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Coping strategy among Parents of children with thalassemia in India

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ABSTRACT

Background: In a country like India, where over 40 million people carry the gene for thalassemia major and over 10,000 children are born each year with the severe form of thalassemia, 80-90% fail to survive beyond the age of ten. Most of thalassaemic children with thalassemia if not treated properly, have the difficulty in daily activities. Yet, there is a cure for thalassemia. Bone marrow transplantation and stem cell transplantation is very costly which is beyond the reach for majority of affected families, even if they have a donor in the family. Long term supportive care with transfusion and iron chelation is beyond the means of most families. Hence Families with thalassemic children often experience difficulties in adaptation to the illness.

Objective of the study were to assess and compare the coping strategy of parents in experimental and control group regarding care of children with thalassemia; and to determine the association of coping strategy of parents with selected variables.

Methods: A quasi-experimental study following pretest post-test research design was conducted among 107 parents and their thalassaemic children (54 in experimental and 53 in control group) in two randomly selected hospitals in Delhi. Structured Teaching Program (STP) comprised of two programme i.e. STP- I includes the items related to knowledge whereas STP-II focused on the psychological problem of parents. Pretest and post-test coping strategy of parents (day 30 and day 60) were assessed using a valid and reliable coping checklist.

Results: The mean posttest coping strategy scores of parents in experimental group was higher than control group as on day 60 (E=50.61, C=47.88). The computed t(106)= 2.14 on day 60 was statistically significant at 0.05 level of significance. The area wise analysis showed effectiveness of coping in the area of planful problem solving, seeking social support, self control. There was no significant association found between the post-test coping strategy score of parents with selected variables except the family history of thalassemia.

Conclusion: Structured teaching Program was effective in improving the adaptive coping strategy among parents of Children with Thalassemia but unfortunately no literature or study was found to explain these finding.

Keywords: *Thalassemia, Coping Strategy, Structured Teaching program , children with Thalassemia*

1. INTRODUCTION

Children in the age group of 0-14 years constitute 40% of the population and they are the most vulnerable section which undergoes various types of health problems. The risk is connected to growth, development and survival. Among all the childhood diseases, hematological and hereditary diseases are most life threatening disease conditions which affects in their early life. It affects upon birth, severely affecting their ability to survive on their own due to chronic anemia resulting from an inherited hemoglobin disorder. With currently available medical treatment, affected children have a substandard quality of life and a shortened life expectancy.[1]

D. Mohanty et al determined the prevalence of haemoglobinopathies in different caste/ethnic groups using uniform methodology in six cities of India by screening the fifty-six thousand seven hundred eighty individuals (college students and pregnant women). The overall prevalence of β-thalassemia trait was 2.78 % and varied from 1.48 to 3.64 % in different states, while the prevalence of β-thalassemia trait in 59 ethnic groups varied from 0 to 9.3 %. HbE trait was mainly seen in Dibrugarh in Assam (23.9 %) and Kolkata in West Bengal (3.92 %). In six ethnic groups from Assam, the prevalence of HbE trait varied from 41.1 to 66.7 %. Few subjects with δβ-thalassemia, HbS trait, HbD trait, HbE homozygous and HbE β-thalassemia as well as HbS homozygous and HbS-β-thalassemia (<1 %) were also identified.[2]

Jaouni Soad Khalil Al conducted a retrospective study to assess the prevalence of survival and disease complications among patients with thalassemia major treated at King Abdulaziz University Hospital from 1990-2004. A total of 360 patients (203

males & 157 females) were transfusion dependant since early childhood and treated with parenteral Deferoxamine. Out of 360 patients, 293 (90.29%) patients were alive, 27 (7.2%) patients had died, 15 (4.2%) patients underwent BMT and 25 (6.9%) patient' follow-up were lost. Twelve (3.3%) patients died from heart disease. Seven (1.9%) patients died from infections, all patients were splenectomized. The serum ferritin levels for patients who died were significantly higher than for those patients who survived (7,500 vs. 3, 200; $p< 0.001$). Cardiac constitutes the first important cause of death followed by infection. Complications and deaths among thalassemics is iron related organ dysfunction and age related. The majority of complicated patients were on non-optimal chelation therapy and non-compliance.[5]

Tsiantis J. explored the psychosocial problems experienced by families with children aged 6 to 14 years suffering from β-thalassemia major (N=188). The psychosocial problems and the family's adjustment to the effects of the illness were compared across a number of cultures where the disease is prevalent, namely Cyprus, Greece, and Italy. A small number of migrant children in the United Kingdom was also included in the study. Semi-structured interviews were conducted with parents who also completed the Rutter Parental Questionnaire and the Goldberg General Health Questionnaire. In all countries the disease seemed to have a binding effect on the family, thus mobilizing adaptive mechanisms. Father's low education level and the presence of major medical complications were predictors of poor family adjustment. Differences between and within countries may well reflected differences in health policies, existing level of socio-economic development, and in the cultural patterns in coping with a chronic illness.[9]

Repeated, long and unpleasant treatments in thalassemia cause this disease cover all aspects of the individuals' life. It has severe and considerable consequences on general and mental health and quality of life of the patients and their families. Diagnosis of the disease and adjusting it to a family is considered as a crisis and families react different responses. Most of the families can successfully adopt themselves with chronic disease of the children. In contrast, some of them also may not be successful in coping with it due to lack of access to accurate information about the disease, lack of appropriate support resources, high treatment costs, mental status and social damages.[7]

Many researchers reported that Mothers consistently reported a lack of knowledge about thalassemia in the health system and they expressed a stressful lifestyle, emotional hardships such as helplessness, fear of their child's death and anxiety over being separated from their child. So, the parents and caregivers should be provided sufficient knowledge on thalassemia and awareness regarding the importance of physical care, diet schooling, psychological and emotional support for children as well as parents which in turn helps to improve the health and prolong the lives of children by controlling the complications as much as possible. Literature search shows that no attempt has been made to assess and evaluate the coping strategy of parents of children with thalassemia in India as well as abroad. Hence the investigator felt the need to assess the coping strategy for parents of children with thalassemia in India. **Objective** of the study were to assess and compare the coping strategy of parents in experimental and control group regarding care of children with thalassemia; and to determine the association of coping strategy of parents with selected variables.

HYPOTHESES : All the hypotheses were tested at 0.05 level of significance.

H_1: There will be a significant difference in mean pretest and posttests (day 30 and day 60) coping strategy scores of parents of thalassemic children who were exposed to STP on care of children with thalassemia as measured by coping checklist.

H_2: There will be a significant difference between the mean posttest (day 30 and day 60) coping strategy scores of parents exposed to STP on care of children with thalassemia and control group as measured by coping checklist.

H_3: There will be a significant association of level of posttest (day 60) coping strategy scores of parents of children with thalassemia related to care of children with thalassemia with selected variables as assessed by coping checklist.

2. METHODS

A quasi-experimental study following pretest post-test non- equivalent control group research design was conducted among 107 parents of thalassaemic childrenof 5-12 years (54 in experimental and 53 in control group) in two randomly selected hospitals in Delhi i.e. Charak Palika hospital, Moti Bagh, New Delhi for the experimental group and Hindu Rao hospital, New Delhi for the comparison group was selected. The hospitals were matched on the following criteria:

i. Providing free chelation medicine to the patients (Inj. desferal , Kelfer and desirox)

ii. Parents are able to get blood for their children from Red Cross society, New Delhi by providing three donors for blood transfusion in a year.

iii. Checking the Hemoglobin level of each child before giving the next date for blood transfusion

Ethical approval to conduct the study was obtained from the institutional ethical committee of Deen Dayal Upadhyay Hospital, New Delhi. Permission has been taken to conduct study from Charak Palika Hospital and Hindu Rao Hospital, New Delhi. Written informed consent has been taken from parents and their children. Structured Teaching Program (STP) comprised of two programme i.e. STP- I includes the items related to knowledge whereas STP-II focused on the psychological problem of parents. Pretest and post-test coping strategy of parents (day 30 and day 60) were assessed using a

valid and reliable coping checklist.

3. RESULTS

Table- 1

Characteristics of the Sample

N=107

S. No.	Sample Characteristic	Experimental n = 54 f (%)	Control n = 53 f (%)	χ^2	df	P
1.	**Informant**					
1.1	**Mother**	47(87.03)	41(77.35)			
1.2	**Father**	07(6.54)	12(22.64)			
2.	**Age of informant (mother)**					
2.1	26-33 yrs	13(24.07)	15(28.30)	1.74	2	0.41
2.2	34-45 yrs	30(55.56)	25(47.17)			
2.3	>45year	4(7.41)	1(1.89)			
3.	**Age of informant (Father)**					
3.1	26-33 yrs	2(3.70)	0	3.83	1	0.05
3.2	34-45 yrs	5(9.26)	12(22.64)			
	Mother					
4.	***Education***					
4.1	Illiterate	0	2(3.77)	5.47	4	0.24
4.2	Primary	0	2(3.77)			
4.3	Secondary	22(40.74)	19(35.85)			
4.4	Higher secondary	13 (24.07)	8(15.09)			
4.5	Graduate and above	19(35.19)	21(39.62)			
5.	***Occupation***					
5.1	House wife	48(88.89)	38(71.70)	11.2*	3	0.01
5.2	Service	6(11.11)	5(9.43)			
5.3	Business	0	6(11.32)			
5.4	Professional	0	4(7.55)			
	Father					
6.	***Education***					
6.1	Illiterate	5(9.26)	1(1.89)	4.38	4	0.36
6.2	Primary	3(5.56)	4(7.55)			
6.3	Secondary	17(31.48)	14(26.42)			
6.4	Higher secondary	9(16.67)	7(13.21)			
6.5	Graduate and above	20(37.04)	27(50.94)			

7.	***Occupation***					
7.1	Laborer	8(14.81)	11(20.75)	1.13	3	0.76
7.2	Service	16(29.63)	15(28.30)			
7.3	Business	29(53.70)	25(47.17)			
7.4	Professional	1(1.85)	2(3.77)			
8.	**Economic status**					
8.1	< Rs. 5000/ month	14(25.93)	10(18.87)	0.19	3	0.98
8.2	Rs. 5001-10000/ month	5(9.26)	6(11.32)			
8.3	Rs.10001-15000/- month	15(27.71)	21(39.62)			
8.4	> Rs. 15000 / month	20(37.04)	16(30.19)			
9.	**Type of family**					
9.1	Nuclear family	42(77.78)	29(54.72)	6.37*	1	0.01
9.2	Joint family	12(22.22)	24(45.28)			
10.	**Place of living**					
10.1	Rural	0	10(18.87)	11.2*	1	0.0
10.2	Urban	54(100)	43(81.13)			
11.	**Family history of thalassemia**					
11.1	Yes	12(22.22)	7(13.21)	1.38	1	0.24
11.2	No	42(77.78)	45(84.91)			
12.	**Migration status**					
12.1	Yes	09(16.67)	6(11.32)	0.634	1	0.42
12.2	No	45(83.33)	47(88.68)			
	If yes					
1.	Pakistan	02	01			
2.	J&K	03	00			
3.	Punjab	04	05			

Data given in table 1 presented that Out of 107, majority of the mothers 47 (87.03%) in experimental and 41 (77.35%) in control group in the age group of 34-45 years were informant. Most of the mothers (40.74%) in experimental and (39.62%) in control group were educated up to secondary and graduate respectively. Majority of the mothers in both the groups (88.89% in experimental group and 71.70% in control group) were housewife. Most of the fathers ((37.04% in experimental and 50.94% in control group) were graduate and businessman (53.7 % in experimental group and 47.17% in control group).. Most of the family were having income between Rs.10001- 15000/-month in control groups (27.71% in experimental group and 39.62 in control group). 77.78% of parents in experimental group and 54.72% in control group belonged to nuclear family. Majority of parents (100%) in experimental group and 81.13% in control group were living in urban area. 77.78% parents in experimental group and 84.91% in control group were not having family history of thalassemia. 83.33% of parents in experimental group and 88.68% in control group were not migrated whereas 16.67% of parents in experimental group and 11.32 % in control group were migrated from Pakistan, Jammu and Kashmir and Punjab. Both the groups were homogenous with respect to demographic variable of parents like age of informant, education of mother, education and occupation of father, economic status, place of living and family history of thalassemia. The groups varied in terms of occupation of mother, type of family and place of living.

Table -2 't' Values between Mean Pretest Coping Strategy Scores of Parents in Experimental and Control Group

N= 107

Variables	Group	Mean±SD	Mean %	M_D	SD_D	SE_{MD}	't' Value
Coping Strategy	Experimental (n=54)	46.81±10.86	52.01				
				0.079	10.34	2.72	0.046
	Control (n=53)	46.74±6.49	51.93				

t (106) = 1.98, p>0.05

Data given in table 2 showed that the mean pretest coping strategy scores of parents were (46.81±10.86) and (46.74±6.49) for experimental and control group respectively. 't' values computed between independent means of pretest coping strategy of experimental and control group were not significant at 0.05 level of significance. It indicated that subjects in experimental group and control group did not differ significantly in terms of their initial coping strategy regarding care of children with thalassemia.

Table – 3 Mean, Standard Deviation and't' Values Computed between Mean Pretest and Posttest; and Posttest (Day 30 and Day 60) Coping Strategy Scores of Parents in Experimental Group

n= 54

Coping checklist	Mean	SD	M_D	SD_D	SE_{MD}	t
Pre- test	46.81	10.86				
			0.98	1.46	3.49	4.94*
Post-test (Day 30)	47.80	10.45				
Pre- test	46.81	10.86				
			3.79	3.18	3.04	8.77*
Post- test (Day 60)	50.61	9.18				
Posttest (Day30)	47.80	10.45				
			2.81	2.56	2.98	8.07*
Posttest (Day 60)	50.61	9.18				

t (53) = 2.00, p<0.05

Data presented in table 3 depicted that mean posttest coping strategy scores 47.80 on day 30 and 50.61 on day 60 for subjects in experimental group were apparently higher than mean pretest coping strategy score i.e. 46.81. The computed 't' values for df (53) 4.94 on day 30 and 8.77 on day 60 was found to be statistically significant at 0.05 level of significance indicating a significant difference between the mean pretest and posttest coping strategy scores in the experimental group. Thus it is established that the mean difference obtained in the mean pretest and posttest coping strategy scores was a true difference and not by chance. Hence, parents exposed to STP on care of children with thalassemia obtained significantly higher coping strategy scores in the posttest on day 30 and day 60 as compared to the pretest. Thus it suggests that STP on the care of children with thalassemia was effective in developing the more adaptive coping strategy of parents in the experimental group regarding the care of children with thalassemia. Data further showed that the 't' value calculated between the mean posttest coping strategy scores on day 30 and day 60 in experimental group, 't'(53)= 8.07 was found to be statistically significant at 0.05 level of significance. Therefore, it can be said that the difference obtained in the mean posttest coping strategy scores on day 30 and day 60 was a true difference and not by chance. Therefore it suggested that reinforcement of STP on day 45 was effective in developing the more adaptive coping strategy of parents towards care of children with thalassemia.

Table-4 Area Wise Mean , Standard Deviation and 't' Values Computed Mean Pretest and Posttest (Day 30 and Day 60) Coping Strategy Score of Parents in Experimental Group

n=54

Areas of Coping Strategy	Mean					
	Pre test	Post test (day 30)	Mean $_D$	SD_D	SE_{MD}	't'
Confrontive coping	6.69	6.83	0.14	0.04	0.53	2.21*
Planful problem solving	5.79	5.93	0.14	0.34	0.05	2.18*
Seeking social support	5.83	5.91	0.08	0.02	0.43	1.65
Distancing	3.79	3.79	0	0	0.32	0
Escape avoidance	4.26	4.29	0.03	0.02	0.43	1.00
Self Control	8.93	9.17	0.24	0.16	0.49	3.23*
Accepting Responsibility	5.48	5.57	0.09	0.04	0.35	1.52
Positive Reappraisal	6.04	6.29	0.25	0.09	0.57	8.24*
Pre to Post test at 60 days						
Confrontive coping	6.69	7.17	0.48	0.3	0.5	3.52*
Planful problem solving	5.79	6.17	0.38	0.05	0.35	3.71*
Seeking social support	5.83	6.33	0.5	0.06	0.43	3.47*
Distancing	3.79	3.79	0	0	0.32	0
Escape avoidance	4.26	4.31	0.05	0.05	0.43	0.13
Self Control	8.93	9.79	0.86	0.28	0.48	5.41*
Accepting Responsibility	5.48	5.91	0.43	0.24	0.33	3.84*
Positive Reappraisal	6.04	7.13	1.09	0.42	0.55	2.98*

$t(53) = 2.00$ $p<0.05$

The data presented in the table 4 showed that 't' value calculated between the mean pretest and posttests on day 30 in the area of confrontive coping, planful problem solving, self control and positive reappraisal was found statistically significant ($p<0.05$) whereas it was not found statistically significant in area of seeking social support, distancing and escape avoidance and accepting responsibility. 't' value calculated between the mean pretest and posttest on day 60 in the area of confrontive coping, planful problem solving, seeking social support, self control, accepting responsibility and positive reappraisal was found statistically significant ($p<0.05$) whereas it was not found statistically significant in area of escape avoidance and accepting responsibility. It is due to that STP had focused in the area of confrontive coping, planful problem solving, seeking social support, self control, accepting responsibility and positive reappraisal.

Table 5 ‘t’ Values Between Mean Posttest Coping Strategy Scores of Parents in Experimental and Control Group

N= 107

Group		Coping Strategy Scores			
	Mean±SD	**M_D**	**SD_D**	**SE_{MD}**	**‘t' value**
Post - test (Day 30)					
Experimental Group	47.80±10.45				
		0.76	10.18	2.13	0.46
Control Group	47.04±6.11				
Post - test (Day 60)					
Experimental Group	50.61± 9.18				
		3.23	9.72	1.97	2.14*
Control Group	47.38± 6.17				

t(106) =1.98, p<0.05

Data given in table 5 showed that the mean posttest coping strategy scores of parents 47.80 in the experimental group on day 30 and 50.61 on day 60 was apparently higher than the mean posttest coping strategy scores 47.04 on day 30 and 47.38 on day 60 in control group. ‘t’ values computed between the mean posttest coping strategy scores of experimental and control group i.e. ‘t’(106)= 2.14 on day 60 were statistically significant at 0.05 level of significance. This suggests that parents in experimental group had developed more adaptive coping strategy than control group. It indicates that STP on care of children with thalassemia was effective in developing the more adaptive coping strategy of parents towards care of children with thalassemia Findings of the study also shows that no significant association was found between the coping strategy of parents and the selected variables (p>0.05) except a significant association was found between the coping strategy of parents and family history of thalassemia.

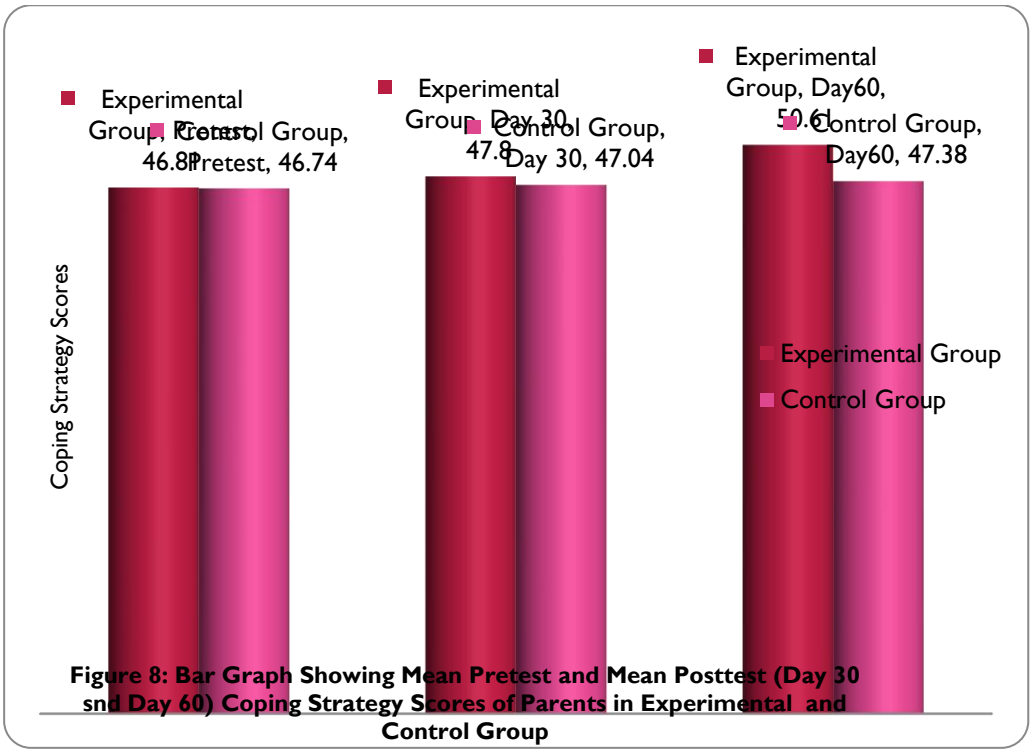

Figure 8: Bar Graph Showing Mean Pretest and Mean Posttest (Day 30 snd Day 60) Coping Strategy Scores of Parents in Experimental and Control Group

4. DISCUSSION

In the present study the coping strategy of parents were assessed in following areas i.e. confrontive coping, planful problem solving, seeking social support, distracting, escape avoidance, self control, accepting responsibility and positive reappraisal. Goldbeck L et al assessed coping strategies used by thalassemic major patients and found the most frequent coping strategy adopted were maladaptive.

Further findings of the present study showed that the mean posttest coping strategy scores of parents in experimental group was higher than control group as on day 60 (E=50.61, C=47.88) but the mean pretest coping strategy score did not differ significantly (E= 47.80, C= 47.04).

The computed t(106)= 2.14 on day 60 was statistically significant at 0.05 level of significance suggesting STP to be effective in developing more adaptive coping strategy of parents. STP-II had focused on confrontive coping, planful problem solving, seeking social support, self control, accepting responsibility and positive reappraisal except distracting and escape avoidance. The further area wise analysis showed effectiveness of coping in the area of planful problem solving, seeking social support, self control. Unfortunately no literature or study was found to explain these finding.

Posttest coping strategy score (day 60) of parents of children with thalassemia is not significantly associated with the age of informant, education and occupation of parents, economic status, type of family, place of living, no. of siblings, migration status, age of child, gender of children, age of diagnosis, age of initiation of treatment and hemoglobin level except family history of thalassemia. Awayi Ghezy[47] also reported no association of coping strategy with age of parents, gender and educational level but occupation of parents was associated with coping.

LIMITATION

- Sample of the study was not selected randomly.
- Study was conducted in only Delhi state of northern region of India as the researcher applied for the permission in the state of Punjab, Haryana and Delhi. But the only permission was sorted from two hospitals of Delhi.

RECOMMENDATIONS

- Multicentric studies can be done in different thalassemic units in hospitals of the country

A follow up study may be conducted to evaluate the effectiveness of structured teaching programme on the coping strategy of parents regarding care of children with thalassemia.

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