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## RESEARCH ARTICLE

# EFFECTIVENESS OF STRUCTURED TEACHING PROGRAMME (STP) FOR PARENTS ON CARE OF CHILDREN WITH THALESSEMIA IN TERMS OF QUALITY OF LIFE OF CHILDREN WITH THALASSEMIA

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**ABSTRACT**

**Background:** Thalassemia is one of the most common human genetic disease which affects overall health of children. Approximately 20% of all children have a chronic illness like thalassemia and 65% suffer an illness severe enough to interfere with daily activities. It is very difficult for both the children and their parents to deal with thalassemia and its treatment. Children with thalassemia often experience poor quality of life due to regular blood transfusion, frequent visit to hospital etc. Successful family adaptation to chronic illness needs nursing interventions. **Objectives:** objectives of the study were to assess and compare the quality of life of children with thalassemia in experimental and control group; to determine the association of level of quality of life of children with thalassemia with selected variables. **Methods:** The 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 selected hospitals in Delhi. Pretest and posttest quality of life of children with thalassemia (day 30 and day 60) were assessed using a valid and reliable PedsQL inventory. **Results:** Data was analyzed using SPSS 16; level of significance was kept at 0.05 level, the 't' values computed between independent means of pretest quality of life scores in experimental and control group were not significant at 0.05 level. It indicated that subjects in experimental group and control group did not differ significantly in terms of quality of life scores of children regarding care of children with thalassemia. 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 ($p< 0.05$). 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, a significant increase in 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. 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.



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## INTRODUCTION

Beta thalassemia is a serious life limiting disease caused by defects in one or more genes of the globin chains of hemoglobin. Beta thalassemia requires regular blood transfusion, clinical monitoring and hospital visits/admissions. Thalassemias major and intermedia are the symptomatic forms of the disease which have impact on several aspects of patients' lives.

But improved diagnostic monitoring, early and prompt identification and therapy of complications and the use of adequate chelation, patients' survival improved and the need is shifting from prolonging life per se to ensuring that children enjoy a better quality of life (QoL).

**Aim:** Aim of the study was to evaluate the quality of life of thalassemic children before and after administration of STP to parents on care of children with thalassemia.

**Objectives:**

1. To assess and compare the quality of life of thalassemic children before and after administration of STP to parents on the care of children with thalassemia
2. To determine the association of level of quality of life of thalassemic children with selected variable.

**Rationale:** Considering the chronic nature of thalassemia, it is necessary for patients and their parents to have adequate information on the disease process and related therapeutic measurements. To empower the parents to face disease and its complications, the knowledge of parents about the disease should be improved so the quality of life of children can be improved. Z. Ghazanfari assessed the knowledge level and educational needs of parents of 300 thalassemic patients' who referred to Kerman special diseases center in year 2005. The mean age of fathers was 42.02±9 years and mothers were 35.9±8.4 years. The mean knowledge score range of 20 items in need questionnaire was between 2.79 and 2.96 (from the maximum score of 4). Parents' knowledge was under 50% considering all items. Mothers' educational needs were more than that of fathers. The study concluded that thalassemic patients' parents don't have adequate information on the disease and need a high level of education.[25]

Under the Thalforum articles & news-Thalassemia Community Forum, Thalassemic child's parent's campaign for awareness had expressed need to spread awareness about Thalassemia. The Thalassemic Society of India (TSI) also feels the need for such campaigns since lack of awareness is the only impediment in thalassemic prevention.[27] The onset of symptoms, confirmation of diagnosis, need for regular blood transfusions and iron chelation therapy, the chronicity of the illness and frequent absenteeism from school, have a great impact on the quality of life of thalassemic children .In developing countries like India, only the medical management of these children is being given importance, whereas in western countries the integrated biopsychosocial form of management is being followed. Depression, anxiety and other behavioural problems in thalassemic children is associated with poor treatment compliance and quality of life. Ismail A et al assessed the health related quality of life in Malaysian children with thalassaemia using PedsQL 4.0 generic scale score. Of the 96 thalassaemia patients approached, 78 gave consent to be interviewed giving a response rate of 81.3%. Out of 235 healthy controls approached, all agreed to participate giving a response rate of 100%. The mean age for the patients and schoolchildren is 11.9 and 13.2 years respectively. The age range for the patients and the school children is between 5 to 18 years and 7 to 18 years respectively. After controlling for age and demographic background, the thalassaemia patients reported having significantly lower quality of life than the healthy controls. Thus thalassaemia has a negative impact on perceived physical, emotional, social and school functioning in thalassaemia patients which was also found to be worse than the children's healthy counterparts.[31] There are various descriptive and exploratory research studies done on assessment of knowledge, attitude of parents and quality of life of children but no interventional study done on effect of knowledge of parents on quality of life of children. Hence the investigator felt the need to develop and evaluate the structured teaching programme for parents on care of children with thalassemia in terms of quality of life of children with thalassemia.

## METHODS

**Design:** This was an Quasi experimental study with pretest posttest design Nov. 2012 to Jan. 2013

**Study Area and Target Population:** The setting of this study comprises of Charak Palika hospital, Moti Bagh, New Delhi and Hindu Rao hospital, Delhi. Charak Palika Hospital is one of the pioneer hospitals in Delhi, managed and controlled by New Delhi Municipal Corporation (N.D.M.C.). It has sanctioned bed strength of 150. This hospital has 27 bedded pediatric unit and 12 beds are assigned for thalassemia patients separately. It caters the population of North India. Hindu Rao Hospital is the largest multi-specialty hospital, managed and controlled by Municipal Corporation of Delhi (M.C.D) and is functioning under the supervision of Director Health Services-cum-Municipal Health Officer and the guidance of Additional Commissioner (Health). It has a sanctioned bed strength of 980 which many a times (epidemics, natural calamities, accidents etc) needs to be supplemented with extra beds. This hospital has 110 bedded pediatric units, out of that, six beds are assigned for thalassemia patients. It caters the population of about 18 lacs –largely from North Delhi, its services are also utilized by patients from rural areas, towns from neighboring states and even from far off places like Assam, Meghalaya. The rationale for selecting these hospitals was that they have separate thalassemic unit and from the point of view of approachability and administrative approval of collection of data obtained to conduct the study. The population for the present study comprised of parents and their children with thalassemia between the age group of 5 – 12 years of the selected Hospitals of Northern region of India.

**Study Tool:**

**Part I**: Participant's basic characteristics: 10 questions concerning parent's socio-demographic and basic characteristics were asked i.e. age of informant, mother's education and occupation, father's education and occupation, economic status, type of family, place of living, family history of thalassemia and demographic characteristic of children i.e. age, gender, age of initiation of treatment, hemoglobin level, no. of sibling, no. of thalassemic sibling.

**Part II:** Standardized PedsQL inventory to assess the quality of life of children with thalassemia. The PedsQL 4.0 generic core scales are multidimensional child self-report and parent proxy-report scales consist of 23 items applicable for healthy school and community populations, as well as pediatric populations with acute and chronic health conditions. Quality of life questionnaire includes parallel child self-reports ( 5-7 yrs and 8- 12 yrs). Item responses are measured on a five-point rating scale ranging from 0 (Never a problem) to 4 (almost always a problem).The 23 items consist of 8 items on physical function, 5 items on emotional function, 5 items on social function, and 5 items on school function. 6 items related to procedural and treatment anxiety have been added from standardized PedsQL of cancer module. As per the scoring system of PedsQL, items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0 and if more than 50% of the items in the scale are missing, the scale scores should not be computed. Internal consistency reliability (α) for the total Scale Score of PedsQL for child report was 0.88 and parent report was 0.90 respectively. Internal consistency reliability for the PedsQL

Generic Core Total Scale Score in cancer patients and cancer module scales were ($\alpha$ = 0.88 for child report, 0.93 for parent report) and (average $\alpha$ = 0.72 for child report, 0.87 for parent report) respectively.[64] Internal consistency reliability ($\alpha$) was calculated by researcher was 0.83 for child report and 0.88 for the parent report respectively.

**Structured Teaching Programme:** STP provides information related to concept, signs and symptoms, diagnosis, prevention and management and complications, psychological problems, types of coping strategy, case scenario related to the common problems of parents and its management, support group available and regional centers for thalassemia. Method of teaching used for parents was lecture cum discussion using Power Point slides. Videos on thalssemia developed by National thalassemia welfare society, Vikaspuri, New Delhi were used depicting the genetic transmission of thalassemia , Signs and symptoms of thalassemia and effect of consanguineous marriages. Relevant part of videos was organized according to the content ofSTP. It was administered only once on day one

**Variables:** The study design indicates that:

**Independent variables**: - consisted of structured teaching programme on care ofchildren with thalassemia for parents.

**Socio-demographic factors:** We examined the following variable of parents i.e. age of informant , mother's education and occupation, father's education and occupation , economic status, type of family, place of living, family history of thalassemia, migration status and characteristic of children i.e. age, gender, age of initiation of treatment, hemoglobin level, no. ofsibling, no. ofthalassemic sibling.

**Dependent variables: -** The dependent variable was the quality oflife ofchildren with thalassemia.

**Sample and Sampling Technique:** For the present study, the sample size calculation was done by statistician with the formula ofpower analysis based on the prevalence of children with thalassemia. The sample size came out to be 46 subjects in each group. Sample of the present study comprised of 107 parents and their children with thalassemia belonging to the age group (5-12 years) receiving blood transfusion. Out of107, 54 parents and their children with thalassemia were in experimental group and 53 parents comprised the control group.

**Sampling Method:** A two stage random sampling method was used.

**First Stage:** Two hospitals having separate thalassemic unit in Delhi were randomly selected by tossing the coin. Thus Charak Palika Hospital was assigned to experimental group and Hindu Rao Hospital was assigned to control group.

**Second Stage:** Purposive sampling technique was used to select the subjects (Parents and children with thalassemia) in experimental and control group. Out of71 registered children, 54 children with thalassemia major and the parent accompanying the child were selected purposively who met the inclusion criteria in experimental group whereas in control group, out of 64 registered children,53 children with thalassemia major were selected.

**Ethical Consideration:** Ethical approval to conduct the study was obtained from the institutional ethical committee of Deen Dayal Upadhyay Hospital, New Delhi. Written consent was taken from the participants. The purpose for carrying out research project was explained to the participant and assurance for confidentiality was given.

**Pilot Study:** A pilot study was conducted on 20 parents and their thalassemic children (5-12years) in Deen Dayal Upadhyay Hospital, New Delhi, in the month of Feb 2012 to April 2012. Data of control group was collected first. On day one, pre test to assess the quality oflife ofthalassemic children regarding care ofchildren with thalassemia was conducted. On day 30 and day 60, post test for quality oflife was conducted. Duration of pretest was 15-20 minutes. In the experimental group, STP on care of children with thalassemia was administered. It took approximately 30 minutes to administer. It was found feasible to conduct the study.

**Procedure of Data Collection:** After obtaining the formal administrative approval, data was collected from November to January 2013.Two hospital in Delhi i.e. Charak Palika Hospital and Hindu Rao hospital were assigned randomly by tossing the coin. Fifty four parents and children with thalassemia in experimental group and 53 parents and children with thalassemia in control group were selected purposively.The parents and children were assured about the confidentiality of their responses and written consent obtained. Parents and their children with thalassemia (5-12years) were selected based on inclusion criteria.

On day one, pre test to assess the quality oflife ofthalassemic children regarding care of children with thalassemia was conducted. On day 30 and day 60, post test for quality of life was conducted. Duration of pretest was 15-20 minutes. In the experimental group, On day one, pre test to assess the quality oflife ofthalassemic children was conducted and STP on care ofchildren with thalassemia was administered on the same day and it took approximately 30 minutes to administer. On day 30, post-test for quality oflife was conducted. On day 60, post-test for quality oflife was conducted.

**Plan for Data Analysis**

The data was analyzed using SPSS-16 and a significance level of $p < 0.05$ was utilized for all analysis.

- Descriptive statistics like frequency, percentage, mean, mean percentage and SD used for describing the demographic characteristics
- Chi – square test used to compare demographic characteristics of parents and their children with thalassemia in experimental and control group and to determine the association of quality of life of children with thalassemia with selected variables
- Paired't' test used to compare pretest and posttest quality of life of children with thalassemia and Independent't' test used to compare pretest and posttest quality oflife of children with thalassemia in experimental and control group.

## RESULTS

Table 1 indicate that there was no statistical difference between the groups related to age of informant, education of

mother, education and occupation of father, economic status, place of living and family history of thalassemia.

**Table 1. Socio-demographic characteristics of parents and children with thalassemia**

N=107

| S. No. | Variable | Experimental n = 54 | Control n = 53 | $\chi^2$ | df | P |
|---|---|---|---|---|---|---|
| | | f (%) | f (%) | | | |
| 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) | | | |

The difference between the groups was found to statistically significant related to occupation of mother, type of family and place of living. Hence 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. Data given in Table 2 showed that difference between the groups was found to statistically non- significant related to age of child (p=0.27) , gender (p= 0.29) , age of initiation of treatment. (p= 0.52), hemoglobin level (p= 0.38), no. of sibling (p=0.29).

**Table 2. Socio-demographic characteristics of children with thalassemia**

| S.No. | Sample Characteristic | Experimental n = 54 | Control n = 53 | $\chi^2$ | Df | P |
|---|---|---|---|---|---|---|
| | | f (%) | f (%) | | | |
| 1. | Age | | | | | |
| 1.1 | 5-7 yrs | 22 (40.74) | 19 (35.85) | 0.271 | 1 | 0.27 |
| 1.2 | 8-12 yrs | 32 (59.26) | 34 (64.15) | | | |
| 2. | Gender | | | | | |
| 2.1 | Male | 21 (38.89) | 26 (49.06) | 1.12 | 1 | 0.29 |
| 2.2 | Female | 33 (61.11) | 27 (50.94) | | | |
| 3. | Age of Initiation of reatment | | | | | |
| 3.1 | <1 year | 20 (37.04) | 25 (47.17) | 2.26 | 3 | 0.52 |
| 3.2 | 1-3 year | 18 (33.33) | 16 (30.19) | | | |
| 3.3 | 3-5year | 09 (16.66) | 09 (16.98) | | | |
| 3.4 | >5year | 07 (12.96) | 03 (5.66) | | | |
| 4. | Hemoglobin | | | | | |
| 4.1 | <7 gm | 03 (5.56) | 07 (13.21) | 1.91 | 2 | 0.38 |
| 4.2 | 7 to 9 gm | 22 (40.74) | 21 (39.62) | | | |
| 4.3 | >9 gm | 29 (53.7) | 25 (47.17) | | | |
| 5. | No. of Sibling | | | | | |
| 5.1 | One | 28 (51.85) | 28 (52.83) | 2.47 | 2 | 0.29 |
| 5.2 | Two | 09 (16.67) | 09 (16.98) | | | |
| 5.3 | Three & more | 05 (9.26) | 01 (1.88) | | | |
| 6. | No. of thalassemic sibling | | | | | |
| 6.1 | One | 0 | 03 (5.66) | | | |

Hence both the groups were homogenous with respect to demographic variable of children like age, gender, age of initiation of treatment, hemoglobin level and no. of sibling.

**Table 3. Comparison of Pretest Quality of Life Scores of Children with Thalassemia in Experimental and Control Group**

| | Quality of Life Scores | | | | |
|---|---|---|---|---|---|
| Group | Mean | $M_D$ | $SD_D$ | $SE_{MD}$ | 't' Value |
| Experimental (n=54) | 2216.20±338.98 | 34.128 | 575.86 | 1697.24 | 0.554 |
| Control (n=53) | 2182.08±295.82 | | | | |

t (106) = 1.98 p<0.05

The data in table 3 showed that 't' values computed between independent means of pretest quality of life scores in experimental and control group were not significant at 0.05 level. It indicated that subjects in experimental group and control group did not differ significantly in terms of quality of life scores of children (5-12years) regarding care of children with thalassemia.

**Table 4. Comparison between the Pretest and Posttest (Day 30 and Day 60) Quality of Life Scores of children in the Experimental group**

| | Quality of Life Scores | | | | | |
|---|---|---|---|---|---|---|
| | Mean | SD | $M_D$ | $SD_D$ | $SE_{MD}$ | t |
| Age group (5-7 Years) | | | | | | |
| Pre- test | 2323.86 | 336.96 | 27.27 | 37.51 | 96.10 | 1.81 |
| Post-test (Day 30) | 2351.13 | 299.45 | | | | |
| Pre- test | 2323.86 | 336.96 | 93.18 | 107.27 | 95.20 | 2.96* |
| Post- test (Day 60) | 2417.04 | 229.70 | | | | |
| Age group (8-12 Years) | | | | | | |
| Pre- test | 2142.18 | 325.0582 | 90.625 | 80.47 | 71.9112 | 4.32* |
| Post-test (Day 30) | 2232.81 | 244.5732 | | | | |
| Pre- test | 2142.18 | 325.0582 | 210.16 | 145.63 | 65.63 | 6.14* |
| Post- test (Day 60) | 2352.34 | 179.42 | | | | |

t (53) = 2.00, p<0.05

Data in table 4 showed that the't' values calculated between the mean pretest and posttest quality of life scores of children (5-7years) in experimental group, 't' (53)= 1.81 on day 30 was not found to be statistically significant at 0.05 level of significance whereas the 't' values calculated between the mean pretest and posttest quality of life scores of experimental group, 't' (53)= 2.96 on day 60 was found to be statistically

significant at 0.05 level of significance. The computed 't' values for the quality of life of children (8-12 Years) for df (53) 4.32 on day 30 and 6.14 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 quality of life scores of children with thalassemia in the experimental group. Hence the STP was effective in improving the quality of life of children with thalassemia.

**Table 5. Comparison Between Mean Post Test (Day 30 and Day 60) Quality of Life Scores of children (5-12 years) with thalassemia in Experimental and Control Group**

| | Quality of Life Scores | | | | |
|---|---|---|---|---|---|
| Group | Mean | $M_D$ | $SD_D$ | $SE_{MD}$ | t |
| Pre- test | | | | | |
| Experimental n=54 | 2216.2 | 34.13 | 575.86 | 1697.24 | 0.55 |
| Control n=53 | 2182.08 | | | | |
| Post - test at 30 days | 2281.02 | 61.20 | 504.96 | 1361.56 | 1.18 |
| Experimental n= 54 | 2219.81 | | | | |
| Control n= 53 | | | | | |
| Post - test at 60 days | | | | | |
| Experimental n= 54 | 2378.7 | 123.04 | 455.33 | 1099.51 | 2.88* |
| Control n= 53 | 2255.67 | | | | |

t(106) = 1.98, p<0.05

Data presented in the table 5 showed that the mean pre test quality of life score of children regarding care of children with thalassemia in experimental group was 2216.2 and control group was 2182.08 with mean difference of 34.13 which was found to be statistically not significant as evident from the't' value of 0.55 for df (106) at 0.05 levels of significance. Data further shows that the mean posttest quality of life score of children on day 30 regarding care of children with thalassemia in experimental group was 2281.02 and control group was 2219.81 with mean difference of 61.20 which was found to be statistically non significant as evident from 't' value of 1.18 for df (106) at 0.05 levels of significance. This showed that the obtained mean difference was not a true difference but by chance. Data further showed that the mean posttest quality of life score of children with thalassemia on day 60 in experimental group was 2378.7 and control group was 2255.67 with mean difference of 123.04 which was found to be statistically significant as evident from't' value of 2.88 for df (106) at 0.05 levels of significance. This showed that the obtained mean difference was a true difference and not by chance. Thus result indicated that the structured teaching programme administered to parents on care of children with thalassemia was effective in improving the quality of life of children with thalassemia.

**Table 6. 't' Values between Mean Posttest Quality of Life Scores of Thalassemic Children in Experimental and Control Group**

| Group | Quality of life Scores | | | | |
|---|---|---|---|---|---|
| | Mean±SD | $M_D$ | $SD_D$ | $SE_{MD}$ | 't' value |
| Age group (5-7 years) | | | | | |
| Post - test (Day 30) Experimental Group | 2351.14±299.45 | | | | |
| | | 84.03 | 77.51 | 84.38 | 0.99 |
| Control Group | 2267.10 ± 336.96 | | | | |
| Post - test (Day 60) Experimental Group | 2417.04±229.70 | | | | |
| | | 117.05 | 41.40 | 66.09 | 1.77 |
| Control Group | 2300±188.30 | | | | |
| Age group (8-12 years) | | | | | |
| Post - test (Day 30) Experimental Group | 2232.81±244.57 | | | | |
| | | 39.43 | 33.02 | 64.30 | 0.61 |
| Control Group | 2193.38±277.59 | | | | |
| Post - test (Day 60) Experimental Group | 2352.34±179.42 | | | | |
| | | 121.46 | 76.26 | 54.65 | 2.22* |
| Control Group | 2230.88±255.68 | | | | |

t(106) = 1.98, p<0.05

It was evident from table 6 that 't' values computed between the mean posttest quality of life scores of children with thalassemia (5-7 years) in experimental and control group i.e. 't'(106)= 0.99 on day 30 and 1.77 on day 60 were statistically non significant at 0.05 level of significance. Data further showed that 't' values computed between the mean posttest quality of life scores of children with thalassemia (8-12 years) in experimental and control group i.e.'t'(106)= 0.61 on day 30 was not statistically significant whereas the mean posttest quality of life scores of children with thalassemia (8-12 years) in experimental and control group i.e. 't'(106)= 2.22 on day 60 was statistically significant at 0.05 level of significance. Hence the STP was effective in improving the quality of life of children with thalassemia (8-12 years).

N=107

**Table 7. Association of Post Test (Day 60) Quality of Life Score of Children in Experimental Group with Selected Variables**

| Variable | Category | df | $\chi^2$ | P |
|---|---|---|---|---|
| Age of informant | 26-33 yrs<br>34-45 yrs<br>>45year | 2 | 1.02 | 0.6 |
| Mother Education | Secondary<br>Higher secondary<br>Graduate and above | 2 | 1.47 | 0.48 |
| Occupation | House wife<br>Service | 1 | 3 | 3.84 |
| Father Education | Illiterate<br>Primary<br>Secondary<br>Higher secondary<br>Graduate and above | 4 | 1.17 | 0.88 |
| Occupation | Laborer<br>Service<br>Business<br>Professional | 3 | 5.28 | 0.83 |
| Economic status | < Rs. 5000/month<br>Rs 5001-10000/ month<br>Rs 10001-15000/ month<br>> Rs 15000 / month | 3 | 2.62 | 0.45 |
| Type of family | Nuclear family<br>Joint family | 1 | 0.851 | 0.36 |
| Age | 5-7 yrs<br>8-12 yrs | 1 | 1.13 | 0.28 |
| Gender | Male<br>Female | 1 | 0.19 | 0.66 |
| Age of initiation of treatment | <1 year<br>1-3 year<br>3-5year<br>>5year | 3 | 8.94* | 0.03 |
| Hemoglobin level | <7 gm<br>7 to 9 gm<br>>9 gm | 2 | 10.1* | 0.0 |
| No. of Sibling | One<br>Two<br>Three & more | 2 | 0.506 | 0.77 |

Data presented in the table 7 showed that the computed $\chi^2$ value of the post test quality of life score of children with age of informant, education and occupation of mother, education and occupation of father, economic status, type of family, family history of thalassemia and migration status , age of child , gender and number of sibling were not found statistically significant (p>0.05).

N=107

As regard to age of initiation of treatment and hemoglobin level, a significant association was observed between age of initiation of treatment and quality of life of children (p=0.03), between hemoglobin level and quality of life of children with thalassemia (p=0.0) . Thus it can be inferred that age of initiation of treatment and hemoglobin level had influence on the quality of life of children with thalassemia.

## DISCUSSION

In the current study, age of informant, education, occupation, economic status, type of family, place of living, family history of thalassemia and migration status were selected as demographic characteristics of parents. Similarly Kukreja A selected age of parents and education of parents as demographic characteristic. Economic status had earlier been selected as demographic characteristic by Lee YL et al[37], M Karimi[38], Pauisri Surangrhut[41] and family history of thalassemia by Upadhyay Jagriti[35] respectively. In the current study, age, gender, age of initiation of treatment, hemoglobin, no. of sibling, no. of thalassemic sibling were selected as demographic characteristic of children.Upadhyay Jagriti[35] had studied on the same demographic characteristic of children except age of initiation of treatment whereas Torcharus K et al [54] selected age and gender of the children and Thavorncharoensap Montarat et al [52], selected age of children & hemoglobin level in the study respectively. The present study also revealed the effect of implementation of STP on quality of life of children with thalassemia. 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 control group (E=2378.7, C=2255.67). It was found to be statistically significant as evident from 't' (106) = 2.88, $p<0.05$). The STP was effective in improving quality of life of children with thalassemia. These findings are consistent with the study of effect of family- centered empowerment model on quality of life of school- aged children with thalassemia major by Fariba Borhani et.al[28]. Computed $\chi^2$ value of the post test (day 60) quality of life score of children with thalassemia with age of initiation of treatment and hemoglobin level showed that age of initiation of treatment and hemoglobin level had influence on the quality of life of children with thalassemia. The findings are consistent with the study conducted by Thavorncharoensap Montarat et al (2010) with respect to hemoglobin level.

### Limitation

- Sample of the study was not selected randomly.
- Study was conducted in only Delhi state of northern region of India

### Conclusions and Recommendation

The current study showed that the STP on care of children with thalassemia was effective in improving the quality of life of children with thalassemia and a significant association was observed between quality of life of children with Hb level, Family history with thalassemia in the experimental group. This study provides implications that Nurses should have advanced knowledge regarding care of children with thalassemia. There should be a link between hospital and community health nursing agencies to follow up the children with thalassemia to increase the child's compliance with treatment of thalassemia to foster the optimal growth and development of children with thalassemia major. Its nurse's responsibility to inform the parents regarding the various organizations like thalassemic societies available to help the thalassemic children in their treatment as only the supportive measures can improve the quality of life in thalassemic children. So the researcher recommended for the Multicentric studies in different thalassemic units in hospitals of the country; measurement of the level of stigma and its impact on quality of life of children with thalassemia; Longitudinal study to evaluate the impact of teaching programme in terms of children's outcome i.e. quality of life.

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## REFERENCES

Allahyari Alhany F, Kazemnejad A, Izadyar Izadyar. The effect of family centered empowerment model on the quality of life of school age beta- thalassemic children. Iranian Journal of Pediatrics;2006, 16(4):455-461

Caocci Giovanni, efficace Fabio, ciotti Francesca, Poncarolo maria Grazia, Vacca Adriana, etal, health related quality of life in middle eastern children with beta-thalassemia, BMC blood disorder. 2012, 12:6, 1-7.

Clark SA, Eiser Christine. The measurement of health related quality of life in pediatric clinical trials: a systemic review.2004;2:66

Dehkordi AH, Heydarnejad M. Effect of booklet and combined method on parents' awareness of children with beta-thalassemia major disorder. J Pak Med Assoc. 2008 Sep;58(9):485-7

George Anice. A study on physical growth parameters in thalassemic children.2007

Ghai OP, Paul Vinod K, Bagga Arvind, Ghai Esssentials of Pediatrics. Seventh Edition. 2009.307-308

Ishaq F, Abid H, Kokab F, Akhtar A, Mahmood S. Awareness among parents of β-thalassemia major patients, regarding prenatal diagnosis and premarital screening.J Coll Physicians Surg Pak 2012 Apr;22(4):218-21

Ismail Adriana, Campbell Michael J, Ibrahim Hishamshah M and Jones Georgina L. Health related quality of life in Malaysian children with thalassaemia. http://www.hqlo.com/content/4/1/39

Ismail Munirah, Chun Choong Yin, Yusoff Noor Aini Mohd, Shahar Suzana, ahara Z Manaf Abdul. Quality of Life Among Thalassaemia Children, Adolescent and Their Caregivers. Sains Malaysiana (2013):42(3): 373–380

Khani H., Majdi M.R., Mazzabadi Azad, Montazer A. ghorbani A and Ramezani M. Quality of life of Iranian B- thalassemia major patients living on the southern coast of the Caspian sea. Eastern mediterrian Health journal. Vol. 8, no. 4, 2012. 539-545

Marcdale Karan, Kliegman Robert M, Jeson Hall B, Behrman Richard E. 2011. Nelson Essentials of Pediatrics. 6th edition, 555-582.

Pakbaz Z, Treadwell M, Yamashita R, Quirolo K, Foote D, Quill L et al. Quality of life in patients with thalassemia intermedia compared to thalassemia major. Ann N Y Acad Sci. 2005;1054:457-61

Sachdeva A, Yadav S P, Berry A M, Kaul D, Raina A, Khanna V *K* .Assessment of Quality of Life in Thalassemia Major; *International Journal of Haematology 2002' 76(SI):4*

Tahir Hira, Shahid Syeda Amna, Mahmood Khawaja Tahir. Complications in Thalassaemia Patients Receiving Blood Tranfusion. J Biomed Sci and Res., Vol 3 (1), 2011,339-346

Torcharus K, Pankaew T.Health-related quality of life in Thai thalassemic children treated with iron chelation. Southeast Asian J Trop Med Public Health. 2011 Jul;42(4):951-9.

Uthman Ed. Hemoglobinopathies and thalassemias. web2.airmail.net/uthman/index.html

Varni JW, Seid M, Kurtin PS. PedsQL 4.0: reliability and validity of the Pediatric Quality of Life Inventory version 4.0 generic core scales in healthy and patient populations. Med Care. 2001 Aug; 39(8):800-12.

Wahyuni masyitah sri, ali mehammad, rosdiana nelly, lubis bidasari, quality of life assessment of children with thalassemia, paediatric indonesiana, may 2011, vol. 51, no.3, 163-169.

Wahyuni Masyitah Sri, Ali Muhammad, Rosdiana Nelly, Lubis Bidasari, Quality of life assessment of children with thalassemia. Paediatr Indones. 2011;51:1639.

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