
KNOWLEDGE REGARDING THALAESSEMIA AMONGST PARENTS OF THALAESSMIC CHILD

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A descriptive study was conducted to assess the knowledge regarding Thalassemia amongst parents of Thalassemic child with a view to develop guidelines in selected hospital, Jalandhar, Punjab. The objectives of the study were to assess the knowledge regarding thalassemia amongst parents of thalassemic child and to develop a guideline regarding thalassemia. The study sample included 30 mothers of thalassemic children from civil hospital and Bhutani hospital, Jalandhar. The sampling technique was purposive sampling technique. A structured questionnaire schedule was used to assess the knowledge of mothers of thalassemic child regarding thalassemia. The findings of the study showed that 63.3% of the mothers had average knowledge with a mean knowledge score of 9.8.

Keywords: thalassemia, knowledge, parents.

Introduction

Thalassemia is a single gene disorder, inherited in an autosomal recessive manner, prevalent in certain parts of the world. Worldwide, 15 million people have clinically apparent thalassemic disorders. Reportedly there are about 240 million carriers of β thalassemia worldwide, and in India alone, the number is approximately 30 million. Every year approx. 100,000 children with thalassemia major are born world over of which 10,000 are born in India. It is estimated that there are about 65000 – 67000 β thalassemia patients in our country with around 9000 – 10000 cases being added every year. The carrier rate for β thalassemia gene varies from 1 to 3% in southern India to 3% to 15% in northern India. Certain communities in India, such as Sindhis and Punjabis from Northern India, etc have a higher carrier rate. Once a child is diagnosed to have thalassemia homozygous disorders, he/ she have to take lifelong treatment. Management includes regular 3 weekly filtered PRBC transfusions, chelation therapy for iron overload, management of complications of iron overload and transfusions, including osteoporosis, cardiac dysfunction etc. the birth of a thalassemic child thus places considerable strain not only on affected child but also on the family and society at large. Thus the researcher felt a need to assess the knowledge of the mothers regarding thalassemia and based on it to develop a guideline regarding the care of thalassemia.

Objectives of the study: The objectives of the study was

1. To assess the knowledge regarding thalassemia amongst parents of thalassemic child.
2. To develop guidelines regarding of thalassemia.

Review of literature:

For the present study an extensive review of literature was done under the headings:

Review of literature related to the incidence and prevalence of thalassemia

- **Sengupta, M. (2004)** conducted a study on thalassemia in tribal community. Among the Indian tribes an extensive study was conducted from the literature published, since last 20 yrs. Literature review showed that thalassemia and other hemoglobinopathies were highly prevalent among tribal communities.
- **Madan, N (2006)** conducted a study on the incidence rate of thalassemia. India is an ethnically diverse country with an approx population of 1.2 billion. The frequency of β thalassemia trait (BTT) has variously been reported from <1% to 17% and an average 3.3. most of this study have been carried out on small population. The overall gene frequency of BTT in Mumbai and Delhi was 4.05% being 2.08% and 5.47% in children of two cities respectively. Majority of children with BTT from Mumbai were Marathi (38.9%) and Gujarati (25%) speaking groups. On statewide analysis, the incidence observed in children of Punjabi origin (7.6%) and 74% from several other states.

Review of literature related to knowledge of parents regarding thalassemia and its care

- Burbahc J (2003) assessed the psychological adjustment of 78 mothers of children and adolescent with sickle cell disease. Support was provided for a transactional stress and coping model in delineating the processes associated with maternal adjustment. Poor maternal adjustment was associated with use of palliative coping methods and high level of stress related to daily hassels. Variables of model accounted for 55% of the variance in maternal psychologic distress.
- **Ghazanfari Z, Arab M. Forouzi M (2010)** conducted a descriptive study on knowledge level and educational needs of thalassemic children's parents in Kerman. The results of the study showed that parents knowledge was under 50% considering all items and they gained 37% of the total score. There was a positive correlation between parents level of education and knowledge as well as their educational need. Mothers educational needs were more than that of fathers. The study concluded that thalassemic patients parents don't have adequate information on the disease and need a high level of education.

Methodology

A descriptive study was conducted to assess the knowledge regarding thalassemia amongst parents of thalassemic child. The study was conducted on 30 mothers whose thalassemic children were admitted in Civil hospital and Bhutani hospital in Jalandhar, Punjab. The samples were selected by purposive random technique. The study was conducted in two phases: phase I of the study included assessing the knowledge of mothers whose thalassemic children were admitted in selected hospital. A structured

questionnaire schedule was given to the mothers to assess their knowledge regarding thalassemia. The results were interpreted using descriptive statics and knowledge was assessed as good, average poor knowledge. Phase II of the study development of a guideline on thalassemia which was based on the knowledge of the mothers. Prior to data collection ethical clearance was taken from the research committee of the college and the hospitals and informed written consent was taken from the samples.

Results

Table 1: Frequency and percentage distribution of mothers of thalassemic child by their sample characteristics in selected hospital, Jalandhar.

N = 30

S.NO.	SAMPLE CHARACTERISTICS	FREQUENCY (f)	PERCENTAGE (%)
1	Age (in yrs)		
A	20-22	4	13.4
B	23-25	10	33.33
C	26-28	10	33.33
D	Above 29	6	20
2	Religion		
A	Hindu	12	40
B	Muslim	2	6.7
C	Sikh	11	35.7
D	Christian	5	16.6
3	Education		
A	8 th	3	10
B	Matric	8	26.7
C	10+2	11	36.7
D	Graduate	8	26.6
4	Parental Occupation		
A	Govt job	3	10
B	Housewife	17	56.7
C	Business	8	26.7

D	Any other	2	6.6
5	Number of family members		
A	Three	10	33.3
B	Four	11	36.7
C	Five	5	16.7
D	Above five	4	13.3
6	Family history of thalassemia		
A	Yes	14	46.7
B	No	16	53.3
7	Family income (in Rs)		
A	5001 – 10000	1	3.33
B	10001-16000	11	36.7
C	16001-22000	11	36.7
D	Above 22001	7	23.3

Figure 1: Findings related to the level of knowledge of regarding thalassemia amongst mothers of thalassemic child

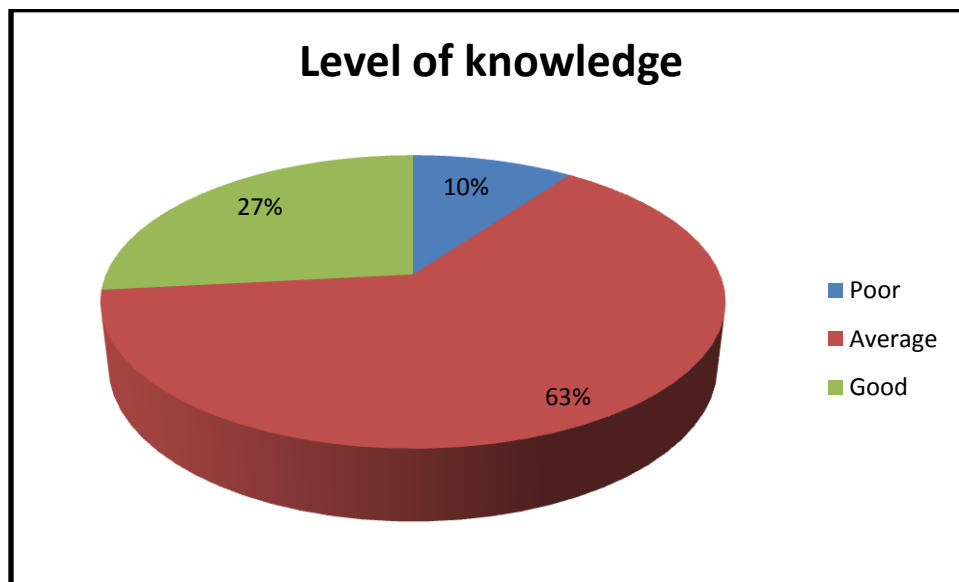


Table 2: Findings related to frequency, mean, median, standard deviation of knowledge score amongst mothers of thalassemic child.

S.NO.	Knowledge Score	FREQUENCY (f)	%age	MEAN	MEDIAN	S.D.
1	0-6 (poor knowledge)	3	10	4.3	4	1.24
2	7-13 (Average knowledge)	19	63.3	10	10	1.51
3	14-20 (Good knowledge)	8	26.7	15.1	15	1.05

Discussion

The findings of the study revealed that 33.3% of mothers belonged to age group of 23-25 yrs, 40% mothers were Hindus, 36.7% mothers had education upto 10+2. With regards to occupation 56.7% mothers were housewives, 36.61% mothers had total 4 members in the family and 53.3% mothers had family history of thalassemia. The study also showed that majority of the mothers 19 (63.3%) had average knowledge regarding thalassemia, 8 (26.6%) mothers had good knowledge and 3 (10%) mothers had poor knowledge regarding thalassemia.

Nursing implications

- Nursing practice: since mothers had average knowledge regarding thalassemia the nurses should provide health education to the parents and care givers regarding thalassemia. Seminars/ workshops can also be conducted to create awareness.
- Nursing education: nursing students and staff nurses working in paediatrics department should have thorough knowledge regarding thalassemia. Workshops/ seminars/ case discussions can be conducted on this.
- Nursing administration: nurses as an administrator has a role in planning fer policies for imparting health information to target population. Nurse administrators can provide continuing education programmes to teach nurses and other students regarding care of thalassemia
- Nursing research: future research work can be conducted related various other fields related to thalassemia.

Recommendations for future study

- Study can be conducted on a large samples in different hospitals to generalize the findings of the study
- Planned teaching programme can be conducted regarding improvements of knowledge of thalassemia among the care givers
- Future study can be conducted on knowledge of staff nurses regarding thalassemia

Conclusion

Thalassemia is a chronic and lifelong disease. The patients as well as the care givers need to have adequate knowledge regarding the disease so that care can be provided to those affect with the disorder. The present study was conducted to assess the knowledge of mothers regarding thalassemia with the aim of developing a guideline regarding thalassemia. The findings of the study showed that majority of the mothers 19 (63.3%) had average knowledge regarding thalassemia. The study concluded that knowledge needs to be provided to the care givers regarding the disorder so that good care can be provided to those affected with the disorder. Increasing knowledge, attitude and practice awareness among thalassemic patients about their disease and treatment has a positive influence in their quality of life. This will improve their performance to deal with their lifelong disease and its challenges during the course of treatment.

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