

## Knowledge and Home Care Managements of Thalassemia Among the Parents of Thalassemic Children : A Descriptive Study

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### Abstract

**Introduction:** Thalassemia is a heterogeneous group of genetic disorders of haemoglobin (Hb) characterized by decline or absent production of globins protein chains. The disorder results in excessive destruction of red blood cells, which leads to anaemia. Nearly 3.9% of Indian population is carrier of thalassemia and the prevalence of thalassemia is more common in south Asian countries. The knowledge and home care management regarding thalassemia is crucial for caregivers and parents. **Methodology:** the present quantitative study was conducted among 120 parents of thalassemic children at P.B.M. Paediatric Hospital, Bikaner (Rajasthan). The samples were selected by purposive sampling technique. Data collection was done with the help of structured knowledge questionnaire. The study was conducted from August 2017 to December 2017. **Results:** most of participants (59.16%) were male. Mainly subjects (40%) were belonging to 30-35 years of age group. The mean knowledge score and standard deviation were 24.87 and 6.11 respectively. Only 30 (25%) parents had good knowledge regarding thalassemia and its home care management. The study communicated that poor knowledge and average knowledge regarding thalassemia were 31.66% and 25.83% respectively. There were positive correlations between income of the parents, religion of parents with knowledge. **Discussion:** thalassemia is passed on through parents who carry the thalassemia gene in their cells. The parents had poor knowledge regarding thalassemia and its home care management. There is a need of sound educational programme for the parents and community to enhance their knowledge and home care management regarding thalassemia. A better home based care of thalassemic children can reduce the disease burden and treatment cost of thalassemia.

**Keywords:** Thalassemia; Knowledge; Home care management; Parents

### Introduction

Thalassemia is an inherited blood disorder in which the body makes an abnormal form of haemoglobin. The disorder results in excessive destruction of red blood cells, which leads to anaemia. Thalassemia is a heterogeneous group of inherited disorders of haemoglobin (Hb) characterized by reduced or absent production of globins chains [1].

A child born with thalassemia is unable to make a sufficient amount of Hb and needs blood

transfusions every 4 to 6 weeks, for whole life. All forms of thalassemia like thalassemia minor, thalassemia major, Alpha-thalassemia, beta-thalassemia, delta-thalassemia are transmitted only through heredity. Most carriers lead completely normal healthy lives [2].

The hemoglobinopathies (thalassemia and sickle-cell disease) are the most common inherited genetic disorders, with some 240,000 infants born annually with major hemoglobinopathies and at least 190 million carriers worldwide [3].

Thalassemia can develop many adverse effects on individuals, families, society and nation. Therefore it is necessary to detect the needs of thalassemic children parents. Determination of needs is the starting point of any educational and care program and developing a training plan is subjected to assessment and identification of the needs [4].

As per WHO, 4-5% of the world's population are carriers of hemoglobinopathies. Worldwide 15

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million people have clinically apparent thalassaemic disorders. There are about 240 million carriers of  $\beta$ -thalassaemia worldwide and in India approximately 30 million thalassaemic patients. Every year nearly 100,000 children with  $\beta$ -thalassaemia major are born worldwide, over of which 10,000 are born in India [5].

A study was conducted among 11080 school children in Delhi and Mumbai for assessing the gene frequency of  $\beta$ -thalassaemia major and other hemoglobinopathies. The study revealed that the overall gene frequency of  $\beta$ -thalassaemia major in Mumbai and Delhi was at 2.68% and 5.47% respectively. In Mumbai the gene frequency was equally distributed but in Delhi a higher incidence was observed in North and West [6]. Thalassaemic children are needed care and attention and the role of family is very important.

## Methodology

The study was conducted at P.B.M. Hospital,

Bikaner (Rajasthan) in Pediatrics ward by using purposive sampling technique. A descriptive survey approach was used to assess the knowledge and home based care of thalassaemia among parents of thalassaemic children. 120 parents of thalassaemic children were selected as sample or the study.

Structured knowledge questionnaire was used for data collection and information was gathered regarding knowledge of parents on thalassaemia and its home care management of their children. Written consent was taken from concern authority.

Data collection was done by using interview method of the parents from August 2017 to December 2017. The level of the knowledge was further categorized in 4 categories as per scoring criteria and maximum score was 42. The score, more than 75% was considered as very good knowledge. Score between 61-75% was evaluated as good knowledge. The scores between 51-60% and 50% were considering as average and poor respectively.

## Results

**Table 1:** Frequency and percentage distribution of samples according to socio demographic data.

N=120

S. N.	Demographic Data	Frequency (F)	Percentage (%)	
1.	Age in years	21-25	15	12.5
		26-30	32	26.666
		31-35	48	40
		above 35	25	20.833
2.	Gender	Male	71	59.166
		Female	49	40.833
3.	Religion	Hindu	65	54.166
		Muslim	51	42.5
		Sikh	4	3.333
		Christian	0	0
4.	Educational status	Primary	41	34.166
		Secondary	28	23.333
		Higher sec.	20	16.66
		Graduation	31	25.833
5.	Source of Health information	Mass media	5	4.166
		News paper	11	9.166
		Health worker	74	61.666
		Family member	30	25
6.	Family income monthly	10000	42	35
		10001-20000	39	32.5
		20001-30000	30	25
		More than 30000	9	7.5
7.	Occupation	Labour	42	35
		Private job	15	12.5
		Govt. Job	27	22.5
		Self business	36	30

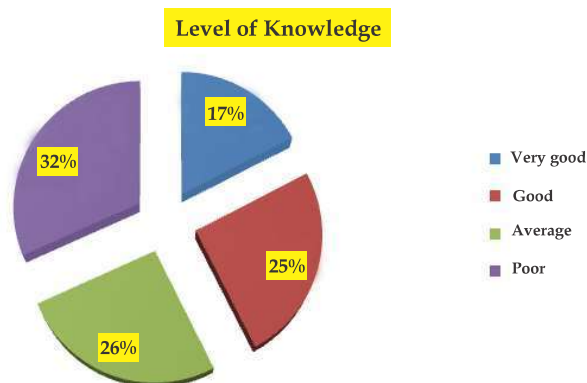


Fig. 1: Distribution of level of the knowledge among the parents of thalassemic children:

Table 2: Chi square computed between knowledge scores of samples regarding thalassemia and its home care management with selected demographic variables. N=120

S. N.	Demographic Variable		Above Median	Below Median	Chi Square Value	Df	Chi Square Table Value
1.	Age in years	21-25	10	5	2.408	3	7.82
		26-30	18	14			
		31-35	22	26			
		above 35	12	13			
2.	Sex	Male	33	38	1.875	1	3.87
		Female	29	20			
3.	Religion	Hindu	29	36	19.24*	3	7.82
		Muslim	31	20			
		Sikh	2	2			
		Christian	0	0			
4.	Educational status	Primary	19	22	5.443	3	7.82
		Secondary	11	17			
		Higher	11	9			
		secondary	21	10			
		Graduation					
5.	Family income (monthly)	Up to 10000	31	11	13.21*	3	7.82
		10001-20000	15	24			
		20001-30000	12	18			
		More than	4	5			
		30000					

(\* = significant at 0.05 level of significance)

## Discussion

Thalassemia is a genetic disorder which does not have any known cure. Prevention is the only way to minimize its disease burden. Home base management of thalassemic children is cost effective. Thus, increasing the knowledge regarding the disease is one of the critical strategies for its prevention [7]. The present study was conducted among 120 parents of thalassemic children regarding knowledge and home care of thalassemia. The findings of present study communicated

that most of the parents had poor knowledge regarding thalassemia. The study revealed that poor knowledge and average knowledge regarding thalassemia among the parents were 31.66% and 25.83% respectively. The study conducted by Kourorian Z *et al.* (2014) had (39%) had similar observations [8]. A study was conducted by Goyal JP *et al.* (2015) among 110 parents regarding awareness of thalassemia in Gujrat, India. The researchers communicated that parents had inadequate knowledge regarding thalassemia. The present study has reported similar observations [9]. In a similar study on parents of thalassemic children

in Kolkata was conducted by Basu M in 2015 revealed that 57.94% of the study population had adequate knowledge. Our study also investigated that 55.83% of the parents had good and average knowledge which is nearly equal to above study [10]. In our study, only 17.5% of the parents had very good knowledge regarding thalassemia and its home care management of their children. There was no study to support the present finding. In current study, 71 (59.17%) participants were male. A study conducted by Saxena A *et al.* also showed the equal proportion of male participants [11]. Sociodemographic factors affect the knowledge of parents regarding thalassemia. The present study revealed that there was a significant association between knowledge and family income. The result was consistent with a study conducted in Pakistan in 2019, showed the equal findings [12]. Our study also finds the association between religion of subjects and knowledge but there was no study to support the findings. Knowledge and home care management of thalassemia is vital for the parents to provide meticulous care to their thalassemic children.

### Conclusion

We conclude that awareness regarding thalassemia is inadequate among parents. Since thalassemic patients are mostly young population in the country, the role of family in their care is very crucial due to the chronic nature of this disease. Parents of thalassemic children should be sensitized about the thalassemia. There is a need for creating knowledge and awareness among the families with thalassemia and the general public through educational material, role play, mass media, booklets, lectures, video, etc., so that the burden of thalassemia in the community can be minimized and children with thalassemia may have a better life.

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