Original Research Article

"TO ASSESS THE EFFECTIVENESS OF SELF-INSTRUCTIONAL MODULE ON KNOWLEDGE REGARDING HOME CARE MANAGEMENT OF THALASSEMIA CHILDREN AMONG THE PARENTS"

Abstract:

Background of study: Thalassemia is a category of hereditary disorders in which the generation of globin chains is decreased or non-existent. Beta-thalassemia is caused by mutations in the beta-globin gene that prevent beta-globin chain production. The following is how beta thalassemia is classified based on clinical severity.

Beta thalassemia major- The most severe form of beta thalassemia, characterized by severe anemia and the need for blood transfusions. Beta thalassemia intermedia- Anemia can be treated with sporadic or transfusions. Beta thalassemia minima- This variant, also known as beta thalassemia trait, is frequently asymptomatic.

Children with beta-thalassemia major require frequent blood transfusions, which can lead to complications such as iron overload and the transmission of diseases such as HIV, HCV and HBsAg which can shorten their lifespan. Inadequate transfusions, on the other hand, cause severe anaemia as well as overall weariness and debility.

Objectives:

1. To measure parents' existing knowledge of thalassemia children's home care management.
2. To analyses 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 undertaken to assess the effectiveness of self-instructional module on knowledge regarding home care management of thalassemia children among parents. In this study the total number of samples 30 who

fulfilled the inclusion criteria was parents of thalassemia children from A.V.B.R. Hospital, Sawangi (Meghe), Wardha. The study was non-probability convenient sampling technique used and the tool was the structured questionnaires on knowledge regarding disease condition of children among the parents and knowledge regarding home care management of thalassemia. The data gathering process began based on the objectives and the hypothesis the data was statistically analysed with various tests such as descriptive statistics and inferential statistics.

Results: This study was planned to assess the effectiveness of self-instructional module on knowledge regarding home care management of thalassemia children among parents. By following the implementation of the seif-instructional module, as per analysis 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. 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.

Conclusion: The present study pre-test findings show that the study participants had inadequate knowledge among parents of thalassemia children regarding home care management of thalassemia. After the self-instructional module, it was a modest effort to increase the knowledge of home care management regarding thalassemia. The finding shows that the pre-test score, 19% of subject was having poor knowledge, 11% of subject were having average knowledge, 00% of subject were having good knowledge. However, in post-test scores, 0% of subject were having poor knowledge, 07% of subject were having average knowledge, 23% of subject were having good knowledge. Hence it was statistically interpreted that post-test knowledge score is higher 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

"Our daily lives are shaped by health and illness. We can live a full life and operate as social beings when we are healthy. Our lives are disrupted by illness, when can be serious at times. However, health has an impact not only on individuals, but also on society as a whole."

The children of today are the future's resources. The safety of their lives will always come first. The care of children from infancy to adolescence is referred to as child health. The majority of the children suffer from one or more illnesses. Some of them may be sick for a short period and not require hospitalization, while others may require hospitalization and long-term therapy.[1]

Children who are healthy grow up to be healthy adults who make better lives for themselves, their communities and their countries. Improving children's health is just one of many responsibilities in the battle against property.

A child's growth and development, as well as his or her functional abilities, are affected by health issues. Some illnesses may render them temporarily or permanently disables.[2]

Thalassemia is the most common hereditary blood illness in the world and it affects people from all walks of life.[3]

According to the World Health Organization (WHO), at least 6.5% of the world's population has inherited haemoglobin abnormalities.[4] According to another WHO research, 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.[5]

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.[6] Patients with beta-thalassemia major and Hb E\beta-thalassemia do not live longer than 5 years without receiving blood transfusions.[7]

Thalassemia (also known as Mediterranean anemia, Coolley'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.[8] The importance of hemoglobin must be understood in

order to gain a better knowledge of this condition.[9]

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 hemoglobin 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. [11]

A thalassemia is a blood disorder that affects persons from South east Asia, the Middle East, China and African Americans.[12] People from the Mediterranean region, Chinese, other Asians and African Americans are all susceptible to b-thalassemia. [12]

Thalassemia is a category of hereditary disorders caused by a deficiency in the synthesis of the globin chain of the RBC's hemoglobin 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 to an aberrant protein chain that is unable to shield 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. [13-14]

Method:

In this study, an evaluation approach was applied. Because 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, this approach was chosen. The research design employed in this study was a pre-experimental one group pre-test, post-test research design. A structural questionnaire was used to conduct a pre-test, and then planned instruction was given as X. The same structured questionnaire represented as 0-2 was used to conduct a follow-up test

The investigator obtained permission from the concerned authorities of Smt. Radhikabai Memorial College of Nursing and the banks in Wardha city respectively. Informed consent is taken from the participants. The subject is requested to complete the tool after assuring

confidentiality of the information. Consent is obtained from the subject. Explained what is the need and purpose behind conducting the research. The participant's 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.

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: ASSESSMENTOFLEVEL 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 with level of knowledge

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.

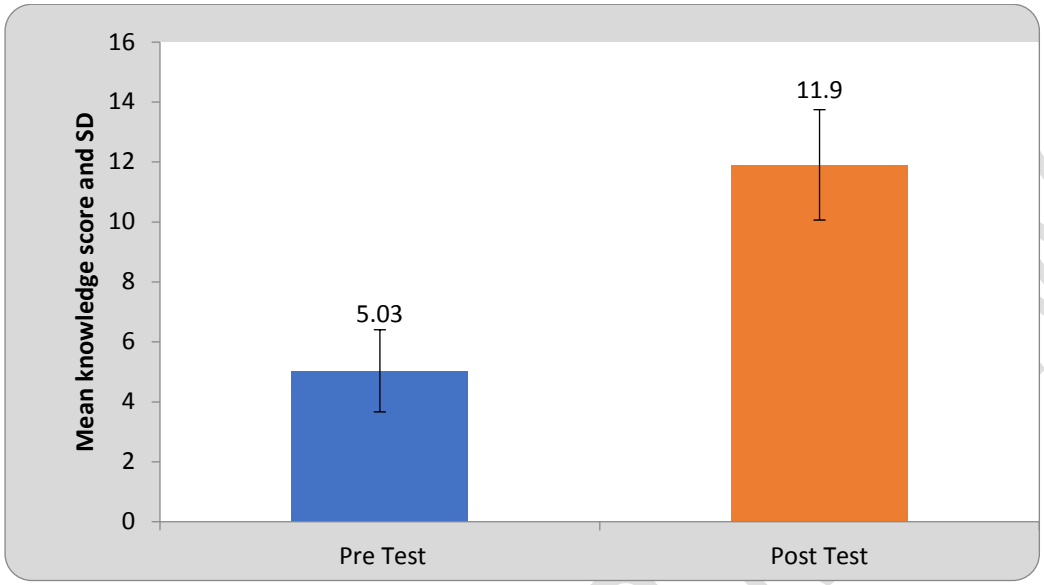
n=30

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

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 above	0	0±0		

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 depends upon the number of genes that are affected. Thalassemia is caused by mutations in the DNA of cells that make haemoglobin - 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 done by using Mentzer index; it is not a definitive test, but it can indicate that thalassemia is present.

The symptoms often noticed during childhood or adolescence are depending 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 appropriate immunizations on schedule is considered as a good health education. The finding of the study was 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 effectiveness of self-instructional module on knowledge regarding home care management of thalassemia children among parents. A detailed review of literature indicated that the they were vast studies indicated that self- instructional module had significant effect 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 finding shows that the pre-test score, 19% of subject was having poor knowledge, 11% of subject were having average knowledge, 00% of subject were having good knowledge. However, in post-test scores, 0% of subject were having poor knowledge, 07% of subject were having average knowledge, 23% of subject were having good knowledge. Hence it was statistically interpreted that 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 seif-instructional module on thalassemia children's home care management. The pre- and post-test knowledge scores of parents on home care practices 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 on 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.

Delimitation:

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

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