avoidance of marriage of carriers	30	42.9
By blood transfusion	1	1.4
Does Not Know	39	55.7
Know about prenatal diagnosis:		
Yes	26	37.1
No	44	62.9

In 80% cases, carrier status of both father and mother were unknown. In more than half families (51.5%) screening of siblings was not done at all. About 34.3% parents wanted to do prenatal diagnosis in future pregnancy and 65.7% parents were ready to accept therapeutic abortion if fetus would be diagnosed as thalassemia by prenatal diagnosis. Cent percent parents showed good awareness by making their child vaccinated against Hepatitis B viruses who were not vaccinated against Hepatitis B infection under EPI schedule. (Table III) But considering all the parameter we can say awareness of parents of thalassemic child was not satisfactory.

Table III : Awareness of parent's regarding thalassemia (n = 70).

Awareness	Number	Percentage (%)
Screening of parents:		
Both not done	56	80.0
Both done	11	15.7
Father carrier, Mother not done	0	0.0
Mother carrier, Father not done	3	4.3
Screening of sibling:		
Not done	36	51.5
All done	15	21.4
One sib done, other not done	4	5.7
No sib	15	21.4
Hepatitis B vaccine coverage of patients:		
Yes	70	100.0
No	0	0.0
Plan for next baby:		
Don't want to conceive	31	44.3
Want to do prenatal diagnosis	24	34.3
Not decided	15	21.4
Will accept therapeutic abortion if confirmed about affected fetus by prenatal diagnosis:		
Yes	46	65.7
No	16	22.9
Not decided	8	11.4

DISCUSSION

Similar to Mallik S et al majority of our patients were from rural background (54.3%) implies that rural health care center in our country are not yet developed up to that level for blood transfusion, cross matching etc so that patients had to come to the city that is sometimes at a long distance from rural area[14]. Facilities for safe blood transfusion, cross matching should be available at the nearest health care center and decentralization of blood screening facility should be organized.

8.6% of our parents were consanguineous parents, the rest others were unknown to each other before marriage whereas in Pakistan 56.9% patient's parents were first cousin, 19.4% parents were also relative and only 23.7% were unknown to each other[15]. The consanguinity rate were also higher (50.9%) in Iran[16]. Our findings indicate that though consanguineous parents is a risk group for thalassemia, a large number of parents being non-consanguineous is prevailing in our society as a silent carrier indicating importance of screening of all couple should be mandatory irrespective of consanguineous or not.

Educational status of majority of our parents (Father=51.5%, mother=48.6%) were up to secondary level, similar results also reported in Kolkata, Pakistan[14,17,18]. 10% fathers and 20% mothers of our study did not go to school ever in their life whereas 66.7% and 78.1% parents were illiterate in different places of Pakistan[9,15]. In contrast only 3.5% parents were illiterate in Iran[19]. Only 21.4% fathers and 10% mothers were graduate or above in our study. Educational level of parents were found better in Foisalabad and Mumbai[18,20].

Regarding knowledge level of parents about thalassemia, we highlighted the conception about inheritance pattern of thalassemia, knowledge about cure and prevention. 44.3% parents of our study considered thalassemia as inherited disease whereas 15% parents in Pakistan and 68.9% in Kolkata considered thalassemia as an inherited disorder[9,14]. 27.1% of our parents told that it can be cured and only 24.3% mentioned bone marrow transplantation as a measure of cure indicating poor knowledge level. In contrast, only 14.7% had good knowledge about thalassemia in Iran[16]. It is obvious that more patients aware of prevention (44.3%) than those aware of cure (27.1%) which is good for social awareness for prevention though the percentage is quite lower than that of Kolkata where 60.7% knew how to prevent thalassemia[14]. About 37.1% our parents knew about prenatal diagnosis of thalassemia whereas in Pakistan 31.1% parents were familiar to prenatal diagnosis that is similar to our finding[15].

Regarding assessment of awareness level of parents towards thalassemia, we found only in 15.7%% cases, father and mother both were screened for thalassemia and in 80%, none was screened for thalassemia. But in Kolkata 72% patients had both parents diagnosed as carrier and only in 17.5% cases carrier status of both parents was not known[14]. This reflects that awareness level of our parents in regards to prevention of disease is still quite low in our country. Screening of all other sibs was done in only 21.4% cases and in 51.5%, it was not done at all reflecting that screening practice is also not satisfactory. But in a study of Arif F et al only 5.8% parents had the sibling screened[9]. It may be related to educational status, religious beliefs and financial condition of parents. In contrast to that study where only 12.5% were immunized against Hepatitis B, all the patients of our study were vaccinated against Hepatitis B virus suggesting good awareness of parents regarding transfusion transmitted infection[9]. About 44.3% of our parents did not want to conceive in future and want to adopt some form of family planning method whereas in Kolkata, Mumbai it is about 51.8% and 73% respectively[14,20]. In Pakistan 70.9% parents were against family planning method due to religious matter and other constrained[15]. This is a message of hope that despite social and religious superstition prevailing in our society, a good percentage of our parents (34.3%) were aware of disease

burden and wanted to do prenatal diagnosis for future pregnancy and 65.7% would accept therapeutic abortion if fetus is prenatally diagnosed as thalassemia whereas in Pakistan and in Canada 18.1% and 31% parents respectively accepted it for affected fetus in future pregnancy[15,21]. Besides screening for carrier detection of parents and siblings, prevention plan for next baby depends on awareness which is contributed by educational status of parents.

LIMITATIONS

- This was a cross-sectional study where only 70 patients were included
- Limited period of study for one year only
- Data were collected only from one hospital.

CONCLUSION

We observed that knowledge of the parents regarding thalassemia is still poor and awareness level of parents regarding screening for carrier identification, prevention of thalassemia is also not satisfactory. An educational intervention program may be effective to provide families with full medical information to help them have healthy children and to reduce social burden to ensure a social, economic and less painful life to them. The most effective approach to reduce the burden to society is implementation of a carrier screening program. Health policy makers should undertake awareness program and antenatal screening program and pre-marital screening towards prevention of thalassemia should be made mandatory before wedding and that should be enforced by law. We did not correlate our findings with the educational status and social background of parents. There are several areas regarding this that could impact on future research and practice.

DISCLOSURE

All the authors declared no competing interest.

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