A study to develop and evaluate the structured teaching programme for parents on the care of children with thalassemia in terms of parental knowledge, attitude, coping strategy and quality of life of children with thalassemia in selected hospitals in Northern region of India.

By:-

Mrs. Jyoti Bala

ABSTRACT

Introduction: Thalassemia is one of the most common human genetic diseases and like other chronic diseases affects the quality of life of children and their families. Approximately 20% of all children have a chronic illness like thalassemia and 65% suffer an illness severe enough to interfere with daily activities (Shaw & McCabe, 2008).

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. Yet, there is a cure for thalassemia. Guido Lucarelli pioneered the use of bone marrow transplantation and documented that if bone marrow transplantation has been done early without too much damage caused by iron overload in the liver, 94% of the children can be cured. If thalassemia is treated later, the survival rate drops to 60%. Long term supportive care with transfusion and iron chelation is beyond the means of most families and very few centers have such supportive facilities. Bone marrow transplantation is available at ten centers in the country approximately at the cost of 10-15 lakhs, which puts it beyond the reach for majority of affected families, even if they have a donor in the family.

Families who have children with chronic illness such as thalassemia often experience difficulties in adaptation to the illness. It may be very difficult for both the children and their parents to deal with thalassemia and its treatment. Successful family adaptation to chronic illness needs nursing interventions. The objectives of the study were: to assess and compare the knowledge, attitude and coping strategy of parents in experimental and control group regarding care of children with thalassemia; to assess and compare the quality of life of children with thalassemia in experimental and control group; to determine the relationship between knowledge
and attitude; knowledge and coping strategy of parents; Parent’s attitude and coping strategy, knowledge of parents and quality of life of children, attitude of parents and quality of life of children, coping strategy of parents and quality of life of children and to determine the association of level of knowledge, attitude, coping strategy of parents and quality of life of children with thalassemia with selected variables.

Methods: This quasi experimental study following pretest posttest research design was conducted among 107 parents and their thalassemic children (54 in experimental and 53 in control group) in two randomly selected hospitals in Delhi. Parents in the experimental group received STP on care of children with thalassemia. STP comprised of two programme i.e. STP- I includes the information related to concept, signs and symptoms, diagnosis, prevention and management, complication and STP-II focused on the psychological problem of parents using group teaching learning strategies viz lecture cum discussion, case scenarios, videos whereas no intervention was given to parents in the control group. Pretest and posttest knowledge (day 15 and day 60), attitude and coping strategy of parents (day 30 and day 60) and quality of life of children with thalassemia (day 30 and day 60) were assessed using a valid and reliable structured knowledge questionnaire, attitude scale, coping checklist and PedsQL inventory.

Results: Data was analyzed using SPSS 16, level of significance was kept at 0.05 level. In the control group, a significant increase in mean knowledge scores and attitude score was observed between pretest and posttest on day 60(p=0.00). There was also a significant difference found between mean pretest and posttests coping strategy scores on day 30 and day 60. (p=0.00).

In the experimental group, the mean knowledge scores were statistically significant between mean pretest and posttests on day 15 and day 30 (p<0.05). There was also a statistically significant difference in attitude and coping strategy scores between pretest and posttest on day 30 and day 60( p<0.05).

Findings further showed that there was a statistically significant difference between the mean posttest knowledge scores in experimental and control group on day 15 and day 60 (p<0.05). The mean attitude scores were statistically significant when compared between the mean posttest attitude scores in experimental and control group on day 30 and on day 60(p<0.05). There was also a statistical significant difference found between the mean posttest coping strategy scores in
experimental and control group whereas no statistical significant difference was found between the mean posttest coping strategy scores in experimental and control group on day 30 (p<0.05).

In the control group, the ‘t’ values calculated between the mean pretest and posttest quality of life scores on day 30 and on day 60 was found to be statistically non significant in the age group of 5-7 years and found statistically significant on day 30 and on day 60 in the age group(8-12 years) (p<0.05). This can be due to their adaptation with regular treatment to live their lives and motivation by the health personnel to lead a normal life like others.

In experimental group, a statistical significant difference was found between the mean pretest and posttest quality of life scores of children with thalassemia (5-12 yrs) on day 30 and day 60. (p<.05).

The mean posttest quality of life scores of children with thalassemia (8-12 years) in experimental and control group on day 60 was statistically significant and it was not found significant on day 30 (p< 0.05).

There was no significant relationship between pretest and postest measures i.e. knowledge, attitude, coping strategy of parents and quality of life of children with thalassemia. There was no significant association of post test knowledge, attitude and coping strategy score of parents with age of informant, education and occupation of mother, education and occupation of father, place of living and migration status were not found statistically significant(p<0.05)

As regard to Family history of thalassemia, no significant association was found between the knowledge, attitude of parents and family history of thalassemia(p>0.05) but a significant association was found between the coping strategy of parents and family history of thalassemia.

Computed $\chi^2$ value of the post test (day 60) quality of life score of children with thalassemia with age, gender and number of sibling were not found statistically significant(p>0.05).

A significant association was observed between age of initiation of treatment and quality of life of children (p=0.03); hemoglobin level and quality of life of children with thalassemia (p=0.0).
**Discussion:** In the current study significant increase in knowledge and attitude of parents and quality of life of children was observed after administration of STP on care of children with thalassemia for parents. Similar significant changes have been reported by Kargar Najafi et al\(^{32}\).

Further findings revealed that knowledge in post test on day 15 and day 60 was increased significantly and retained which is consistent with the result of the study by Paholpak S\(^{59}\).

In the present study, 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. Unfortunately no literature or study was found to explain these finding.

The findings of the study showed that the mean posttest quality of life score of children on day 60 regarding care of children with thalassemia in experimental group was higher than and control group (E=2378.7, C=2255.67). It was found to be statistically significant (p<0.05). These findings are consistent with the study conducted by Fariba Borhani et al\(^{28}\).

Study also highlights that nursing intervention can help parents to better understand and identify coping strategies which will allow them to gain control over their children’s illness and their family life. So it is recommended to assess the knowledge of the staff nurses working in thalassemia unit to educate the parents and improve the quality of life of children with thalassemia. With the holistic care that nurses provide, they can also make an important contribution in understanding the public at large about thalassemia and its consequences.

**Key words: Thalassemia, STP, Parents, Children with Thalassemia, Knowledge, Attitude, Coping Strategy, Quality**