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A STUDY ON ATTITUDE AMONG PARENTS WITH BETA THALASSEMIA MAJOR CHILDREN IN GOVERNMENT DISTRICT HOSPITAL KALABURAGI

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ABSTRACT

Background: Thalassemia is a public health problem worldwide. With the high disease burden of thalassemia, low socioeconomic conditions and poor preventive strategies, our patients are left with no other option except the repeated blood transfusion. So prevention is the only tool to reduce the burden of this disease. This study was done to identify the gap in attitude about β-thalassemia among the parents of beta thalassemia children. So that it will be helpful to reduce the burden of the disease in the society in the near future.
Objectives: To assess the attitude among parents with beta thalassemia major children regarding beta thalassemia major disease.
Materials and Methods: A semi structured pre-validated questionnaire designed to assess the attitude in relation to beta thalassemia major disease was administered to all the parents fulfilling the inclusion criteria. Collected data was analysed.
Results: In this study, about 34(52.3%) felt that Premarital screening is necessary for general public. About 60(92.3%) felt that termination of pregnancy due to Thalassemia. Major in fetus should be done. About 36(55.4%) of them said that taking Hep B Vaccination is good to their child.
Conclusion: It was seen from our study that parents don't have positive attitude towards thalassemia major. Health education and periodic counselling of parents and care takers about prevention of thalassemia needs to be implemented at every thalassemia day care centre.

Keywords: *Thalassemia Major, Attitude, Parents.*

INTRODUCTION

Beta thalassemia is one of the most common single-gene inherited disorders worldwide and represents a significant global public health challenge. It is an inherited hemoglobin disorder characterized by reduced or absent synthesis of the beta-globin chains of hemoglobin, leading to chronic hemolytic anemia of varying severity. The most severe form, beta thalassemia major, is characterized by the inability of the body to produce adequate functional hemoglobin, resulting in severe anemia that requires lifelong medical management.[1,2]

Globally, approximately 70,000 infants are born with beta thalassemia each year, while an estimated 270 million individuals are carriers of hemoglobinopathies. The disease is highly prevalent in the Mediterranean region, the Middle East, South and Southeast Asia, and parts of Africa, with carrier frequencies ranging from 2% to 25% in different populations.[1,3,4] Owing to its high prevalence and lifelong treatment requirements, thalassemia continues to pose a major public health burden, particularly in low- and middle-income countries.

Children with beta thalassemia major depend on regular blood transfusions for survival. However, repeated transfusions are associated with several complications, including iron overload, transfusion-transmitted infections such as hepatitis B and hepatitis C, and various immunological reactions.[5] These complications adversely affect the physical, psychological,

educational, and social well-being of affected children, significantly reducing their quality of life. Furthermore, the continuous need for medical care imposes a substantial emotional and financial burden on families.[6]

At present, hematopoietic stem cell transplantation (bone marrow transplantation) is the only established curative treatment for beta thalassemia major. However, this treatment is available only at a limited number of specialized centers in India and is often inaccessible because of its high cost and the requirement for a compatible donor. Consequently, prevention remains the most effective strategy for reducing the burden of thalassemia. Preventive measures include increasing public awareness, providing genetic counseling, carrier screening among high-risk families, antenatal screening, and premarital screening of prospective couples to prevent the birth of affected children.[7]

Recognizing the growing burden of hemoglobinopathies, the Ministry of Health and Family Welfare, Government of India, introduced the Policy for Prevention and Control of Hemoglobinopathies—Thalassemia, Sickle Cell Disease, and Variant Hemoglobins (2018). The policy aims to ensure equitable access to affordable and quality healthcare services for individuals affected by thalassemia, HbE disease, and sickle cell disease while reducing the prevalence of these disorders through comprehensive awareness campaigns, population screening, early diagnosis, genetic counseling, and preventive interventions.[8]

Despite advances in diagnosis and treatment, awareness and knowledge regarding beta thalassemia among parents and the general population remain inadequate in many parts of India. Since parents play a crucial role in treatment adherence, genetic counseling, and preventive decision-making, assessing their knowledge is essential for planning effective educational and preventive programs.

The purpose of this study is to assess the awareness about thalassemia major disease among parents with thalassemia children and to identify the gap in attitude about β-thalassemia among the parents of beta thalassemia children. So that it will be helpful to reduce the burden of the disease in the society in the near future.

MATERIALS AND METHODS:

This cross sectional descriptive study was conducted over a period of 3 months (from July 2023 to September 2023) among 65 parents of beta thalassemia major children attending department of Pediatrics, Gulbarga institute of Medical sciences, Kalaburagi .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 semi structured pre-validated questionnaire designed to assess the Attitudes in relation to beta thalassemia major disease was administered to all the parents fulfilling the inclusion criteria. The data collected through this questionnaire includes: socio demographic details of parents and children and various information to assess the attitude of parents with respect to thalassemia major disease.

Statistical data was analyzed by using statistical package for social sciences (SPSS, version 25.0). If p value is <0.05, it is considered as statistically significant.

RESULTS:

Table 1: Socio Demographic profile of study participants

Variables	Categories	No. of participants	Percentage
Age of participant	**20—30 years**	27	41.5
	31—40 years	31	47.7
	41—50 years	7	10.8
	Mean ± SD	33.84 ± 7.54	----
Gender of participant	**Male**	36	55.4
	Female	29	44.6
Area of residence	**Urban area**	20	30.8
	Rural area	45	69.2
Religion/ caste	**Muslims**	6	9.2
	General	6	9.2
	OBC	18	27.7
	SC/ST	35	53.9
Socio-economic status (B G Prasad classification) [9]	**Upper Class**	0	0.0
	Upper Middle Class	0	0
	Middle Class	3	4.5
	Lower Middle Class	24	37.0

	Lower Class	38	58.5
Educational status of participant	**Illiterate**	22	33.8
	Primary	13	20.0
	Secondary and degree	30	46.2
Occupation of participant	**House wife**	23	35.4
	Daily wage worker	38	58.4
	Employed	4	6.1

In the study, the mean age of participants was 33.84 years. Majority of participants 31 (47.7%) were belonging to the age group of 31 to 40 years, The male (father) participants were 36 (55.4%) and female (mother) participants were 29 (44.6%). Majority of participants 45 (69.2%) residential area was rural.

Majority of participants 38 (58.5%) were belonging to the socio-economic status of lower class, followed by 24 (37.0%) were belonging to lower middle class and 3 (4.5%) of the participants were belonging to middle class, no participants were seen in upper middle class and upper class.

Out of 65 participants; 22 (33.8%) participants were illiterate, 13 (20.0%) had primary education and 30 (46.2%) had secondary and degree education. Majority of participants 38 (58.4%) were daily wage workers.

Table 2: Attitude of participants regarding Thalassemia major

SL No	Survey questions related to attitude	Decision	No.	%
1	Do you think that two thalassemia carrier's should marry?	Yes	0	0.0
		No	65	100.0
2	Do you feel that carrier couple should have biological children?	Yes	0	0.0
		No	65	100.0
3	Do you believe that Premarital screening is necessary for general public?	Yes	34	52.3
		No	31	47.7
4	Do you believe that taking Hepatitis B Vaccination is good to your child?	Yes	36	55.4
		No	13	20.0
		Don't know	16	24.6
5	Do you agree that medical termination of pregnancy should be considered if the fetus is diagnosed with beta thalassemia major?	Yes	60	92.3
		No	5	7.7

Table 2 shows Attitude of participants regarding thalassemia, All of them said that two thalassemia carrier's should not marry and all of them were of the opinion that carrier couple should not have children. About 34(52.3%) felt that Premarital screening is necessary for general public. About 60(92.3%) felt that termination of pregnancy due to Thalassemia. Major in fetus should be done. About 36(55.4%) of them said that taking Hep B Vaccination is good to their child.

DISCUSSION:

Thalassemia is a hereditary hemoglobin disorder and a lifelong chronic disease that poses a significant public health burden. Therefore, prevention remains the most effective strategy to reduce its incidence and socioeconomic impact. Healthcare professionals, including physicians, genetic counselors, nurses, and social workers, play a pivotal role in creating awareness, providing genetic counseling, and promoting preventive strategies among at-risk individuals and families. Government tertiary care hospitals frequently manage a large number of patients with thalassemia major, making comprehensive counseling and continuous motivation of parents essential components of patient care. In addition to managing recurrent infections and chronic complications, healthcare providers should focus on educating families about disease prevention, treatment adherence, and psychosocial support. Government initiatives to strengthen counseling services and expand access to trained genetic counselors are essential for improving the quality of care and reducing the burden of hemoglobinopathies.[10]

In the present study, the majority of participants, 31 (47.7%), belonged to the age group of 31–40 years. Among the participants, 36 (55.4%) were fathers and 29 (44.6%) were mothers. Most participants, 45 (69.2%), were from rural areas. A slight male predominance was observed among children with thalassemia major, with 41 (63.1%) males and 24 (36.9%) females. Similar findings of male predominance have been reported by Goyal JP et al. and Saxena A et al.[11,12] In contrast, Arif F et al., in a study conducted in Pakistan, reported a slight female predominance among children with thalassemia.[13]

The attitude of participants toward thalassemia prevention was generally favorable. All participants believed that two thalassemia carriers should not marry and expressed the opinion that carrier couples should avoid having children without appropriate genetic counseling. More than half of the participants (52.3%) considered premarital screening necessary for the general population. Furthermore, 92.3% supported medical termination of pregnancy when the fetus

was diagnosed with beta thalassemia major. These findings are comparable with those reported by Basu M, in which 99.06% of participants considered premarital carrier screening essential, while 81.31% believed that termination of an affected pregnancy was preferable to allowing the child to suffer from the disease after birth.[14]

From our study, it was found that, attitude of the parents regarding the cause, course, complications, management and prevention of Thalassemia is not adequate. This emphasizes the need for such a social worker/counsellor to be associated with every Thalassemia day care center so that it helps in creating awareness regarding this disease in the parents.

In our study, there is a lack of positive attitude towards prevention of this disease in their subsequent child or in their near and dear ones. The major reason for this could be the lack of availability of prenatal diagnostic tests and genetic counseling in the local hospitals. This suggests that government sponsorship is needed to make prenatal diagnostic tests and genetic counseling available in the government set up so as to prevent the birth of thalassemic children and thereby decreasing the disease burden in the families as well as in our country.

CONCLUSION:

It was seen from our study that parents don't have positive attitude related to thalassemia major disease prevention and treatment; Health education and periodic counseling of parents and care takers about prevention of thalassemia needs to be implemented at every thalassemia day care centre. Dedicated social worker/counsellor should be associated with every thalassemia day care centre to counsell the parents and care takers of thalassemia major. And it is better to have a child psychologist in the thalassemia day care centre to take care of mental health of thalassemia major children.

The chronicity and complications of Thalassemia will affect the quality of life of the patients and their families. Majority of the families either cannot find a matched donor or cannot afford bone marrow transplantation, so they will depend on blood transfusions as the primary management, which creates a burden on the health system and also on the affected families. So prevention of this disease with adequate practice of prenatal diagnosis and premarital screening is necessary, which needs government sponsorship to make these prenatal diagnostic tests available in government set up so that disease burden in the families as well as in the country can be reduced.

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