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Original Research Article

Effectiveness of SCOPE Programme on Health Related Quality of Life and Health Status of Thalassemic Children: A Pilot Study

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ABSTRACT

Background: Thalassemia is a single gene disorder characterized by defect in synthesis of globin chains results in breaking down of red blood cells. The health related quality of life and health status of thalassemic children are very poor when compare to normal children of the same age.
Aim: The present pilot study was undertaken to assess the effectiveness of SCOPE (Supportive and Coping strategies, Ongoing Assessment, Prevention of complication and Empowerment) Program on health related quality of life and health status of thalassemic children.
Methods & materials: Quasi experimental non equivalent control group pretest-post design with follow up evaluation was adopted. The sample consisted of 12 children (6 each in experimental and control group) diagnosed with beta thalassemia major selected by purposive sampling technique. Demographic profile, PedsQL 4.0 version and clinical profile were used to collect data.
Results: The result revealed that majority of study participants were male (66.66%); most of them were diagnosed with thalassemia major below 6 months of age. The unpaired t test revealed that there was no significant difference between 2 groups regarding health related quality of life score before intervention. However, the ANOVA test showed that there was significant improvement in quality of life score and health status of thalassemic children after the administration of SCOPE Program.
Conclusion: SCOPE Program is very effective in enhancing the quality of life of thalassemic children.

Key words: Thalassemic children, health related quality of life, health status, beta thalassemia major

INTRODUCTION

Thalassemia is an autosomal recessive disorder characterized by defect in synthesis of hemoglobin which leads to destruction of red blood cells. Children with beta thalassemia Major need to undergo repeated blood transfusion throughout their life. [1] Problems associated with ineffective erythropoiesis and blood transfusion and other factors results in poor physical and emotional health, disturbed social functions and absent from school or inability to continue schooling. [2] These children may also prone to get other complications such as cardiac, dental or orthopedic. Overall, it can be said that health related quality of life and health status of children with thalassemia is poor. Their health conditions are also influenced by multiple factors such as family income, facilities for financial and social support, parental knowledge about the chronic nature of condition and its management etc. [3] Children taking treatment in well established thalassemic

care centers have good life expectancy and increased survival rate when compare to children who are from remote and backward areas where such facilities are less. [4] The basic requirements of care such as packed cell volume (PCV), iron chelators are not adequate or not able to be afforded by the parents. Moreover caregivers from remote areas are not having adequate knowledge about the thalassemia and its management. These factors contribute to the poor quality of life among thalassemic children. [4]

Hence the present pilot study was aimed to assess the effectiveness of SCOPE Programme on Health related quality of life and health status of thalassemic children in selected hospitals of Vijayapur, North Karnataka.

MATERIALS AND METHODS

For the present pilot study, Quasi experimental non equivalent control group pretest-post design (non-randomized clinical trial) with follow up evaluation was adopted. The sample consisted of twelve children with beta thalassemia Major (six each in experimental and control group respectively) who met the sampling criteria were selected by using purposive sampling technique. Since it is a pilot study and aimed to assess the feasibility of intervention, small sample was selected. To reduce the selection bias and minimize threat to internal validity the measures such as matching of pair in both groups was followed. Demographic questionnaire, Pediatric Quality of Life Inventory version 4.0 and clinical profile were used to collect the data from study participants.

The plan of intervention for the present pilot study i.e. SCOPE (Supportive and Coping strategies, Ongoing Assessment, Prevention of complication and Empowerment) Program was prepared by the investigators based on literature review and own clinical experience and validated by experts in the field of pediatric nursing, pediatricians, psychologists and dietitian.

Ethical clearance

The researchers obtained approval from institutional research ethical committee (ref.no. 309/17/18 dated 23/08/2017).

After obtaining informed consent, pretest was administered to both groups. Then SCOPE program was administered for the experimental group. The parent support group was created with six parents and motivated them to support each other by identifying positive coping strategies used by the members of the group and reinforcement was done for positive coping. Health advocacy was given for blood transfusion and chelation therapy free of cost. Nutritional counseling was given for parents regarding foods to be included in thalassemic children diet, foods to be avoided and restricted. Family centered health education was given regarding home care management of children with thalassemia. Weekly phone calls were made to parents for clarifying their doubts, identifying their needs and problems as part of supportive and empowerment strategies.

Post test was conducted after 1month for both experimental and control group children using same tools as of pretest. Also, follow up was done for three months to see the progress in health related quality of life and health status of thalassemic children.

RESULTS

The data was analyzed using descriptive statistics such as mean, frequency and standard deviation as well as inferential statistics procedures like t test and ANOVA. The pilot study findings showed that majority of children were between the age group of 6 to 8 years (66.66% each) and were males (66.66% each) in both groups (table 1).

Table 1: Demographic variables of thalassemic children n= 12

Demographic variables	Experimental Group Frequency	Percentage	Control group Frequency	Percentage
Age:				
6-8yrs	4	66.66%	4	66.66%
8-10yrs	1	16.67%	1	16.67%
10-12yrs	1	16.67%	1	16.67%
Gender:				
Male	4	66.67%	4	66.67%
Female	2	33.33%	2	33.33%
Education:				
Pre-Primary	3	50%	4	66.67%
Primary	3	50%	2	33.33%
Order of the child:				
First	3	50%	2	33.33%
Second	1	16.67%	3	50%
Third & above	2	33.33%	1	16.67%
No. of siblings:				
One	0	0	2	33.33%
Two	5	83.33	3	50%
Three &above	1	16.67%	1	16.67%

Around 5 out of 6 children in experimental group and 4 children in control group diagnosed to have thalassemia major before 6 months of age (fig.1).

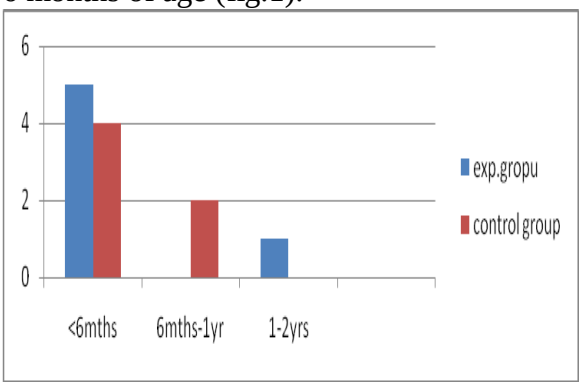

Fig. 1: Age at diagnosis of beta thalassemia major n= 12

On an average the children belonged to experimental group had blood transfusion 14 times per year whereas control group children had transfusion therapy 21 times per year. 66.66% of children in experimental group and 83.33% in control group had previous history of hospitalization at least 2 times for reasons other than blood transfusion like recurrent fever, cough and cold. All the children in both groups were missing chelation therapy due to financial constraints, side effects etc. Only one child in experimental group and 2 children in control group underwent splenectomy. Around 83.33% of children in each group were taking supplements like folic acid.

The pretest results revealed that the health related quality of life (HRQoL) was poor in both groups. The unpaired t test results showed that there was no significant difference between HRQoL score of Experimental group and control group thalassemic children during pretest (table 2).

Table 2: Pretest levels of Health related Quality of Life Score of Experimental group and control group

n=12				
		t-test for Equality of Means		
		t value	df	Level of significance (2-tailed)
Physical functioning		-.215	10	.834
Emotional functioning		-1.697	10	.121
Social activities		.094	10	.927
School activities		2.236	10	.049

It was also identified that the there was significant difference between mean scores of experimental group and control group in relation to physical functioning, and emotional functioning($p \leq 0.05$). However, there was no significant difference in mean scores of social activities and school functioning of thalassemic children among the experimental and control group (table 3).

Table 3: Effectiveness of SCOPE Program on Health Related Quality of life of Children n=12

Domain	Source	Sum of squares	Df	Mean square	F	Significance
Physical functioning	Within group	170.267	4	42.567	9.167	.001
	Between group	365.067	1	365.067	10.824	.008
Emotional functioning	Within group	22.100	4	5.525	6.255	.001
	Between group	228.150	1	228.150	19.868	.001
Social activities	Within group	49.233	4	12.308	5.810	.001
	Between group	72.600	1	72.600	2.227	.166
School activities	Within group	64.500	4	16.125	3.300	020
	Between group	3.750	1	3.750	.065	.804

The health status of thalassemic children was analyzed based on the presence or absence of clinical problems, pre-transfusion hemoglobin (Hb) level and body mass index (BMI). Signs and symptoms like fever, pallor, weakness, loss of appetite,

weight loss, body ache, cough, coryza, abdominal distention, irritability, hepatomegaly, splenomegaly, bone and joint pain and jaundice were observed in majority of children in pretest (table 4).

Table 4: Mean score and Standard deviation for the presence/absence of clinical features to determine the health status of thalassemic children n=12

Observation	Mean score	Standard deviation
Pretest(O1) Exp.group	9.83	2.137
Con.group	10.33	2.160
Post test(O2) Exp.group	8.17	3.656
Con.group	9.67	1.966
Post test(O3) Exp.group	5.33	2.805
Con.group	9.83	1.722
Post test(O4) Exp.group	5.17	2.787
Con.group	9.33	1.033
Post test(O5) Exp.group	4.500	2.8810
Con.group	25.183	3.4925

There was no significant difference between the two groups in pre-transfusion level of Hb (t=0.378, P=0.713) (table 5); as well as BMI (t=0.426, P=0.679) (table 6).

Table 5: pretest level of pretransfusion hemoglobin among thalassemic children n=12

Pre-transfusion Hemoglobin level	Mean Hb (gm%)	Standard deviation (gm%)	df	t test value	P value
Experimental group	4.933	0.972	10	0.378	0.713
Control group	4.700	1.183			

Table 6: Pretest level of BMI among thalassemic children n=12

Pretest level of BMI	Mean score	Standard deviation	df	t value	P value
Experimental group	13.555	0.972	10	0.426	0.679
Control group	13.896	1.705			

The post test findings showed that there was significant improvement in health status of thalassemic children who were exposed to SCOPE Program when compared to control group (F= 10.824, P=0.001) (table 7).

Table 7: Effectiveness of SCOPE program on health status of thalassemic children n=12

Source	Sum of squares	df	Mean square	F	Significance
Within group	814.041	4	203.510	71.492	.001
Between group	589.693	1	589.693	26.891	.001

Family centered health education regarding home care management of thalassemic children and nutritional counseling also contributed to improved health status in this group. It was evident through the reduction in mean score for health problems in experimental group (mean=4.500; standard deviation=2.8810) after 4 months of intervention when compare to control group (mean= 25.183; 3.4925).

DISCUSSION

The health related quality of life (HRQoL) was poor in thalassemic children of both groups during pretest. Devershi S et.al noted that the overall quality of life was significantly lower in thalassemic children and the school function domain was the most affected. [5] However, the overall health related quality of life score of thalassemic children in the experimental group was improved in the present study after implementation of SCOPE Program. Interventions like arrangement of blood donors, health advocacy for availing transfusion therapy and chelating agents (Desirox) free of cost enhanced the quality of life score of thalassemic children. Similar results were reported in previous studies. [6,7]

Limitations

This pilot study is undertaken to identify the feasibility of methods and materials. Due to the small sample size, the findings cannot be generalized.

CONCLUSION

The health related quality of life of thalassemic children is poor when compare to other children of same age group.

Interventions like SCOPE Program can help to enhance the quality of life as well as health status among them. However due to the small sample size the results cannot be generalized.

Conflict of interest: the authors declare that there is no conflict of interest.
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REFERENCES

1. Khani H, Majdi M, Azadmarzabadi E, Montazeri A, Ghorbani A et.al. (2009). Quality of life in Iranian Beta thalassemia Major patients of Southern coastwise of the Caspian Sea. Behavioral Sciences., 2: 325-32
2. Kaheni S, Yaghobian M, Sharefzadah GH, Vahidi A, Ghorbani H, et al. (2013) Quality of Life in Children with B-Thalassemia Major at Center for Special Diseases. Iran J Ped Hematol Oncol 3: 108-113.
3. Jameel T, Suliman M.I, Rehman. (2016). The compromised quality of life in β-Thalassemia Major Children in Non-Urban Setup in a Developing Country. Hematol Thrombo Dis;, 4:3
4. Verma IC, Saxena R, Kohli S. (2011). Past, present and future scenario of thalassaemic care and control in India. Indian J Med Res;, 134: 507- 521.
5. Devarshi S, James S, Najafzadeh E, Pawar S, Kalrao V, Bafna V. (2016). Assessment of quality of life, complications and post transfusion adverse reactions in thalassemia Pediatric in Tertiary Care Hospital. J Pharm Pharm Sci; 2(8): 317-23
6. Sandya Rani P, Vijayakumar S, Chandana N. (2013). Beta-thalassemia: mini review. Int. J Pharmacol Res; 3: 71-9
7. Shanthi G, Balasubramanian D, Srinivasan R. (2013). Clinical and demographical studies of beta thalassemia in Tamilnadu. Res J Pharm Biol Chem Sci; 4: 952-6

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