

**“ASSESSMENT OF THE EFFECTIVENESS OF SELF-INSTRUCTIONAL MODULE
ON KNOWLEDGE REGARDING HOME CARE MANAGEMENT OF
THALASSEMIA CHILDREN AMONG THE PARENTS IN A.V.B.R. HOSPITAL,
WARDHA”**

Abstract:

Background of study: Thalassemia is a genetic condition in which the production of globin chains is reduced or non-existent. Beta-thalassemia is caused by mutations in the beta-globin gene, which impede the formation of beta-globin chains. Based on clinical severity, beta thalassemia is categorised as follows.

The most severe form of beta thalassemia is characterised by severe anaemia and the requirement for blood transfusions. Anaemia caused by beta thalassemia intermedia can be treated with medication or transfusions. Beta thalassemia minima- Also known as beta thalassemia trait, this type is typically asymptomatic.

Children with beta-thalassemia major require regular blood transfusions, which can result in issues such as iron overload and the transfer of illnesses such as HIV, HCV, and HBsAg, all of which can shorten their life. Inadequate transfusions, on the other hand, result in severe anaemia as well as fatigue and debility.

Objectives:

1. To measure parents' existing knowledge of thalassemia children's home care management.
2. To analyse the efficiency of a self-instructional module on thalassemia children's home care management expertise.
3. To link the post-test knowledge score to the demographic factors chosen.

Material and method: A descriptive research design study was conducted to evaluate the efficiency of a self-instructional module on parental understanding of thalassemia children's home care management. The total number of samples in this study was 30. All of them were parents of thalassemia children from A.V.B.R. Hospital in Sawangi (Meghe), Wardha. The study employed a non-probability convenient sampling strategy, with the instrument being designed questionnaires on parental understanding of their children's

medical conditions and knowledge of home care management of thalassemia. Based on the aims and hypothesis, the data was statistically analysed using various tests such as descriptive statistics and inferential statistics.

Results: The purpose of this study was to determine the efficiency of a self-instructional module on parental understanding of thalassemia children's home care management. Following the installation of the self-instructional module, 63.33 percent of Thalassemia parents had a poor level of knowledge and 36.67 percent had an average level of knowledge prior to the exam, according to analysis. The lowest knowledge score on the pre-test was 2 and the highest knowledge score was 7. The pre-test mean percentage of knowledge score was 33.559.17, and the pre-test mean knowledge score was 5.031.37. Post-test knowledge scores were average for 23.33 percent of Thalassemia parents and excellent for 76.67 percent of Thalassemia parents. The minimum post-test knowledge score was 8 and the maximum post-test knowledge score was 14. The mean post-test knowledge score was 11.901.84, and the mean percentage of knowledge score was 79.3312.29.

Conclusion: The current study's pre-test results reveal that parents of thalassemia children had insufficient information about thalassemia home care management. Following the self-instructional module, it was a modest attempt to develop understanding of thalassemia home care management. Based on their pre-test scores, 19% of subjects had low knowledge, 11% had moderate knowledge, and 0% had strong knowledge, according to the findings. However, according to post-test results, 0% of subjects had low knowledge, 7% of subjects had average knowledge, and 23% of subjects had strong knowledge. As a result, the post-test knowledge score was statistically interpreted to be greater than the pre-test knowledge score.

Keywords: Effectiveness, Home care management, self-instructional module, thalassemia.

Introduction:

“It is the children who grow up to preserve the world when it is on the verge of breaking.”

- Frank Warren

According to the World Health Organization (WHO), at least 6.5% of the world's population has inherited haemoglobin abnormalities. According to another WHO

study, 3% of Bangladesh are beta-thalassemia carriers and 4% are Hb E carriers. Each year, more than 7000 children in Bangladesh are born with thalassemia.

The majority are born in nations with little resources, where high rates of infant and child mortality due to infectious illnesses and malnutrition are prioritized. Patients with beta-thalassemia major and Hb E\beta-thalassemia do not live longer than 5 years without receiving blood transfusions.

Thalassemia (also known as Mediterranean anemia, Cooley's anemia, beta-thalassemia or alpha-thalassemia) is the most common inherited single-gene illness in the world. Anemia is caused by the excessive breakdown of red blood cells caused by a certain type of blood disorder. The importance of haemoglobin must be understood in order to gain a better knowledge of this condition.

Hemoglobin is an iron-containing oxygen transport protein present in red blood cells that transports oxygen from the lungs to the rest of the body and subsequently returns carbon dioxide to the lungs to be exhaled. People with thalassemia manufacture fewer healthy human globin proteins, as well as less healthy red blood cells in their bone marrow. There isn't enough haemoglobin to assist carry oxygen to the body because there aren't enough normal red blood cells. Thalassemia is a hereditary condition, meaning it is handed down from one generation to the next.

Athlasemia is a blood disorder that affects people from Southeast Asia, the Middle East, China, and African Americans. People from the Mediterranean region, Chinese, other Asians, and African Americans are all susceptible to b-thalassemia. This entry was posted on July 8, 2010.

Thalassemia is a category of hereditary disorders caused by a deficiency in the synthesis of the globin chain of the RBC's haemoglobin component. Anemia is caused by the excessive breakdown of red blood cells caused by this type of blood illness. RBC breakdown occurs early in this condition because of an aberrant protein chain that is unable to shield the RBC from oxidative damage. As a result of the RBC breakdown, bilirubin is produced, which is then processed in the liver and excreted.

The pace of RBC destruction in thalassemia is so fast that it exceeds the liver's ability to digest the extra bilirubin. They are most common in countries where their control and management are hampered by a lack of awareness of their true prevalence, effective services for their management and control and government and international health agency support. However, considerable progress has been made in addressing these issues and there are various ways in which the future prospects of children with thalassemia in poor nations could be improved.

In the richest countries of the globe, the control and management of thalassemia has improved dramatically during the previous 20 years. Unfortunately, this is not the situation in many developing countries, where there has been no improvement in the control of the number of thalassemia babies born or in the care of thalassemia.

Material and Methods:

In this study, an evaluative approach was applied, as the goal of this study was to assess the efficiency of a self-instructional module on knowledge of thalassemia child home care management among parents at A.V.B.R. Hospital. Informed consent was taken from the participants. The subject is requested to complete the tool after assuring confidentiality of the information. I explained the need for and purpose behind the research. The participants actively participated; data got collected and finally the investigator thanked all of the research samples as well as the authorities for their assistance after the data collection process was completed.

POPULATION

In this study, the population is divided into two groups: target and accessible.

TARGET POPULATION

The target population consists of a collection of cases that the researcher wishes to generalise. The parents of children with thalassemia were the study's target demographic.

ACCESSIBLE POPULATION

The aggregated of cases that confirm to design criteria and that are accessible as subject for a study. The accessible population for this study was parents of thalassemia child from A.V.B.R. Hospital, Sawangi (Meghe), Wardha

- **Inclusion criteria**

- Parents of children aged between 1-18 years with thalassemia**

1. Parents who could understand/read/write Marathi or English.
2. Parents of children who are admitted in pediatric ward and who are attending outpatient department.
3. Those who are willing to participate in the study.

- **Exclusion criteria:**

1. Those who are not willing to participate in the study.

SAMPLE SIZE

“A sample is a subset of units that make up a population that is accessible.” The sample size for this study was 30 parents of children with thalassemia who are admitted to a pediatric unit and attend outpatient clinics.

SETTING OF THE STUDY

This research was carried out in a few areas of the hospital, such as the outpatient department and the ward. The investigator determined that the context was suitable for conducting the study since a sufficient number of samples (parents of thalassemia children) were available, and the hospital authorities were cooperative and granted permission to do the study.

SAMPLING TECHNIQUE:

CRITERIA FOR SAMPLE SELECTION

Non-probability purposive sampling method was utilised in the investigation. This sample technique comprises choosing the most readily available individuals as study subjects; it represents a typical situation, and the researcher's knowledge of his population and its components can be used to hand pick cases. Because of the time constraint, the investigator preferred to employ this sample approach to complete the data collection in the allotted time.

TOOL PREPARATION

A tool is an instrument or equipment used for collection of data.

DEVELOPMENT OF THE TOOL

The investigator created the tool after updating their theoretical understanding of thalassemia home care management, as well as their own experience, theoretical knowledge, and guidance from specialists, as well as a review of literature that aided in the development of the tool required for the study. Three sections make up the structured questionnaire.

Section-I: contains demographic information about the parents who will take part in the research. Age, gender, education, income, and so on are examples of variables to consider.

Section II: consists of four questions about parents' understanding of their child's illness condition, spanning three domains.

- Definition and causes of thalassemia.
- Sign and symptom of thalassemia.
- Diagnostic evaluation of thalassemia.

Section-III: There are 11 questions on knowledge about thalassemia home care management, with the majority of them focusing on:

- Diet and nutrition
- Exercise
- Personal hygiene and
- Infection control

Scoring:

- Score 1 was given for correct answer.
- Score 0 was given for wrong answer.

Knowledge was graded from poor knowledge to very good knowledge based on score.

Area of knowledge	Question of items	Maximum score obtained
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• Thalassemia	1(6)	1
• Causes of thalassemia	1(7)	1
• Sign and symptoms and diagnostic evaluation of thalassemia	2(8-9)	2
• Home care management	11(10-20)	11
Total	15	15

Table: scoring procedure on knowledge regarding home care management of thalassemia.

METHOD OF DATA COLLECTION

The degree to which an instruction measures what it is meant to measure is referred to as validity. The tool was handed to four specialists from various areas to ensure content authenticity. After consulting with specialists and consulting with the guide, certain changes were made to the item's framing, which were then included into the tool.

The data collection procedure began on March 24th and 25th, 2021. The investigator paid a pre-arranged visit to Acharya Vinoba Bhave Rural Hospital in Sawangi (Meghe), Wardha, and got the required authorization from the authorities. To promote greater cooperation during data collection, the investigator introduced himself and told them about the purpose of the study.

At the outpatient department and in the paediatric hospital, the investigator addressed parents of thalassemia children and explained the objective of the research and how it will benefit them. They gathered information about the study and participants, made them feel at ease, orientated them to the study, and presented a questionnaire to them. They told them not to contact them directly if they had any questions, and any concerns were cleared up. Once the questionnaires were completed, the investigators returned them to the participants. Each sample took an average of 30 minutes to complete the structured questionnaire. Following the pre-test, the self-instructional module on thalassemia home care management was provided. For a better understanding of these issues, this was translated into Marathi.

On the seventh day, the same questionnaire was used for the post-test. The data collection was completed in the allotted time. The investigator thanked everyone in the research sample

as well as the authorities for their cooperation once the data collection procedure was completed.

Result:

The findings are organized and presented in four parts as shown below:

SECTION A: PARENTAL DEMOGRAPHIC DISTRIBUTION.

This section examines the percentage distribution of Thalassemia parents by demographic factors. A suitable sample of 30 participants was selected from the research population, all of whom were residents of a certain location. Age, education, family type, and monthly family income (Rs) were all used to define the sample characteristics.

n=30

Demographic Variables	No. of older adults	Percentage (%)
Age of Parents (yrs.)		
25-30yrs	22	73.3
31-35yrs	5	16.7
36-40yrs	3	10.0
40yrs and above	0	0
Education		
Primary	21	70.0
Secondary	8	26.7
Higher Secondary	1	3.3
Under graduation	0	0
Types of Family		
Nuclear	23	76.6

Joint	2	6.7
Extended	5	16.7
Monthly Income (Rs)		
Rs 5000	23	80.0
Rs 5000-10000	3	10.0
Rs 10000-15000	3	10.0
> Rs 15000	0	0

Table 1: Percentage wise distribution of parents according to their demographic characteristics.

SECTION B: ASSESSMENT OF LEVEL OF KNOWLEDGE REGARDIN THE HOME CARE MANAGEMENT OF THALASSEMIA CHILDREN AMONG THE PARENTS IN SELECTED AREA.

This section examines the degree of knowledge among parents in a given location about how to care for their Thalassemia children at home. Poor, average, and good are the three levels of knowledge.

n=30

Level of pre-test knowledge	Score Range	Level of Pre-test Knowledge Score	
		No of parents	Percentage
Poor	0-33% (1-5)	19	63.33
Average	34-67% (6-10)	11	36.67
Good	68-100% (11-15)	0	0
Minimum score		2	
Maximum score		7	

Mean knowledge score	5.03 ± 1.37
Mean % Knowledge Score	33.55 ± 9.17

Table 2: Assessment of level of knowledge regarding home care management of thalassemia children among parents

According to the table above, 63.33 percent of Thalassemia parents had a low level of knowledge and 36.67 percent had an average level of knowledge before to the exam. The pre-test had a minimum knowledge score of 2 and a maximum knowledge score of 7 The mean percentage of knowledge score in the pre-test was 33.559.17, and the mean knowledge score in the pre-test was 5.031.37.

n=30

Level of post-test knowledge	Score Range	Level of Post-test Knowledge Score	
		No of parents	Percentage
Poor	0-33% (1-5)	0	0
Average	34-67% (6-10)	7	23.33
Good	68-100% (11-15)	23	76.67
Minimum score		8	
Maximum score		14	
Mean knowledge score		11.90±1.84	
Mean % Knowledge Score		79.33±12.29	

Table 3: Assessment with level of post-test knowledge

The above table shows that 23.33% of parents of Thalassemia children had average and 76.67% of parents had good level of post-test knowledge score Minimum knowledge score in post-test was 8 and maximum knowledge score in post-test was 14. Mean knowledge score in post-test was 11.90±1.84 and mean percentage of knowledge score in post-test was 79.33±12.29.

SECTION C: EVALUATION OF THE SELF-INSTRUCTIONAL MODULE'S EFFICACY ON PARENTS' UNDERSTANDING OF HOME CARE MANAGEMENT FOR THALASSEMIA CHILDREN.

This part examines the efficiency of a self-instructional module for Thalassemia children's home care management among parents in a specific location. The hypothesis is statistically evaluated using post-test and post-test mean and standard deviation distributions, as well as the mean percentage knowledge score. To demonstrate the efficacy of the Self-Instructional Module, the levels of knowledge during the pre-test and post-test are compared. Student's paired 't' test is used to determine the significance of the difference at the 5% level of significance, and the tabulated 't' value is compared to the computed 't' value. The computed p values are also compared to an acceptable p value of 0.05.

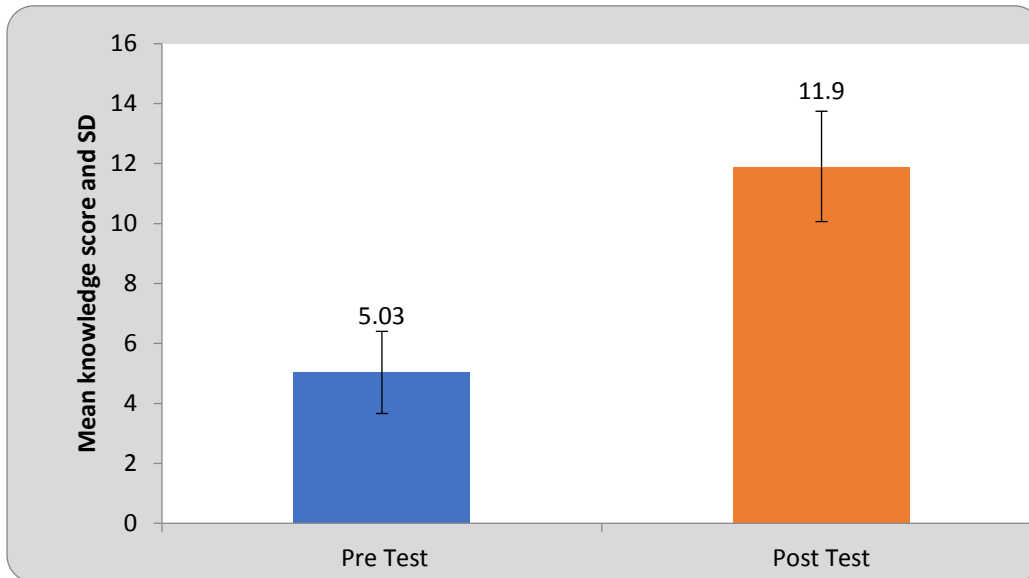
n=30

Overall	Mean	SD	Mean Difference	t-value	p-value
Pre-Test	5.03	1.37	6.86±2.62	14.34	0.0001
Post-Test	11.90	1.84			S,p<0.05

Table 4: Significance of difference between knowledge score in pre and post-test of parents of Thalassemia children

This table compares the knowledge scores of Thalassemia parents about home care management before and after the pre-test. The mean, standard deviation, and mean difference values are compared, and the student's paired' test is used at a significance level of 5%. For n=30-1 (29 degrees of freedom), the tabulated result was 2.05. The computed 't' value, 14.34, is significantly higher than the tabulated value for overall knowledge score of parents of Thalassemia children at a statistically acceptable level of significance of 5%. As a result,

statistical analysis indicates that the Self-Instructional Module on home care management knowledge was successful. As a result, the H1 gets approved.



Graph 1: Significance of difference between knowledge score in post and post-test of Parents of Thalassemia children

SECTION D: ASSOCIATION OF LEVEL OF POST TEST KNOWLEDGE SCORE REGARDING HOME CARE MANAGEMENT OF THALASSEMIA CHILDREN AMONG PARENTS IN RELATION TO DEMOGRAPHIC VARIABLES.

n=30

Age (years)	No. of parents	Mean post-test knowledge score	F-value	p-value
25-30 years	22	11.31±1.80	5.65	0.009 S,p<0.05
31-35 years	5	13.20±0.44		
36-40 years	3	14±0		
40 years and	0	0±0		

above				
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Table 5: Association of post-test knowledge score regarding home care management of thalassemia according to their relation to age.

This table depicts the relationship between a parent's knowledge score and their age in years when it comes to thalassemia child home care management. The computed 'F,' i.e., 5.65 at a 5% level of significance, was significantly higher than the tabulated 'F,' which was 3.35 (df=2,27). Furthermore, the computed 'p'=0.009 was much greater than the accepted level of significance, which was 'p'=0.05. As a result, it is concluded that parents' age in years is statistically unrelated to their post-test knowledge score.

n=30

Qualification	No. of parents	Mean post-test knowledge score	F-value	p-value
Primary	21	11.85±2	0.17	0.84 NS,p>0.05
Secondary	8	11.87±1.55		
Higher secondary	1	13±0		
Graduate	0	0±0		

Table 6: Association of post-test knowledge score regarding home care management of thalassemia according to their qualification.

This table depicts the relationship between parental knowledge and educational degree in terms of thalassemia child home care management. The estimated 'F,' i.e., 0.17 at the 5% level of significance, was significantly higher than the tabulated 'F,' which was 3.35 (df=2,27). Furthermore, the computed 'p'=0.84 was much greater than the accepted level of

significance, which was $p=0.05$. As a result, it's assumed that elder parents' educational degree has no statistically significant relationship with their post-test knowledge score.

n=30

Type of family	No. of parents	Mean post-test knowledge score	F-value	p-value
Nuclear	23	12±1.75	0.26	0.76 NS, $p>0.05$
Joint	2	11±4.24		
Extended	5	11.80±1.64		
Govt. Servant	10	14.70±2.11		

Table 7: Association of post-test knowledge score regarding home care management of thalassemia children according to their type of family

This table depicts the relationship between parental knowledge and the sort of family they come from when it comes to thalassemia children's home care. The computed 'F,' i.e., 0.26 at the 5% level of significance, was significantly higher than the tabulated 'F,' which was 3.35(df=2,27). Furthermore, the computed $p=0.76$ was much greater than the accepted level of significance, which was $p=0.05$. As a result, it is concluded that a parent's family type is statistically unrelated to their post-test knowledge score.

n=30

Monthly income (Rs)	No. of parents	Mean post-test knowledge score	F-value	p-value
Rs 5000	24	11.62±1.92	1.47	0.24 NS, $p>0.05$
Rs 5000-10000	3	12.66±1.15		
Rs 10000-15000	3	13.33±0.57		
> Rs 15000	0	0±0		

Table 8: Association of post-test knowledge score regarding home care management of thalassemia according to their monthly income (Rs)

This table depicts the relationship between a parent's monthly income (Rs) and their knowledge on how to care for their thalassemia children at home. The estimated 'F,' i.e., 1.47 at a 5% level of significance, was significantly greater than the tabulated 'F,' which was 3.35 (df=2,27). Furthermore, the computed 'p'=0.24 was much greater than the accepted level of significance, which was 'p'=0.05. As a result, it is concluded that parents' monthly income (Rs) has no statistically significant relationship with their post-test knowledge score.

Reliability Analysis: By Karl Pearson's coefficient formula.

Pearson's Correlation Coefficient	0.705
Reliability (%)	0.8269%

It is determined to be 0.8269 percent utilizing Karl Pearson's coefficient formula technique of dependability, indicating that the instrument is trustworthy and valid.

DISCUSSION:

One of the most frequent and significant mutations in the world is haemoglobin (Hb) E. In many places, it has surpassed -thalassemia as the most prevalent haemoglobinopathy.

Thalassemia includes a number of different forms of anaemia. The severity and type of anaemia depend upon the number of genes that are affected. Thalassemia is caused by mutations in the DNA of cells that make hemoglobin, the substance in your red blood cells that carries oxygen throughout your body. The mutations associated with thalassemia are passed from parents to children.

An entire blood count, haemoglobin electrophoresis or high-performance liquid chromatography, and DNA testing can all be used to diagnose thalassemia. Because haemoglobin electrophoresis is not generally available in impoverished countries, the diagnosis of thalassemia can also be done by using the Mentzer index. It is not a definitive test, but it can indicate that thalassemia is present.

The symptoms often noticed during childhood or adolescence depend on the kind of disease which may be:

Deformities of the bones, specifically in the face, excessive fatigue, dark shaded urine, growth and development delays, breathing problems, skin that is yellow or light in hue, swelling and pain in the abdomen.

Blood transfusions, bone marrow transplants, medicines, and surgery are among options for treating thalassemia, depending on its severity. Iron chelators are medications that help the body eliminate extra iron that has accumulated as a result of numerous blood transfusions needed to treat anaemia. Surgical excision of the spleen may be necessary if it gets excessively oversized. Patients with thalassemia who do not respond well to blood transfusions may be prescribed hydroxyurea or thalidomide, or a combination of approaches. The sole FDA-approved prophylaxis for thalassemia is hydroxyurea.

The client had considerably better haemoglobin levels who received 10 mg/kg hydroxyurea daily for a year, and it was a well-tolerated medication for patients who did not respond well to blood transfusions. Thalidomide is another haemoglobin-inducer; however, it has not been tried in a clinical context.

All people who wish to conceive should be checked for thalassemia, according to the American College of Obstetricians and Gynaecologists. For families that have a thalassemia trait, genetic counselling and testing are recommended, as well as prenatal screening and abortion.

In India, both government and non-government organisations are organising large-scale awareness campaigns in support of optional premarital screening to detect thalassemia carriers, and marriage between both carriers is severely discouraged.

Avoiding iron-rich meals and supplements, consuming a healthy & well-balanced diet, defending yourself against infections, and getting appropriate immunizations on schedule is considered good health education. The findings of the study were discussed with references to the objectives started in chapter-I and with the findings of the other studies in the section. The present study undertaken was "A Study to Assess the Effectiveness of a Self-Instructional Module on Knowledge Regarding Home Care Management of Thalassemia

Children". A detailed review of the literature indicated that there were vast studies that indicated that self-instructional modules had significant effects in improving the knowledge regarding home care management of thalassemia children among parents.

This study was a modest effort to increase the knowledge of home care management regarding thalassemia. The existing knowledge and post-test knowledge among parents about home care management of thalassemia children was measured with the efficacy of the self-instructional module. The finding shows that of the pre-test scores, 19% of the subjects had poor knowledge, 11% of the subjects had average knowledge, and 0% of the subjects had good knowledge. However, in post-test scores, 0% of subjects had poor knowledge, 7% of subjects had average knowledge, and 23% of subjects had good knowledge. Hence, it was statistically interpreted that the post-test knowledge score is higher than the pre-test knowledge score.

Conclusion:

This study comes to the following conclusion after a thorough examination:

The home care management for thalassemia children is unknown to the parents. The amount of knowledge about the issue has significantly increased. A patient who visited the outpatient department and was admitted to the Acharya Vinoba Bhave Rural Hospital's ward was chosen as the study's subject. Following the implementation of the self-instructional module on thalassemia children's home care management. The pre-and post-test knowledge scores of parents on home care practises were assessed using a student paired t-test. In all domains, a student paired t-test was computed between the mean pre-test knowledge score and the mean post-test knowledge score. According to the findings, 63.33 percent of individuals have low understanding, 36.67 percent have average knowledge, and 0 percent have good knowledge of home care management for thalassemia children.

As a consequence, the self-instructional module was shown to be beneficial in improving comprehension of the home care management of thalassemia children. The parents were helped to improve their knowledge by the investigator's self-instructional module, which was produced in the form of a self-test. According to the findings, 0% of individuals have low knowledge, 23.33 percent have average knowledge, and 76.67 percent have good understanding of thalassemia children's home care management. Giving health education to

parents about disease conditions can help them to increase their knowledge while also improving the quality of their child's care.

Delimitation:

Study is limited up to Acharya Vinoba Bhave Rural Hospital, Sawangi(M), Wardha.

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