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Effectiveness of Multimodal Intervention Package to Assess the Nutritional Status & Psycho-Social Wellbeing among Children with Thalassemia Attending Thalassemia Unit of HSK Hospital & Research Center Bagalkot, Karnataka

Sureshgouda S Patil¹, Daisy Rani¹, Deelip S Natekar²

¹Professor and HOD, Department of Paediatric Health Nursing, BVVS Sajjalashree Institute of Nursing Sciences, Navanagar, Bagalkot, Karnataka, India, ¹Basic B Sc Nursing 4th year, B.V.V.S Sajjalashree Institute of Nursing Sciences, Navanagar Bagalkot, Karnataka, India, ²Principal, B.V.V.S, Sajjalashree Institute of Nursing Sciences, Navanagar, Bagalkot, Karnataka, India

Abstract

Background of the study: Every year approximately 100,000 children with Thalassemia Major are born world over, of which 10,000 are born in India. It is estimated that there are about 65,000-67,000 β -thalassemia patients in our country with around 9,000-10,000 cases being added every year

Once a child is diagnosed to have thalassemia homozygous disorders, he/she has to take lifelong treatment. Management includes regular 3 weekly filtered packed red cell transfusions, chelation therapy for iron overload.

Objectives of the study: • To find out the effectiveness of multi-model interventional package on nutritional status & psycho-social well being of children

- To find out the association between nutritional status & psycho-social well being with selected socio-demographic variables
- To identify the correlation between nutritional status & psycho-social well being of children

Materials & Methods: An experimental research approach was used for the study with pre experimental one group pre test -post test without control group design. Study was conducted at thalassemia unit of Hanagal Shri Kumareshwar Hospital and research center Bagalkot, Karnataka. Using digital weighing machine weight of children has been collected followed by this Likert;s scale is used to assess the Psycho-social wellbeing of 100 children who were selected by purposive sampling technique. The effectiveness was determined by paired t test and the association was explored by chi-square test, correlation is determined by Karl Pearsons Correlation coefficient.

Results: A sample of 100 children were taken in the study, amongst 60% of children were in the age group of 7-9 years. 32% children were severely malnourished. 90% children had fair quality of life. The calculated t value is 6.84 at 5% level of significance and the p value is less than 0.00001 which determines there is a significant difference between the pre-test nutritional scores and Post-test nutritional scores of children. The value of R is 0.0917, indicating the relationship existing between two variables is weak.

Conclusion: results revealed that more than 90% of children were having fair quality of life and 32% of children are in severe malnutrition category. Hence it is concluded that thalassemia severely affects the nutritional status and quality of life of children. In the present study multimodal interventional package has played a significant role in improving the quality of life and nutritional status of children. Study recommends for future researchers to conduct studies to improve other aspects of quality of life of thalassemic children.

Key words: Malnutrition, Psycho-social wellbeing, quality of life, multi-model interventional package, thalassemia.

Introduction

Thalassemia is a blood disorder caused by weakening and destruction of blood cells. It inhibits production of hemoglobin and RBCs. Children with thalassemia require regular blood transfusions and bone marrow transplantations. Over 10,000 children in the country are born with thalassemia every year.¹

Thalassemia syndromes are a heterogeneous group of single gene disorders, inherited in an autosomal recessive manner, prevalent in certain parts of the world.² Worldwide 15 million people have clinically apparent thalassaemic disorders. It is estimated that there are about 65,000-67,000 β -thalassaemia patients in our country with around 9,000-10,000 cases being added every year (1-7). The carrier rate for β -thalassaemia gene varies from 1 to 3% in Southern India to 3% to 15% in Northern India. They are encountered among all ethnic groups and in almost every country around the world.³

Nutritional deficiencies are common in thalassemia, due to hemolytic anemia, increased nutritional requirements, and morbidities such as iron overload, diabetes, and chelator use.⁴

Thalassemia has severe complications such as heart failure, cardiac arrhythmia, liver disease, endocrine complications, and infections are common among thalassemia patients. Despite the critical advances in the knowledge of the psychological assessment in chronic patients, very few studies are carried out to investigate correlation between psychological conditions and quality of life in Thalassemia major (TM) patients. As the mean age and life expectancy of TM patients expands, psychosocial issues related to quality of life become an increasingly important focus of attention. It is universally known that chronic diseases have a psychological implication, which in pediatric age has a great importance. Children with chronic physical illnesses exemplified by thalassemia are vulnerable to emotional and behavioral problems.⁵

Various authors have reported that up to 80% of children with thalassemia are likely to have psychological problems like oppositional defiant disorder, anxiety disorder and depression.⁶ Although children with all types of blood disorders are exposed to similar stressors, those with thalassemia are unique in that they have to

attend hospital regularly for blood transfusions.⁶

Material and Methods

Study Design and Participants

An experimental research approach with pre experimental one group pretest post-test design without control group was used in the present study. Study conducted for the period of 6 months from Oct 2019 to March 2020 in HSK Hospital and Research center Bagalkot Karnataka. The sample for the present study was 100 children in the age group 3-12 years with thalassemia selected by purposive sampling technique. Digital weighing machine for weight measurement & structured Likert's scale to assess the quality of life of children were used. Observation and structured interview schedule were data collection techniques. Intervention was given in the form of Nutritional training intervention; peer group interaction & parental support group & post test was conducted by using the same scales to assess the effectiveness of intervention.

Criteria for Sample selection:

Inclusion Criteria:

The study includes children who were

- Attending thalassemia unit of HSK hospital & Research center Bagalkot Karnataka
- Able to understand Kannada.
- Available at the time of data collection
- Willing to participate in the study

Exclusion criteria

The study excludes children who were

- Not able to co-operate during the study.
- Sick and not able to provide data.

Sample size

A total of 100 children suffering from thalassemia attending thalassemia unit of HSK Hospital & research center Bagalkot were taken.

Instruments

For Weight Measurement: A digital weighing machine has been used to record weight of children. Used WHO Anthro Plus software for assessment of nutritional status of children.

For Quality of life: Structured Likert's scale was administered to assess the quality of life of children.

Description of Instrument

The instrument was divided into two parts

Part – I: It consists of 8 items regarding the demographic information of the children such as Age, Gender, Educational status, Type of family, Religion, Family monthly income, area of residence,

Part – II: It consists of 20 items with 5 points ranging from never to almost always to assess the quality of life of children. The tool consists of 4 domains like Physical functioning, emotional functioning, and school functioning & social functioning and in all the domains 5 items were included.

Scoring:

Weight: Scoring system for weight of children is Less than -2 Normal. -2 to -8 Moderate malnutrition. More than -3 severe malnutrition.

Quality of life: Grades of quality of life on a scale are excellent, good, fair & poor.

Data Collection Procedures

Prior permission was taken from Hospital authority to conduct the study, Pre-test nutritional status was assessed by digital weighing machine, and quality of life was assessed by taking mothers report on a Likert's scale.

Administration of (multi-model interventional package) intervention as follows

- Nutritional Training Intervention on 10/11/2019 for 2 Hrs.
- Peer Group Interaction on 11/11/2019 from morning 10am to 3pm
- Parent Support Group on 12/11/2019 form

morning 11 am to 4.30 pm.

- After 3 months on 2/2/2020 we have conducted post-test for the same 100 children by using same instruments.

- The investigator has started data collection at 10 am and the whole process has been completed by 5.30 pm.

Data Analysis

Descriptive Statistics

- Frequency and Percentage distribution was used for analysis of demographic variables of children
- Frequency, Percentage distribution, mean and standard deviation for analysis of nutritional status and psycho-social well being (quality of life).

Inferential Statistics

- Paired “t” test was used to compare pre-test and post-test scores for nutritional status & psycho-social well being (quality of life)
- The chi squared (X^2) test was used to find out the association between the nutritional status & psycho-social well being with selected socio-demographic variables
- Karl Pearson's correlation coefficient was used to find out the correlation between nutritional status & psycho-social well being (quality of life).

Results

A: Sample characteristics

A Percentage wise distribution of children according to their age groups reveals that 60% belong to the age group of 7-9 years, followed by 36 % in the age group of 3-6 years, 4% in the age group of 10-12 years. Majority (52%) were female children. Similarly 52% children belong to 1st STD to 3rd STD. A majority 61 % of children were from nuclear family. Majority 92% of children were from Hindu religion. Family monthly income reveals that out of 100 children, 54% of children belongs to Rs.5000- Rs10000/-majority children were (62%) from rural area.

B: Effectiveness of Multi-Model Interventional Package on Nutritional status of children.

Table 1: Mean, SD and mean percentage of nutritional status scores in Pretest and Post-test.

Nutritional status	Pre-test (O ₁)		Post-test (O ₂)		Effectiveness (O ₂ -O ₁)	
	Mean ± SD	Mean %	Mean ± SD	Mean %	Mean ± SD	Mean %
Nutritional status	-2.2108±1.70	4.42%	-1.629 ±1.53	3.25%	-0.589±0.17	1.178

C: Effectiveness of Multi-Model Interventional Package on quality of life of children.

Table 2: Mean, SD and mean percentage of nutritional status scores in Pretest and Post-test.

Quality of Life	Pre-test (O ₁)		Post-test (O ₂)		Effectiveness (O ₂ -O ₁)	
	Mean ± SD	Mean %	Mean ± SD	Mean %	Mean ± SD	Mean %
Quality of Life	52.44±5.35	104.88	30.66±3.43	61.32	-21.78±-1.92	-43.56

Table 1 & 2 presents the mean and standard deviation related to the effectiveness of multi-model interventional package on nutritional status & quality of life among children.

D: To evaluate the effectiveness of Multi Model Interventional Package the following research hypotheses were formulated

Paired ‘t’ test was used to find out the significance of the differences between the pre-test nutritional scores and Post-test nutritional scores of children

Table 3: Significant difference between the pre-test and Post-test scores of nutritional status

Test	Mean	Std. Error	Mean Diff	SD. Diff	Paired t-Value	Table Value
Pre-Test (O ₁)	-2.21	0.011	0.59	0.08	6.84	3.84
Post-Test (O ₂)	-1.62					

The value of t is 6.844863. The value of p is <0.00001 Hence the result is significant at p <0.05.

The calculated t value is 6.84 at 5% level of significance and the p value is less than 0.00001 which determines there is a significant difference between the pre-test nutritional scores and Post-test nutritional scores of children.

Paired 't' test was used to find out the significance of the differences between pre-test scores of quality of life and Post-test scores of quality of life of children.

Table 4: Significant difference between the Pre-test and Post-test scores of quality of life.

Test	Mean	Std. Error	Mean Diff	SD. Diff	Paired t-Value	Table Value
Pre-Test (O₁)	52.44	0.71	21.78	1.92	26.96	2.01
Post-Test (O₂)	30.66					

The calculated value of t is 26.96. The value of p is <0.00001 Hence the result is significant at p <0.05.

The calculated t value is 26.96 at 5% level of significance and the p value is less than 0.00001 which determines there is a significant difference between the pre-test scores of quality of life of children and Post-test scores of quality of life of children. After analysis of findings it reveals that the multi-model interventional package (Nutritional training intervention, peer group interaction & parents support group) is effective in improving the nutritional status & quality of life of children.

E: Association between variables

Part-1 Association between Nutritional status of children and selected Socio demographic variables.

Chi-square was calculated to find out the association between Post-test scores of nutritional status of children with thalassemia with their selected socio demographic variables by using 2x2 contingency table.

There is no significant association between Post-test scores of nutritional status and selected socio-demographic variables: age, gender, and educational status, type of family, religion, family monthly income, child living with and area of residence.

Part-2: Association between quality of life of

children and selected socio demographic variables.

Fisher's exact test was used to calculate the association between Post-test scores of quality of life of children with thalassemia with their selected socio demographic variables by using 2x2 contingency table.

There is no significant association between quality of life of children with the socio-demographic variables: age, gender, educational status, religion, family monthly income, and area of residence. There is a significant association between quality of life of children with the socio-demographic variables: type of family and child living with.

F: Correlation between Nutritional Status & Quality of Life of children

Pearson's Correlation Co-Efficient Formula

Correlation between nutritional status and quality of life of children is determined by Persons correlation coefficient formula. r value is obtained after putting the values of X (Post-test scores of nutritional status) and Y (Post-test scores of quality of life) into the formula. The value of **R is 0.0917**. The value of R is positive which shows that there is a positive correlation-ship exists between two variables & since the R value is near

to **Zero** that indicates the relationship existing between two variables (Nutritional status of children & quality of life of children) is weak. The p value of R is 0.5265 hence the relationship existing between two variables is not significant.

Discussion

The present study was conducted with the aim to assess the nutritional status and psycho-social wellbeing of Thalassaemic children. Study included a sample of 100 children selected using the purposive sampling technique.

Findings of the study showed that, Majority 92% of children were from Hindu religion.

Similar findings were observed by Ankush et al. in their study conducted to assess the quality of life in children with thalassemia majora following up at a tertiary care center in India. In their study, major sample were belonging to Hindu religion.

In the present study findings showed that there is no significant association between quality of life of children with the socio-demographic variable like age.

Findings of the present study were supported by the findings of the study conducted by Sh Ansari,¹ A Baghersalimi,² A Azarkeivan,³ M Najomi,⁴ and A Hassanzadeh Rad.⁵ to assess the quality of life in patients with thalassemia majora result suggested that age had no effect on the QOL (7,15,17 questions in WHOQOL-BREF).

Limitations

The present study has included 100 children because of unavailability of thalassemia children. The study was limited to children with thalassemia attending thalassemia unit of Hanagal Shri Kumareshwar Hospital & Research Center. The present study assessed only the quality of life of children; other aspects of psycho-social well being are not attended. Age of the children was limited to 3years to 12 years.

Recommendations

The similar study can be conducted on a large scale with the sample size more than 1000

The similar study can be conducted on other aspects of psycho-social wellbeing like autonomy, competence, self acceptance, self efficacy etc.

The true experimental study can be conducted with experimental and control group.

Conclusions

The present study concluded that 32% children were with severe malnutrition after introducing nutritional training intervention the extent of malnutrition has been reduced to 22%. Similarly in respect to quality of life 6% children were in poor category which has been reduced to 4% after implementation of parent support group and peer group interaction. Hence it is concluded that interventional programmes are effective in improving the health aspects of children with thalassemia.

Ethical Clearance

Ethical clearance was obtained from the institutional ethical committee of BVVS Sajjalashree Institute of Nursing Sciences, Bagalkot.

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Conflict of Interest: Nil

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