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# Perception of Parents of Children Suffering From Thalassemia in Karimnagar District of Telangana State in India

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## Abstract

### Introduction

Thalassemias are a group of inheritable hemoglobinopathies where abnormal hemoglobin is synthesized leading to decreased hemoglobin levels in the body. Thalassemias are classified according to which chain of the hemoglobin molecule is affected. In α-thalassemias, production of the α-globins chain is affected, while in β-thalassemia, production of the β-globins chain is affected. Thalassemias are a grave menace in the modern world which need to be tackled effectively and quickly to improve the health status of people around the world.

### Objectives

To assess knowledge and awareness of parents of thalassemia patients regarding preventive measures and treatment options available for thalassemia.

### Methodology

The present study is an observational study design conducted in a district called Karimnagar of Telangana state in India amongst 130 parents of children suffering from thalassemia with the use of a pre-designed direct questionnaire with additional variables.

### Results

Out of the 130 parents, 68% knew that thalassemia was a hematological disorder, 57 % parents

understood the role of heredity in the transmission of the disease, 54% parents were aware that it could be prevented by pre-natal genetic counselling, 73% parents understood that consanguineous marriage was a risk factor contributing to the disorder, 84% parents were made aware of thalassemia only through their healthcare personnel and nearly 64% parents had an idea about various modalities of treatment of the disorder.

**Conclusion**

This study provides an important insight into the level of understanding regarding thalassemia disorders amongst parents and the amount of awareness still required to make a difference in improving the statistics surrounding the same.

**Introduction**

Thalassemias are a group of inherited hematological disorders following autosomal recessive pattern of inheritance. The genetic defect causes a reduction in the rate of globin chain synthesis which causes the formation of abnormal hemoglobin molecules. The resultant microcytic anemia is the characteristic presenting symptom of the thalassemias. These disorders are of two types: alpha (α) thalassemia and beta (β) thalassemia. The various combinations of hemoglobin polypeptide chains present during first trimester of intrauterine life include Hb Gower 1, Hb Gower 2, Hb Portland and HbF. Thalassemias are prominently prevalent in South African and Asian ethnicities. There is a 25% risk for each pregnancy resulting in a diseased child if both parents are carriers of the thalassemia. In 2016, thalassemia was reported in 270 million people worldwide and resulted in 16,700 deaths. Strategies for prevention of thalassemias include providing up-to-date and accurate information to healthcare professionals and screening centre with appropriate counselling. However, since India is a developing country with a large population and almost 4.5 million β-thalassemia carriers - spreading awareness about thalassemias is the need of the hour if there has to be a significant positive change in the statistics for the same.

**Material and Methods**

It is an observational study design conducted in a district called Karimnagar of Telangana state in India to estimate the knowledge about thalassemia in families whose members are suffering from thalassemia, and to assess the awareness about prevention and treatment in the affected families. The study population consisted of 130 parents of thalassemia patients who visited the thalassemia unit of Prathima Institute of Medical Sciences for their treatment in a span of 2 months (October 1st, 2022 - November 30th, 2022).

The samples were selected through non-probability convenient sampling. Thalassemia patients were diagnosed by appropriate diagnostic methods like hemoglobin electrophoresis with quantification of fetal hemoglobin (Hb F). The aim of the study was explained to all volunteer participants and written informed consent was taken from them in their language of understanding. Questionnaires were distributed to parents under proper moderation and guidance of the researcher.

**Results**

For the purpose of reference:

Out of the 130 participants in the study, 69 parents (53%) were illiterate, 82 parents (63%) had consanguineous marriages and 87 parents (67%) belonged to the lower-middle class socioeconomic group (according to Kuppuswamy scale)

**Table 1: Participants' perception regarding the system of the body involved in Thalassemia**

| | Perception of System Affected | Frequency ( n ) | Percentage (%) |
|---|---|---|---|
| 1 | Digestive system | 21 | 16 |
| 2 | Skeletal system | 9 | 7 |
| 3 | Haematological system | 88 | 68 |
| 4 | No idea | 12 | 9 |
| | TOTAL | 130 | 100 |

As shown in Table 1, 88 participants (68%) knew that thalassemia is a hematological disorder

**Table 2: Participants' perception regarding the mode of transmission of thalassemia**

As shown in Table 2, 74 participants (57%) knew that thalassemia is a genetic disease.

**Table 3: Participants' awareness regarding the prevention methods that can be adopted to reduce the prevalence of thalassemia**

| | Perception of Preventive Methods | Frequency (n) | Percentage (%) |
|---|---|---|---|
| 1 | Only public awareness | 31 | 16 |
| 2 | Preventing the birth of children amongst two thalassemia carriers | 17 | 13 |
| 3 | Prenatal Diagnosis | 70 | 54 |
| 4 | Postnatal Diagnosis | 12 | 9 |
| | TOTAL | 130 | 100 |

As shown in Table 3, 70 parents (54%) were aware about the need for prenatal diagnosis in people with thalassemia.

**Table 4: Participants' awareness regarding the risk factors that may cause thalassemia**

| | Perceived Risk Factor | Frequency (n) | Percentage (%) |
|---|---|---|---|
| 1 | Smoking | 10 | 8 |
| 2 | Alcohol Consumption | 10 | 8 |
| 3 | Consanguinity | 95 | 73 |
| 4 | Vitamin Deficiencies | 15 | 12 |
| | TOTAL | 130 | 100 |

As shown in Table 4, 95 participants (73%) were aware that consanguineous marriages were a risk factor contributing towards the increasing prevalence of thalassemia disorders.

**Table 5: The mode of awareness about thalassemia amongst parents of the patients**

| | Mode of awareness about thalassemia | Frequency (n) | Percentage (%) |
|---|---|---|---|
| 1 | From health professionals | 109 | 84 |
| 2 | From peers and colleagues | 5 | 4 |
| 3 | From media and news outlets | 14 | 11 |
| 4 | From self interest | 2 | 1.5 |
| | TOTAL | 130 | 100 |

As shown in Table 5, 109 participants (84%) of the study learnt about thalassemia through their healthcare provider/ other healthcare personnel.

**Table 6: Participants awareness about the modalities treatment of thalassemia**

| | Perceived Modality of Treatment | Frequency (n) | Percentage (%) |
|---|---|---|---|
| 1 | Iron chelation therapy | 22 | 17 |
| 2 | Blood transfusion | 53 | 41 |
| 3 | Stem cell transplant | 8 | 6 |
| 4 | No idea | 47 | 36 |
| | TOTAL | 130 | 100 |

As shown in Table 6, nearly 84 participants (64%) were aware of some modality of treatment of thalassemia whereas nearly 36% participants were not aware of any proper modality for the same.

**Other findings of the study were as follows**

Nearly 67% participants knew that screening of blood is mandatory before every transfusion.

Of them 64% participants understood the reason behind the screening of blood.

Almost 10% participant parents underwent diagnostic testing before marriage and almost 90% parents did not undergo any form of testing. Unfortunately nearly 8% participants believed that the disorder was a curse upon them by a deity or a supernatural power for their wrong doings.

However, 99% of the participants believed that there should be many thalassemia public awareness programs, and that premarital screening must be performed.

**Discussion**

The study included 130 parents of patients suffering from β- thalassemia. The main aim of our study was to estimate the knowledge about these disorders among the affected families.

The study found that still 27% of the parents do not know the hazardous aftermath of consanguinity with respect to thalassemia inheritance and nearly 46% of

the parents still did not understand the need for prenatal screening to prevent thalassemia disorders.

Nearly 5% of the parents were still unaware of the mode of transmission of thalassemias and nearly 36% of the parents had little to-no-knowledge about the various modalities of treatment of thalassemia.

It is clearly evident that the need to spread awareness about thalassemias is the need of the hour. India must follow the screening policies which have shown a remarkable decrease in the incidence of thalassemias, to identify carriers of thalassemia.

The life expectancy of thalassemia patients can be increased by national planning and special care but knowledge of the exact rate and age distribution of inherited blood disorders is limited. Many families are still suffering from a menace much bigger than thalassemia - that of misguided beliefs and religious superstitions that are creating stigma around the disorder. It is believed that an increase in maternal education would lead to dispelling such beliefs and while also allowing a significant increase in the utilization of prenatal tests, carrier screening and prenatal diagnosis.

**Limitations**

This study included β-thalassemia patients from only one thalassemia centre, which limits the generalisability of the results. A study consisting of patients from different nationalities and centres will give more accurate responses and will help to understand the pattern of behaviour common among thalassemia patients/ parents.

This study should also ideally factor in the fact that socio-economic variables like consanguinity, religious apprehensions around abortion and high rates of illiteracy lead to an overwhelming amount of cases going unnoticed and undetected, which could not be accounted for in this study.

**Conclusion**

The research findings exhibited that awareness about thalassemia, its prevention and treatment is on the correct path but yet not ideal and there is significant room for improvement. There is a long way to go for the healthcare sector to spread awareness about the disorders. Only with awareness of the general public can thalassemias be prevented efficiently, for which the public should be informed and encouraged to undergo screening to detect carriers. Families that are thalassemia carriers should receive appropriate genetic counseling. An effort to educate parents about prenatal diagnosis must be made. Lastly, the government should organize campaigns to encourage premarital screening.

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