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A Cross-Sectional Study on Practice 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 practices 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 practices 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 Practices 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 18(27.6%) got both mother and father screened for thalassemia. About 12(18.5%) of them are practising chorionic villous sampling test. Only 39(60.0%) of them got other siblings of the thalassemia children screened for thalassemia. Only 5(7.6%) children took hep B Vaccination in the past five years.
Conclusion: It was seen from our study that parents don't have positive practice on 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, Parents, Practices.*

INTRODUCTION

Beta thalassemia is one of the most common single-gene inherited disorders worldwide and represents a major public health challenge, particularly in developing countries.[1] Thalassemia major is a severe hereditary blood disorder characterized by the reduced or absent synthesis of the β-globin chains of hemoglobin, resulting in severe anemia that requires lifelong medical management.[2]

Globally, approximately 70,000 infants are born each year with beta thalassemia, while nearly 270 million individuals are carriers of hemoglobinopathies.[3] The disease is highly prevalent in the Mediterranean region, the Middle East, Southeast Asia, and parts of Africa, with carrier frequencies ranging from 2% to 25% depending on the population.[4] Owing to its high prevalence and lifelong treatment requirements, thalassemia continues to impose a substantial health, social, and economic burden on affected families and healthcare systems.

In many low- and middle-income countries, limited preventive measures and poor socioeconomic conditions result in dependence on regular blood transfusions as the primary treatment modality. Although lifesaving, repeated blood 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, social, and educational well-being of affected children, significantly impairing their quality of life while placing a considerable financial burden on their families.[6]

Currently, hematopoietic stem cell transplantation (bone marrow transplantation) remains the only definitive curative treatment for beta thalassemia. 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 lack of suitable donors. Consequently, prevention remains the most effective strategy for reducing the burden of thalassemia. Preventive approaches include increasing public awareness, carrier screening, genetic counseling, prenatal diagnosis, and premarital screening of at-risk couples.[7]

Recognizing the importance of prevention, 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 in 2018. The policy aims to ensure equitable access to affordable, high-quality care for individuals affected by thalassemia, HbE disorders, and sickle cell disease, while simultaneously reducing the prevalence of hemoglobinopathies through comprehensive awareness, screening, counseling, and early detection programs.[8]

The purpose of this study is to assess the awareness about thalassemia major disease among parents with thalassemia children and to identify the gap practices 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 Practices 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 practice 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: Practice of participants regarding Thalassemia major

SL No	Survey questions related to Practice	Opinion	No.	%
1	Have you and your spouse undergone thalassemia carrier screening?	Yes Both(mother and father)	18	27.6
		Yes Only Father	0	0.0
		Yes Only Mother	0	0.0
		Not Tested	47	72.3
2	Have you undergone prenatal diagnosis using chorionic villous sampling test?	Yes	12	18.5
		No	53	81.5
3	Did you get other siblings of the thalassemia child screened for thalassemia?	Yes	39	60.0
		No	26	40.0
4	Do you plan to have more children despite having a child with thalassemia major?	Yes	4	6.2
		No	61	93.8
5	Does the Child's disease known to the relatives?	Yes	58	89.2
		No	7	10.8
6	Do you practice sharing of food with Thalassemia child?	Yes	65	100.0
		No	0	0.0
7	Has your child received the hepatitis B Vaccination within the past five years?	Yes	5	7.6
		No	60	92.3
8	Have you received genetic counseling regarding thalassemia?	Yes	28	43.1
		No	37	56.9

Table 2 shows Practice of participants regarding Thalassemia major, About 47(72.3%) had not been screened for thalassemia, About 18(27.6%) got both mother and father screened for thalassemia. About 12(18.5%) of them are practising chorionic villous sampling test. Only 39(60.0%) of them got other siblings of the thalassemia children screened for thalassemia. Majority of them 61(93.8%) told that they are not wishing for having more children although one children is sick. About 7(10.8%) of them didn't disclose the Child's disease to the relatives. All of them practice sharing of food with the thalassemia child. Only 28(43.1%) received genetic counseling about thalassemia major. Only 5(7.6%) children took hep B Vaccination in the past five years.

DISCUSSION:

Thalassemia is a hereditary hemoglobinopathy and a chronic lifelong disorder that poses a significant public health burden. As there is no universally accessible cure, prevention remains the most effective strategy to reduce the incidence and burden of the disease. Healthcare professionals, including physicians, genetic counselors, nurses, and social workers, play a vital role in creating awareness, providing genetic counseling, promoting carrier screening, and supporting affected families. Tertiary care government hospitals are frequently overburdened with patients requiring regular blood transfusions and long-term follow-up. Therefore, continuous counseling and sustained motivation of parents of children with thalassemia are essential to improve disease management and encourage preventive practices. Government initiatives should strengthen preventive services by ensuring the availability of trained genetic counselors, prenatal diagnostic facilities, and comprehensive counseling services at all levels of healthcare.[10]

In the present study, the majority of participants (31; 47.7%) belonged to the age group of 31–40 years. Fathers constituted 36 (55.4%) of the participants, while mothers accounted for 29 (44.6%). Most participants (45; 69.2%) were from rural areas. A slight male predominance was observed among children with thalassemia, 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. reported a slight female predominance among patients with thalassemia in Pakistan.[13]

The assessment of preventive practices among participants revealed several gaps. Only 18.5% of parents had undergone chorionic villus sampling (CVS) for prenatal diagnosis, while 60.0% had their other children screened for thalassemia. Furthermore, only 43.1% of participants had received genetic counseling regarding thalassemia major. Although awareness of the importance of screening was relatively higher, the actual utilization of preventive services remained low. Saxena A et al. reported that approximately 60% of participants were aware of the importance of screening; however, only 27.5% underwent screening during subsequent pregnancies.[12] Similarly, Basu M reported that only 12.38% of participants had received premarital counseling, while 4.9% underwent prenatal diagnosis during pregnancy.[14]

With regard to preventive healthcare, only 7.6% of children in the present study had received hepatitis B vaccination within the past five years. In comparison, Goyal JP et al. reported that approximately 42% of children with thalassemia were completely immunized against hepatitis B.[11] Considering the lifelong requirement for repeated blood transfusions among children with thalassemia major, complete hepatitis B immunization is essential to minimize the risk of transfusion-transmitted infections.

Overall, the findings of the present study demonstrate inadequate preventive practices among parents of children with beta thalassemia major. The limited utilization of prenatal diagnostic services, carrier screening, and genetic counseling may be attributed to inadequate awareness, poor accessibility, financial constraints, and the non-availability of these services in many government healthcare facilities. These findings underscore the need for strengthening preventive healthcare services by establishing accessible prenatal diagnostic centers, expanding genetic counseling services, and implementing community-based awareness and carrier screening programs. Government support and policy-level interventions are essential to improve the uptake of preventive strategies, reduce the birth of affected children, and ultimately lessen the social, emotional, and economic burden of thalassemia on families and the healthcare system.

In our study, there is a lack of positive practice 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 practices 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.

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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