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A descriptive study to assess the burden of caregivers of children suffering from Thalassemia in selected hospitals of Punjab.

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ABSTRACT
Thalassemia is characterized by insufficient production of hemoglobin. 3% of the world's population carries genes for beta Thalassemia. Around 4% of the existing population in India carries the Thalassemic genes. Parents suffer from psychosocial burden because of expenses, stress and fear of death. The burden can affect the quality of life of the families. Caregivers of children with β-thalassemia major are always facing with multiple and extreme challenges to provide high quality care of their patients and, therefore, may experience increased social isolation which in turn could decrease the social support. The investigator used non experimental quantitative approach and descriptive design to assess the burden of caregivers of children suffering from Thalassemia. Tools used for study were Socio – Demographic Performa, and The Zarit Burden Interview Schedule to assess the caregiver's burden. Sample consists of 17 Children suffering from Thalassemia and 28 caregivers of these children visiting the thalassemia units at Civil Hospital Roopnagar and Civil Hospital, Phase 6, Mohali. Results show that out of 28 Caregivers of children suffering from Thalassemia 22(79%) had Mild to Moderate Burden and there is no association between care giver burden and selected demographic variables.

I. INTRODUCTION

Thalassemia major is an inherited hematological disorder leading to anemia among affected children. It is an autosomal recessive disease in which chromosome 11 is involved. It affects synthesis of β globin chain of hemoglobin, which is either decreased or absent, leading to an early turnover of red blood cell(RBC).When one of the beta globin chain genes is normal and other abnormal, it is Thalassemia minor[1].

Thalassemia is a major health problem and is the most common genetically inherited disorder with a corner role of 240 million of beta Thalassemia worldwide and in India alone, the number is approximately 30 million with a mean prevalence of 3.3%.The corner rate of β Thalassemia gene varies from 1-3% in southern India ,to 3%-15%in Northern India[2]

WHO has estimated that 7% of the world's population are carriers of hemoglobin path and an estimated 300,000-400,000 babies born will be affected by this disease each year. The highest carrier frequencies of beta thalassemia have been reported in the Maldives (16-18%), Cyprus (14%), Sardinia (10.3%) and Southeast Asia (3-5%)[3].

In India,the prevalence of thalassemia in the world with a carrier rate of 18% of the population. The overall prevalence of β thalassemia in India is 3-4% with an estimate that around 10,000-12,000 children are born every year with β thalassemia major.a recent study in India showed that overall prevalence of β thalassemia trait was 2.78% and varied from 1.48% to 3.64% in different states[4]. Thalassemia challenges every individual as well as their family members at physical, emotional, cognitive level and disrupts their quality of life[5].

Caregivers of children with β-thalassemia major are always facing with multiple and extreme challenges to provide high quality care of their patients and, therefore, may experience increased social isolation which in turn could decrease the social support. The social support could affect caregiver's burden in chronic conditions such as β-thalassemia major[6].

Globally, 15million people are estimated to suffer from thalassemia. In India, approximately 30 million people are affected; and 10,000 thalassemia major children are born every year. The carrier rate for beta thalassemia varies from 1-17% in India with an average one in every 25 Indian is a carrier of

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thalassemia. One among 204 children born in year is affected with thalassemia. Children with thalassemia need monthly blood transfusion and regular iron chelating therapy[7].

Over the past 3 - 4 decades,it is observed that regular blood transfusion(BT) and iron chelation therapy has the potential to improve the quality of life and transform β-thalassemia from a rapidly fatal disease in early childhood to a chronic disease compatible with prolonged life. However several complications like growth retardation, endocrine, cardiac dysfunction and transfusion transmitted infections arise as a result of iron overload and use of unsafe blood Management and prevention of these complications needs a multidisciplinary and a comprehensive approach and is one of the many challenges in delivering comprehensive care for patients with thalassemia major[8.]

II. MATERIALS AND METHODS :

Quantitative research approach with descriptive survey design was used. The study was conducted on 17 Children suffering from Thalassemia and 28 caregivers of these children visiting the thalassemia units at Civil Hospital Roopnagar and Civil Hospital, Phase 6, Mohali. Data was collected by using Purposive sampling technique. The tool was prepared on the basis of the objectives of the study. **Section -1** sociodemographic profile sheet –it consists Socio – Demographic Performa was developed by the investigator. A data sheet was developed to record socio – demographic variables which consists of 12 items which includes Age, Gender, Religion, Residence, Type of family, number of siblings, occupation of father, occupation of mother, income of family, blood group. **Section – 2 The Zarit burden interview** was used to assess the care giver burden among patients undergoing thalassemia. It includes 22 items which was used to assess the burden of caregiver during the care of client.

Content validity of the tool was determined by the expert's opinion on the relevance of items. Socio demographic data sheet and care giver burden Performa were submitted to ten experts in the field of nursing and there suggestion were accepted and incorporated. There were initially 10 variables in the socio demographic data sheet and 22 items in Zarit burden schedule. Reliability of tool was established by administering the tool to 16 subjects. Tool was administered at different time interval to same subjects to evaluate reliability of tool. Guttmann split- half coefficient was calculated and tool was found reliable. The reliability of the tool Zarit burden interview i.e. k=0.4

ETHICAL CONSIDERATION

1. Written permission was taken from the Principal of Saraswati Nursing Institute Dhainpura, Roopnagar.
2. Written permission was taken from ethical clearance committee of Saraswati Nursing Institute Dhainpura, Roopnagar.
3. Assent was taken from Children suffering from Thalassemia.
4. Informed consent was taken from study subject caregivers of these children
5. Confidentiality and anonymity of the subjects was maintained throughout the study.
6. Ethical permission for conducting study was taken from the head of hospital.

III. RESULTS:

This chapter deals with the analysis and interpretation of data collection from the children and care giver from the selected hospital of Punjab. Analysis of data involved the translation of information collected during course of research project into interpretable, convenient and descriptive term to draw inferences from them by using statistical method. Data gathered was analyzed by using descriptive and inferential statistics on the basis of the objectives of the study.

ORGANIZATION OF DATA ANALYSIS

Section A – Frequency and Percentage distribution of Children suffering from Thalassemia as per their socio – demographic variables

Section B – Assessment of caregiver burden.

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SECTION – A

Table 1 : Frequency and Percentage distribution of Children suffering from Thalassemia as per their socio – demographic variables

N=17

SOCIO-DEMOGRAPHIC VARIABLES	RANGE	f (%)
Age (in years)	1-5	4(23.5%)
	6-10	**8(47.1%)**
	11-15	5(29.4%)
	Above 15	0(0.00%)
Gender	**Male**	**10 (58.8%)**
	Female	7(41.2%)
Religion	**Hindu**	**10(58.8%)**
	Sikh	7(41.2%)
	Muslim	0(0.0%)
	Christian	0(0.0%)
Residence	**Rural**	**14(82.4%)**
	Urban	3(17.6%)
Types of family	Nuclear	8(47.1%)
	Joint	**9(52.9%)**
Number of Siblings	1	6(35.3%)
	2	**9(52.9%)**
	3	1(5.9%)
	More than 3	1(5.9%)
Occupation of father	Govt.Employed	2(11.8%)
	Private employed	**14(82.4%)**
	Businessman	1(5.9%)
	Others	0(0.0%)
Occupation of mother	**Housewife**	**12(70.6%)**
	Govt.employed	2(11.8%)
	Private employed	3(17.6%)
	Any Others	0(0.0%)
Total family income per month (in Rs)	5000-10,000	6(35.3%)
	11,000-15,000	5(29.4%)
	>15,000	6(35.3%)
Blood group	0+	5(29.4%)
	A+	3(17.6%)
	B+	**7(41.2%)**
	AB+	2(11.8%)

Table 1 shows that according to age, 8(47.1%) subjects were in the age group of 6 – 10years, 10(58.8%) subjects were male whereas 7(41.2%) subjects were female. 10(58.8%) were Hindu, 14 (82.4%) were residing in rural area, 9(52.9%) subjects were living in Joint family. 9(52.9%) subjects had 2 siblings. fathers of 14(82.4%) subjects were private employed, mothers of 12(70.6%) subjects were housewives. Total family income per month of 6 (35.3%) subjects was 5000-10,000 and 6 (35.3%) had more than 15,000. 7(41.2%) subjects had blood group B+

Table – 2

Frequency and Percentage distribution Burden of Caregivers of children suffering from Thalassemia

N=28

S.No	CATEGORY	f (%)
1.	LITTLE OR NO BURDEN	6(21%)
2.	**MILD TO MODERATE BURDEN**	**22(79%)**
3.	MODERATE TO SEVERE BURDEN	0 (0%)

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4.	SEVERE BURDEN	0(0%)

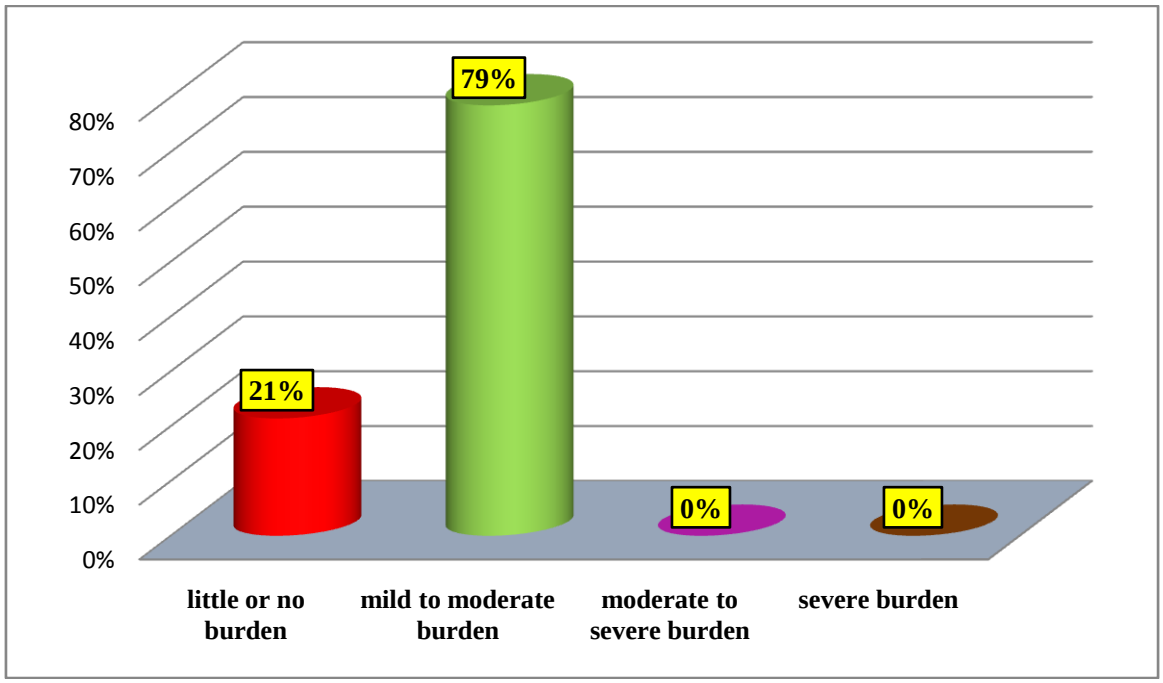

Figure – 1 Frequency and Percentage distribution Burden of Caregivers of children suffering from Thalassemia

Table 2 and Fig 1 depicts that 22(79%) Caregivers of children suffering from Thalassemia had Mild to Moderate Burden.

IV. DISCUSSION

This chapter deals with the finding of the present study entitled "A descriptive study to assess the burden of caregivers of children suffering from Thalassemia in selected hospitals of Punjab (2018-2020)"

In order to achieve objectives of the study, descriptive design was used and purposive sampling technique was done. Data was collected from 17 Children suffering from Thalassemia and 28 caregivers of these children. The finding of the study is discussed in accordance with the objectives of the research. Out of 28 Caregivers of children suffering from Thalassemia 22(79%) had Mild to Moderate Burden.

V. CONCLUSION:

Thalassemia major is an inherited blood disorder leading to anemia among affected children. It is an autosomal recessive disease in which autosomal 11 is involve. The prevalence of 3.3% in India and corner rate of beta thalassemia gene varies from 1 – 3% in Southern India to 3 – 5% in Northern India. Caregivers of children with beta thalassemia major are always facing with multiple and extreme challenges to provide high quality care of their patients and therefore may experience increased social isolation which in turn could decrease the social support.17 Children suffering from Thalassemia and 28 caregivers of these children visiting the thalassemia units at Civil Hospital Roopnagar and Civil Hospital, Phase 6, Mohali were selected by purposive sampling technique. Finding of the study revealed that Out of 28 Caregivers of children suffering from Thalassemia 22(79%) had Mild to Moderate Burden.

IMPLICATIONS

The findings of the study have several implications in different area such as Nursing education, Nursing practice, Nursing administration and Nursing research. The findings of the study have several implications which are discussed in following areas.

NURSING EDUACTION

- The nurse educator should improve the knowledge of nursing students regarding of life, care giver burden among children undergoing thalassemia.

- The study has an implication on nursing education with regard to preparing nursing students competency in giving nursing education to thalassemia children.
- Nurse educator can create awareness regarding availability of treatment, counselling, rehabilitation and effective coping methods.

NURSING PRACTICE

- Nurse should be actively involved in community awareness programmes to educate public about thalassemia and remove misconceptions related to thalassemia and its management.
- The nurse working in community plays a role to reduce stigma and discrimination due to thalassemia by changing the public attitude towards children suffering from thalassemia.

NURSING ADMINISTRATION

- Nurse administrator should organize in- service education program for staff nurses and paramedical health workers on thalassemia.
- Nurse administration can organize seminar on preventive measure dues to complication of thalassemia.

NURSING RESEARCH

- Research should be directed towards describing the caregiver burden with children undergoing thalassemia.
- Nursing research should be conducted to assess care giver burden among patients undergoing thalasemia..

RECOMMENDATION

- On the basis of present study, the following recommendations have been made for further study:-
- A similar study may be replicated on a large sample to validate and generalize the findings.
- A comparative study can be done on caregivers burden between rural and urban patients undergoing thalassemia

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