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A STUDY TO ASSESS THE KNOWLEDGE OF PARENTS REGARDING THALASSEMIA AND ITS HOME CARE OF THEIR CHILDREN ADMITTED IN THALASSEMIA WARD OF SELECTED HOSPITAL, BATHINDA, PUNJAB.

Nursing

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ABSTRACT

Background: Thalassemia is taken into consideration as one of the foremost health hasslein India due to its high occurrence charge as it is far common single gene disorder and heredity disease.The present study was changed into carried out to assess the knowledge of parents regarding thalassemia and its home careof their children admitted in thalassemia ward. The existing study aimed to assess: To assess the knowledge of parents regarding thalassemia and its home care of their children. To find out the association between knowledge of parents with their selected socio-demographic variables.

Methods: A non-experimental descriptive research design was used for the study. Sample size was 30 parents and sampling technique used was non- probability purposive technique. A structured knowledge questionnaire was prepared to assess the knowledge of parents regarding thalassemia.

Results and conclusion: 30 parents of thalassemic children were participated in the study, among 0 (0%) parents were having adequate knowledge, 12(forty %) of parents having moderately adequate knowledge and 18(60%) of parents having inadequate knowledge regarding thalassemia. There was no association between socio-demographic variables with the knowledge of thalassemia among parents.

KEYWORDS

Thalassemia, parents.

INTRODUCTION

Thalassemia is an inborn blood disease because of ordinary hemoglobin production,signs and symptoms depend upon the kind and severity (none to intense),of the circumstance,regularly there is moderate to intenseanaemia which leads to feeling tired and pale skin. There can also be bone problems,yellowish pores and skin,enlarged spleen, slow growth and the urine can also appear dark.[2]

As look at study conducted by Global Burden of Disease in 2013, about international280 million humans stays with thalassemia. It's far most commonplace genetic sickness among people of Italian, South Asian Greek, center Japanese, and African descent. Thalassemia costs are identical in men and women.[3]

As per WHO estimates, four% - five% of the world's populace is carrier of Hemoglobinopathies. World-extensive 15 million human beings have clinically apparent thalassemic disorders. There are approximately 240 million providers of β-thalassemia global-extensive and in India; the variety is approximately 30 million with a median incidence of 3.3. Every year about one hundred, 000 kids with β -thalassemia predominant are born global over of which 10,000 are born in India. In our country, with around 9,000 to 10,000 instances being introduced every 12 months. The carrier charge for β - thalassemia essential gene varies from one-three percentage in Southern parts of India to a three-15 percent in Northern components of India.[4]

AIMS AND OBJECTIVES

1. To assess the knowledge of parents regarding thalassemia and its home care of their children.
2. To find out the association between knowledge of parents with their selected socio-demographic variables.

Assumptions:

1. Parents may have some knowledge regarding thalassemia and its home care.
2. Pamphlets may help the parents to improve their knowledge and thus provide better care to their children.
3. Parents may be willing to express their knowledge regarding thalassemia and its home care.

MATERIALS AND METHODS

Research design: The research approach adopted for the study was non-experimental with descriptive design.

Settings and Study population: The study was conducted in thalassemia ward of Adesh Hospital, Bathinda and 30 parents were the study population having children with thalassemia.

INCLUSION CRITERIA

1. Parents who have thalassemia major children at age of 1-18 years.
2. The parents who seek services in selected tertiary care centre during data collection.
3. Parents who are ready to implement the therapeutic knowledge in the home.

EXCLUSION CRITERIA

1. Parents who are non co-operative.
2. Parents who are ready to express knowledge regarding thalassemia and its home care.

Tool Description

The tool developed and used for Data collection was socio-demographic variables and Structured Knowledge Questionnaire.

PART-1: included socio-demographic variables such age, gender,educational status of parents, occupation family income, religion, relation with child, consanguineous marriage, undergone genetic screening,age of child at diagnosis, duration of treatment, frequency blood transfusion.

PART-2: Structured knowledge Questionnaire regarding the knowledge of parents about thalassemia and its home care.It consists of 30 multiple choice questions. Each correct answer was given a score of (1) and each wrong answer score of (0) total possible score were (30).

Criterion measure:-

The structured knowledge questionnaire was administered by researcher. There were 30 questions, correct answer was given a score of (1) and wrong answer was given a score (0)
Maximum knowledge score -30
Minimum knowledge score -0
Knowledge score categorized into 3 levels:

Level of knowledge	Score	%
Adequate	21-30	67-100
Moderately adequate	11-20	34-66
Inadequate	0-10	0-33

RESULTS

Demographic Characteristics of Parents

Table 1 revealed that most of 11(36.66%) in the age group of 31-40 years. Maximum of 9(30%) were having 10th pass education, regarding religion 14(46.66%) were Sikhs. Regarding family income 12(40%) were having 10001-15,000 income, regarding relation with child most of 15(50%) were mothers, regarding age of child (in years)

most of 8(26.66%) were in age group of 1-4 years, 5(16.66%) were in the age group of 5-8 years, 9 (30%) and 8(26.66%). Regarding Gender, maximum of 16 (53.33%) were males and 14(46.66%) were females.

S.no	Demographic Variables	f	%
1.	**Age of parents (in years):**		
	a) 20-25	4	13.33
	b) 26-30	8	26.67
	c) 31-40	11	36.67
	d) ≥40	7	23.33
2.	**Educational status of parents:**		
	a) No formal education	1	3.33
	b) Primary	8	26.67
	c) Middle	9	30
	d) Senior secondary	8	26.67
	e) Graduate or above	4	13.33
5.	**Family income:(in rupees)**		
	a) ≤10,000	5	16.67
	b) 10,001-15,000	12	40
	c) 15,001-20,000	7	23.33
	d) ≥20,001	6	20
6.	**Religion:**		
	a) Sikh	14	46.67
	b) Hindu	12	40
	c) Muslim	3	10
	d) Christian	1	3.33
7.	**Relation with child:**		
	a)mother	15	50
	b)father	14	46.67
	c)grand	1	3.33
8.	**Genetic-Testing:**		
	a) Yes	16	53.33
	b) No	14	46.67
9.	**Consanguineous marriage:**		
	a) Yes	0	0
	b) No	30	100
10.	**Age of child (in years):**		
	a) 1-4	8	26.66
	b) 5-8	5	16.67
	c) 9-12	9	30
	d) 13-18	8	26.67
11.	**Gender:**		
	a) Male	16	53.33
	b) Female	14	46.67
12.	**Age of child during disease:**		
	a) At 1 year	23	76.67
	b) At 4 years	7	23.33
13.	**Duration of blood transfusion:**	6	20
	a) After 1 week	13	43.33
	b) Every 15 days	9	30
	c) After 1 month	2	6.67
	d) Above 3 years		

Frequency and percentage distribution of parents

To assess the parent's knowledge regarding thalassemia and its home care of their children.

The results of revealed that most of the parents 18

Level of Knowledge	Score	f	%
Inadequate Knowledge	0-10	0	0
Moderately Adequate Knowledge	11-20	12	40
Adequate Knowledge	21-30	18	60

(60%) had inadequate knowledge, 12(40%) had moderately adequate knowledge and 0(0%) had adequate knowledge.

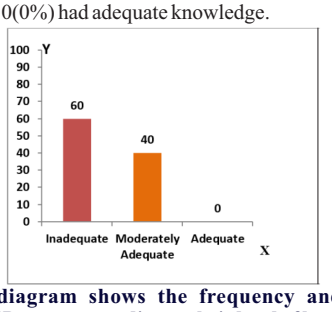

Fig. 1: Bar diagram shows the frequency and percentage distribution of Parents according to their level of knowledge.

Second objective showed that there was no significant association between Knowledge and their socio-Demographic Variables at ($p<0.05$).

DISCUSSION

The findings are discussed in relation to objectives, need for the study, related literature of study and conceptual frame work. It was presented in line with the objectives of the study. The problem statement was **"A study to assess the knowledge of parents regarding thalassemia and its home care of their children."**The present have a look at revealed that most of parents 18 (60%) had inadequate knowledge,12 (40%) had moderately adequate knowledge and zero (0%) had adequate knowledge. The findings have been distinctive to the study**(Sheela William)** revealed that 38 (sixty three.4%) had good level of knowledge and 21 (35%) had average level of knowledge and 1 (1.6%) had poor level of knowledge regarding thalassemia.

The findings of present take a look at revealed that there was no significant association of level of knowledge with their socio-demographic variables. These findings are supported by way of similar study carried out via **(Sheela Williams)** found out that the knowledge scores of mothers regarding Thalassemia had no significant association with their decided on demographic variables.

CONCLUSION

Parents play a totally critical position within the care of thalassemic children. So, mother and father of thalassemic children have to be having good enough knowledge regarding his/her child, so that they'll provide desirable care to his/her child. The existing study concluded that parents were having inadequate information about thalassemia and its home care; this call for intervention in the form of public health education programs/awareness concentrating more on high risk populace.

IMPLICATIONS OF THE STUDY:

Nursing education:

1. The nurse educator plays a vital function in organizing fitness education campaign concerning thalassemia.
2. Nurse educators can conduct teaching sessions for mother and father inside the health center so as to help them in improving their understanding.

Nursing research:

1. The findings of take a look at serve a basis for nursing expert and the scholars to conduct further research about thalassemia.

Nursing administration:

1. The nurse administrators in community ought to broaden recommendations for educating the network of people concerning thalassemia

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