

# Effectiveness of Home Care Teaching Programme on Knowledge of Parents Regarding Home Care Management of Their Children with Thalassemia in Coronation Hospital, Dalanwala, Dehradun

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## ABSTRACT

Thalassemia is an inbred blood disorder caused when the body doesn't make enough protein called hemoglobin. While the number of Thalassemia growing in India, because people lack adequate knowledge about Thalassemia. About 100,000 babies worldwide are born with severe forms of Thalassemia each year. It is estimated that there are about 65,000-67,000  $\beta$ - Thalassemia patients in our country with around 9,000-10,000 cases being added every year. It is the responsibility of government, health professionals and society to support and encourage preventive programs, in order to reduce the burden of the disease. Home Care Teaching programme is a vital tool by that the quality of life of their children can be improved and Knowledge enhanced. The nature of the study was Pre-Experimental [one group pre-test post-test design]. The study was conducted in coronation hospital Dehradun. The conceptual framework used for this study is based on General System Model. The research design used for the study was one group pre-test, posttest design. Data was collected using non-probability convenient sampling. The data was collected to assess the effectiveness of Home Care Management among 60 parents of Thalassemia children regarding improvement of their knowledge score. A structured knowledge questionnaire was used for the data collection. The data collected were analyzed and interpreted by using descriptive and inferential statistics. In my study finding reveals that the Posttest level of knowledge score is significant higher than Pretest mean level of knowledge score. After administering home care teaching programme the Posttest score (Mean=25.5, SD= 3.94) in comparison with the Pretest score (mean = 16.15, SD = 5.17). The statistical paired "t" Test level for overall level of knowledge score is found 11.57 that is greater than table values(2.00) at  $p < 0.05$  Level of significance Hence the hypothesis (H1) is accepted. The demographic variables such as age of the parents, types of the family, birth order of the child, education of the parents, area of living, source of information, knowledge regarding homecare management of their child shows statistical no significant association with the pretest level of knowledge. As the tabulated value is more than the calculated value, research hypothesis (H2) rejected and statistical hypothesis accepted at less than 0.05 shows that the level of knowledge increased after intervention of Home Care Teaching programme. There it can be said that the home care teaching programme is effective among parents of Thalassemiac children regarding home care management. This study reveals that there is lack of knowledge among parents about the care of their child at home.

**KEYWORDS:** THALASSEMIA, INBRED, EFFECTINESS, KNOWLEDGE, HOME CARE TEACHING PROGRAM, HOME CARE MANAGEMENT

## INTRODUCTION

*"Children are the world's most valuable resource and its best hope for future"*

J F Kennedy

Thalassemia is a genetic blood disorder that leads to insufficient production of hemoglobin in the body. When the red blood cells in the body do not produce enough hemoglobin, leads to anemia in children. The two main types

of Thalassemia are alpha and beta. In alpha Thalassemia, the hemoglobin does not produce enough alpha protein. To make alpha-goblin protein chains we need four genes, two on each chromosome 16. We get two from each parent. If one or more of these genes is missing, alpha Thalassemia will result. Alpha Thalassemia is common in southern China, Southeast Asia, India, the Middle East, and Africa. If one or both genes are faulty, beta Thalassemia will occur.

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Prevalence is higher in North Africa, West Asia, and the Maldives. Children inherit this gene from one or both parents. If a child inherits the faulty gene from both parents, the child will have Thalassemia major. If the faulty gene is only passed on by one parent, the child has Thalassemia minor. The child then becomes a carrier of the defective gene, also known as “**Thalassemia Trait**”. During the 1960s a genetic basis of the Thalassemia diseases was proposed, linking them to unbalanced globins chain synthesis. At Johns Hopkins University, David Wetherill and associates labeled reticulocyte of Thalassemia patients with radioactive amino acids in vitro and were able to demonstrate that in patients with alpha- and beta-Thalassemia, alpha- or beta-chain production was defective because of unbalanced globins chain synthesis. Hence a clear picture of the genetic control of human hemoglobin had emerged. Symptoms will not show until the age of 6 months in most infants with beta Thalassemia and some types of alpha Thalassemia. This is because neonates have a different type of hemoglobin, called fetal hemoglobin. After 6 months "normal" hemoglobin starts replacing the fetal type, and symptoms may begin to appear in the first two years of life and include paleness of the skin, poor appetite, irritability, and failure to thrive, drowsiness and fatigue, chest pain, cold hands and feet, shortness of breath, leg cramps, rapid heartbeat, poor feeding, headache, greater susceptibility to infections, Skeletal deformities may result as the body tries to produce more bone marrow.

Thalassemia is the disease which does not have any known cure. Prevention is the only way to reduce its burden. It is more cost effective approach compare to the provision of optimal treatment to the victims of the Thalassemia. Thus, raising awareness regarding the disease is one of the critical strategies for its prevention.

Thus, Health care teaching programme is vital in terms of prevention of the disease. With this background, the current study was designed to find out the knowledge level of parents of Thalassemiac children regarding Thalassemia and its socio-demographic determinants. It will help to design suitable interventions not only for parents of Thalassemia affected children but also society at large.

**OBJECTIVES:**

1. To assess the knowledge of parents regarding home care management of their children with Thalassemia.
2. To find out the effectiveness of homecare teaching programme on knowledge of parents regarding home care management of their children with Thalassemia.
3. To find out the association between knowledge scores and selected demographic variables.

**HYPOTHESIS:**

**H1** : There will be a significant difference in the level knowledge among the parents regarding home Care management of Thalassemiac child and practice of care of child before and after-home care teaching programme.

**H2** : There will be a significance association between socio demographic variables and Knowledge score regarding home care management among the parents of Thalassemia children.

**MATERIAL AND METHODS:**

**Research Approach:**

A quantitative research approach is used for this study.

**Research Design:**

The research design adopted for the study is pre-experimental. (one group Pretest- Posttest design).

**Research Setting:**

The study was conducted at Coronation hospital, Dehradun Uttarakhand.

**Population**

In this study accessible population is 60 parents of Thalassemiac children, of coronation hospital, Dehradun Uttarakhand.

**Sample Size**

In this study, sample comprises of 60 parents of Thalassemiac children.

**Sampling Technique**

In this study, non-probability convenient sampling technique was used for sampling the parents of the Thalassemiac children.

**Description of the Tool:**

The tool used in the present study consists of following:

**Section A:** It comprised of seven items seeking information on demographic characteristics of the parents of Thalassemiac children such as, age of the parents, birth order of the child, Education of the parents, types of the family, Area of living, source of information and knowledge about Home care management of Thalassemia.

**Section B:** This part of the tool consists of thirty items from all the aspects of HCTP.

The items were closed ended statements of multiple choice questionnaires. The total score was thirty. Each correct response carried ‘one score’. The tool was prepared in English and Hindi.

The knowledge of the respondents was arbitrarily categorized into three categories:

**SCORE INTERPRETATION**

- Below 49%- inadequate knowledge
- 50-74%- Moderate knowledge
- 75-100%- Adequate knowledge

**Description of HCTP:**

The HCTP was entitled “A Sample guide for parents of Thalassemiac children on Home care management of Thalassemia”.

The HCTP was prepared to enhance the assessment knowledge of the parents of Thalassemiac children regarding home care management of their children.

It consists of the following content area.

- Introduction and Definition of Thalassemia
- Its Incidence, causes
- Types and Diagnosis

- Clinical manifestation and treatment options
- Living with Thalassemia & Thalassemia and Pregnancy
- Home care management and Complications.

**Plan for data analysis**

The data obtained was planned to be analyzed based on objectives and hypothesis of the study using descriptive and inferential statistics. Analyzed data is represented in the form of tables, graphs and figures.

**Descriptive statistics:**

- Frequency and percentage were used to analyze the demographic variable regarding home care management of Thalassemic children, such as age of the parents, birth order of the child, Education of the parents, types of the family, Area of living, source of information and knowledge about Home care management of Thalassemia.
- Mean, median and standard deviation was used to assess the effectiveness of health care teaching programme.

**Inferential statistics:**

- Paired t-test was used to assess the effectiveness of home care teaching programme (HCTP) regarding care of Thalassemic children on knowledge of their parents.
- Chi-square was used to find association between the knowledge with their selected demographic variables. Level of significance is set at 0.05 to interpret the hypothesis and finding.

**RESULTS:**

The major findings of the study were as follows:

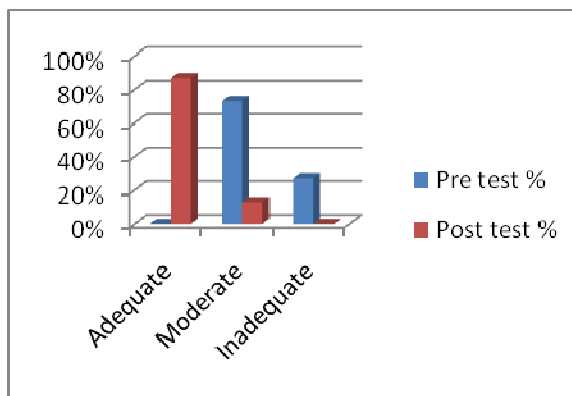
**Section I: Distribution of respondents according to demographic variables.**

According to their demographic details the majority of the respondent 36 (60%) were in the age group between 26-30 years, 45(75%) are of the child order first in the family, 40(67%) parents have secondary education, 40(67%) have nuclear type of family, 32(53%) are living in urban area, 30(50%) of sample got the information from T.V 50(83%) of samples are saying no knowledge regarding home care management of their children.

**Section II: Comparison between pretest and posttest knowledge level.**

**TABLE (2):- Frequency and percentage distribution of parents knowledge level on immediate HCTP.**

Knowledge level	Pre test		Post test	
	f	%	f	%
Adequate	00	00%	52	87%
Moderate	44	73%	08	13%
Inadequate	16	27%	00	00%



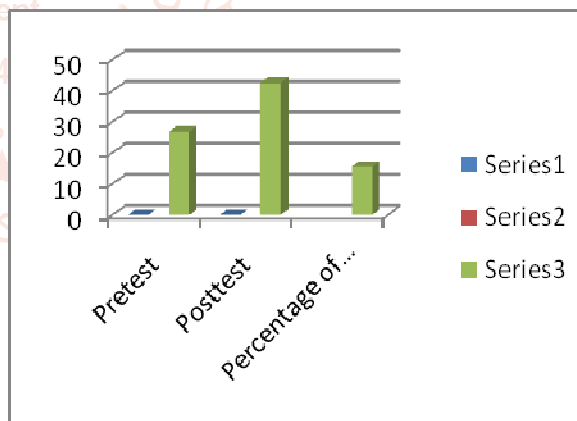
**Fig-1: Bar diagram showing percentage distribution of parents according to their knowledge level on immediate HCTP.**

Data in table 2 and fig-1 shows that the knowledge of parents regarding immediate HCTP, 27% sample score ranging < 50% (inadequate Knowledge) and 73% had score between 51-75% (Moderate Knowledge) which shows that majority of sample are having inadequate level of knowledge in Pretest, 13% sample score ranging between 51-75% (Moderate Knowledge) and 87% sample score ranging between 76 -100 % (Adequate Knowledge) in posttest.

**Section III: Enhancement of knowledge scores on immediate HCTP.**

**Table 3: Aspect wise enhancement of knowledge scores on immediate HCTP**

Mean	Pretest		Posttest			Percentage of enhancement
	Mean %	SD	Mean	Mean %	SD	
16.15	26.91	5.17	25.5	42.5	3.94	16.31



**Fig-2:-Aspect wise enhancement of knowledge scores on immediate HCTP.**

Table 3 and fig-2 reveals that the highest enhancement of knowledge 16.31 percent was seen in the aspect of immediate HCTP with the pretest mean percentage and post-test mean percentage of 26.91% and 42.5% respectively.

**Section IV: Mean, Standard Deviation, and Paired t value of pretest and posttest knowledge scores.**

**Table 4: Mean, Standard Deviation, and Paired t value of pretest and posttest knowledge scores.**

COMPONENTS	PRETEST		POSTTEST		PAIRED't value
	MEAN	SD	MEAN	SD	
Questionnaire on HCTP	16.15	5.17	25.5	3.94	11.57

\* Significant at 5% level of 59 df (i.e ,P<0.05)

The above table 4 represents the mean pre- test (16.15) and post-test (25.5) knowledge score regarding immediate HCTP. The paired t- test value for immediate HCTP knowledge value is 11.57. It was found to be significant at  $P < 0.05$  level, Hence research hypothesis ( $H_1$ ) is accepted and null hypothesis was rejected. It evidence that the Home care teaching program (HCTP) is significantly effective on improving the knowledge of parents regarding immediate HCTP.

#### **Section V: Association between pretest knowledge scores with their demographic variables**

The results of chi square analysis depicts that the demographic variable such as birth order of the child, area of living of the parents shows statistical significant association with the pretest level of knowledge and there was no significant association of other demographic variables with their pretest level of knowledge. The obtained chi square value of the variables such as Age of the parents ( $\chi^2 = 2.467$ ,  $P > 0.05$ ), Birth order of the child ( $\chi^2 = 4.09$ ,  $P > 0.05$ ), Educational status of the parents ( $\chi^2 = 1.19$ ,  $P > 0.05$ ), type of family ( $\chi^2 = 0.17$ ,  $P > 0.05$ ), Area of living ( $\chi^2 = 11.95$ ,  $P > 0.05$ ), and Source Of Information ( $\chi^2 = 0.511$ ,  $P > 0.05$ ) and knowledge regarding home care management of the child ( $\chi^2 = 0.272$ ,  $P > 0.05$ ). Hence research hypothesis ( $H_2$ ) rejected and statistical hypothesis accepted at less than 0.05.

#### **CONCLUSION:**

Although medical advances in the treatment of Thalassemia have led to increased survival rates, patients still suffer from disease complications, frequent blood transfusion has also led to iron overload with many complications including endocrinopathies, behavioral and neurotic problems, growth failure, cardiovascular problems, liver disease, gonad dysfunction and delayed puberty, iron overload requires Iron Chelation Therapy (ICT) in order to reduce the excess iron load that is not eliminated properly. The Quality of Life of individuals with Thalassemia major is influenced by many factors such as the impact of the diagnosis and treatment, having a chronic condition, appearance, and treatment components like frequent hospital visits for transfusion.

Once a child is diagnosed to have Thalassemia homozygous disorders, he/she has to take lifelong treatment. Management includes regular 3weekly filtered packed red cell transfusions, chelation therapy for iron overload, management of complications of iron overload and transfusions, including osteoporosis, cardiac dysfunction, endocrine problems, Hepatitis B & C, HIV infection, CMV etc. However, this optimal treatment comes at a prohibitive cost. The cost of treatment of an average weight 4-year-old thalassaemic child is around Rs. 90,000-100,000 annually in a private set-up. Therefore, not more than 5-10% of thalassaemic children born in India receive optimal treatment.

People suffering from Thalassemia are unknowingly passing on this genetic disorder to their children. So genetic counseling is important aspect for diagnosis and aiming to replace misunderstandings about the causes of Thalassemia. Teenage screening and pre-marriage counseling is the step-forward for antenatal diagnosis. This will definitely bring down the above incidences. Therefore home care teaching programme can promote the self efficiency of the parents.

#### **IMPLICATION:**

The finding of the study had varied implications in different areas of nursing practice, nursing administration, nursing education and nursing research.

#### **Nursing practice:-**

The study reveals that there is need of motivation for education program on home Care Management of Thalassemia. The study stress that there is need of involvement of parents of Thalassemia children, caregivers and community leaders and health professionals in Planning and conducting such programme regarding care of child having Thalassemia. Nowadays Thalassemia is a common disorder occurring among children it is directly affect the entire family members and Society so parents should have adequate knowledge regarding their child care at home or home Care Management of their children and so they can give better care to their children. Parents should have clear knowledge about the occurrence of Thalassemia its causes sign and symptom, types, management and treatment, home Care Management of their children. Only having knowledge is not enough to use knowledge in practical setting so the study reveals about the home care management of emphasize on care of children at home

#### **General and nursing education:-**

This study reveals that there is lack of knowledge regarding home Care Management of Thalassemia children among their parents. The major implication of this study in general and nursing education enhance the knowledge on Homecare management of Thalassemia children among parents and important aspect of basic programme. The primary task of education would be to implement education through the curriculum for school and college students and special training should to be given to the teachers about pre-marital premarital counseling, and should conduct awareness programme regarding home care of children suffering from Thalassemia at home because it improves awareness regarding Thalassemia.

#### **Nursing administration:-**

The nursing administration should plan and organize the in-Service education and continuing nursing education regarding Thalassemia their causes and prevention and home Care Management to the nursing staff, So they can organize different programme regarding prevention of Thalassemia and their home Care Management in hospital and community settings So the knowledge can enhance in the community and the burden of the disease can be reduced.

#### **Nursing research:-**

This study has already reveals that there is lack of knowledge among parents about the care of their child at home. This study enlightens that there is need to continue the effective awareness among the parents of Thalassemiac children. Newer and advance methods of teaching focusing of Home Care Management can improve care of Thalassemia children at home to reduce the complications and to improve the quality of life.

#### **RECOMMENDATIONS**

1. A future study can be conducted about Thalassemia on their parents.
2. Prevention of Thalassemia and pre-marital counseling can be implemented in the curriculum of school and

- colleges.
3. Special knowledge should be given to the caregivers and community people to involve, plan, organize and motivation regarding prevention of Thalassemia and care of Thalassemia children.
  4. Government should take actual Participation in prevention of Thalassemia programme by educating the community regarding Importance of premarital counseling.
  5. A comparative study regarding prevention of Thalassemia and home Care Management Can be consider on Urban and rural parents of Thalassemia children.

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