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RESEARCH ARTICLE

A STUDY TO ASSESS THE QUALITY OF LIFE AMONG CHILDREN SUFFERING FROM THALASSEMIA WITH A VIEW TO DEVELOP A PARENTAL GUIDELINE IN THE SELECTED DAY CARE CENTRE OF KOLKATA, WEST BENGAL

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Abstract

Thalassemia is an inherited blood disorder, which is characterized by decreased synthesis or absence of globin. The study was conducted to assess the quality of life among children suffering from thalassemia with a view to develop a parental guideline in the selected day care centre of Kolkata, West Bengal. A non-experimental survey approach with descriptive research design was adopted for the study. The data were collected using convenience sampling technique among 100 parents of children suffering from thalassemia and receiving blood transfusion at Institute of Blood Transfusion Medicine & Immunohaematology, Central Blood Bank, Maniktala, Kolkata. Findings revealed that out of 100 children suffering from thalassemia, 86 (86%) had good quality of life, rest 14 (14%) had satisfactory quality of life and none of them had poor quality of life. There was significant association of quality of life with selected variables like age, religion, educational status of father, educational status of mother, age of detection of thalassemia, age of starting blood transfusion at < 0.05 level of significance.

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Introduction:-

Naturally and inevitably the health & wellbeing of a growing child is always a matter of great interest and concern to the parents. Most of the cases, the wellbeing of a child suffering from major illness is significantly diminished than the healthy child. Children may suffer from an acute or chronic illness and many times these chronic illnesses occur as a result of chromosomal disorders. Thalassemia is a kind of chronic illness of children occurs as a result of inheritance of defective gene. According to Bagga A¹, Ghai OP, Paul K Vinod thalassemia is defined as an inherited blood disorder which is characterized by decreased synthesis or absence of globin. This synthetic defect leads to the formation of fragile abnormal red blood cells (RBC), which can be easily haemolysed, leading to chronic anemia.

The health bulletin of the World Health Organisation² stated that over 56, 100 (17%) infants are born annually worldwide with thalassemia (2006). About 100000 patients are currently living with regular transfusions, and at least 3000 die annually in their teens or early 20s from uncontrolled iron overload. According to a joint report of World Bank & WHO³ meeting on november 2007, **300,000 – 500,000 children are born annually with a severe haemoglobin disorder and around 30% are born with thalassemia disorder**. A total 50,000 – 100,000 children with β -thalassemia major die in each year in low and middle income countries.

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Madan N⁴, Sharma S, Sood SK, Colah R, Bhatia LH conducted a study to find the gene frequency of beta Thalassemia among school children in India. The overall carrier frequency of β thalassemia was 4.05%.

Considering these above studies, the researcher strongly feels that there is a need to assess the quality of life of children suffering from thalassemia and developing a parental guideline on some important activity necessary to manage the condition and promote quality of life through enhancing knowledge of parents.

Objectives:-

1. To assess the Quality of Life among children suffering from thalassemia.
2. To find association of the Quality of Life of children suffering from thalassemia with selected variables.
3. To develop a parental guideline for children suffering from thalassemia.

Methodology:-

In this study, the researcher collected data from 100 parents of children suffering from thalassemia using convenience sampling technique depending on inclusion and exclusion criteria. The setting for the study was thalassemia day care centre, Institute of Blood Transfusion Medicine & Immunohaematology, Central Blood Bank, 205 Vivekananda Road, Maniktala, Kolkata- 700006. Children suffering from β thalassemia major within the age group of 6-12 yrs who was treated in this selected thalassemia day care centre were included and children with other chronic diseases except thalassemia were excluded. An eleven item structured demographic proforma was used to measure the background data. And a Quality of life assessment scale of children suffering from thalassemia was used. It is a five point rating scale consisted total 35 items which were developed from 4 domain, Physical wellbeing, psychological wellbeing, social wellbeing and environmental wellbeing. The minimum and maximum scores that can be obtained are 35 and 175 respectively. The scores can be arbitrarily categorised into three groups.

- 35- 81 - Poor quality of life
- 82-128 - Satisfactory quality of life
- 129-175 - Good quality of life

The validity of tool and content was established by seeking opinion from seven experts. Reliability was conducted in the Thalassemia management and day care centre, Thalassemia Guardian Association, 58 Neemtala Ghat Street, Kolkata-700006. The reliability was calculated using Cronbach's alpha method. The r value obtained was 0.84, which indicates that the tool had internal consistency. The quality of life assessment scale was pre-tested on 10 parents of the children suffering from thalassemia in the Thalassemia management and day care centre, Thalassemia Guardian Association, 58 Neemtala Ghat street, Kolkata-700006. The pilot study was conducted at The Thalassemia Society of India, 48a, Mukhtaram Babu Street, Kolkata - 700007 among 20 parents of children suffering from thalassemia from 2/11/15 to 6/11/15. The mean score of quality of life was 139.25. All the 20 samples (100%) had good quality life (129-175). The parental guideline was prepared after reviewing the related literature and with the guidance of experts in the field and was validated by seven experts.

Results:-

Findings of the study were analyzed and organized in relation to objectives and hypotheses. The major findings of the study were organised under the following headings:

Section I- Sample characteristics:

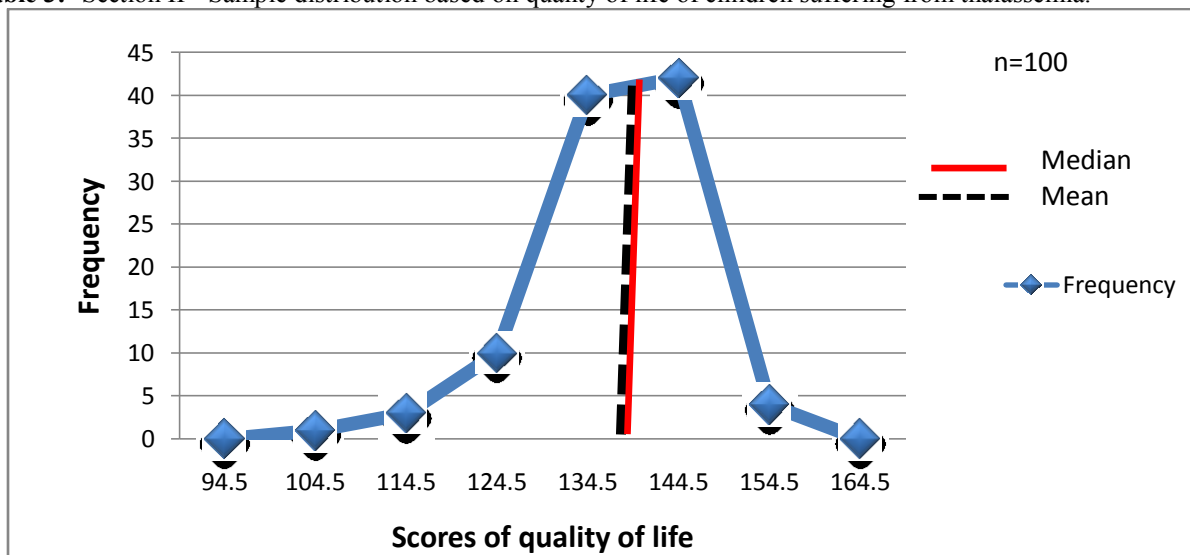
1. Out of the 100 children 37 (37 %) were suffering from thalassemia belong to age group (8-9) years.
2. Out of the total 100 children more than half of them 56 (56%) were female.
3. 53% of the children were Muslim.
4. Most (91%) of them were going to school.
5. Out of the 100 children, 54 (54%) of them thalassemia was diagnosed in 6-12 months of age.
6. 57% of the children received both iron chelation and blood transfusion.
7. More than half (53%) of the children's blood transfusion was started in 6-12 months of age.
8. 48% of the children received blood transfusion twice in a month.
9. More than half (56%) of the mother's educational status was primary education.
10. Out of 100 children 45 (45%) of the father's educational status was primary education.
11. Majority (77%) of their mother's were unemployed.

12. Majority (62%) of their father were employed in private or government.
13. Most (87 %) had family income of <10,000 rs per month.
14. Majority (61%) of them did not have any siblings and the rest 39(39%) had siblings and among these 39 siblings, 7 of them are affected with thalassemia.

Section II

Distribution of sample based on quality of life among children suffering from thalassemia

Table 3:- Section II - Sample distribution based on quality of life of children suffering from thalassemia.



Data showed that out of 100 children suffering from thalassemia, score of quality of life was between 108-150 where as maximum possible score were 175 and minimum possible score was 35. Findings showed that mean, median and standard deviation of quality of life of children suffering from thalassemia is 137.60, 137.60 and 8.91 respectively.

Fig 3:- Frequency polygon showing mean scores of quality of life.



Fig 4:- Bar diagram showing sample distribution based on level of quality of life.

The data reflected that out of 100 sample majority (84%) of them had good quality of life and rest 16(16%) of them had satisfactory quality of life.

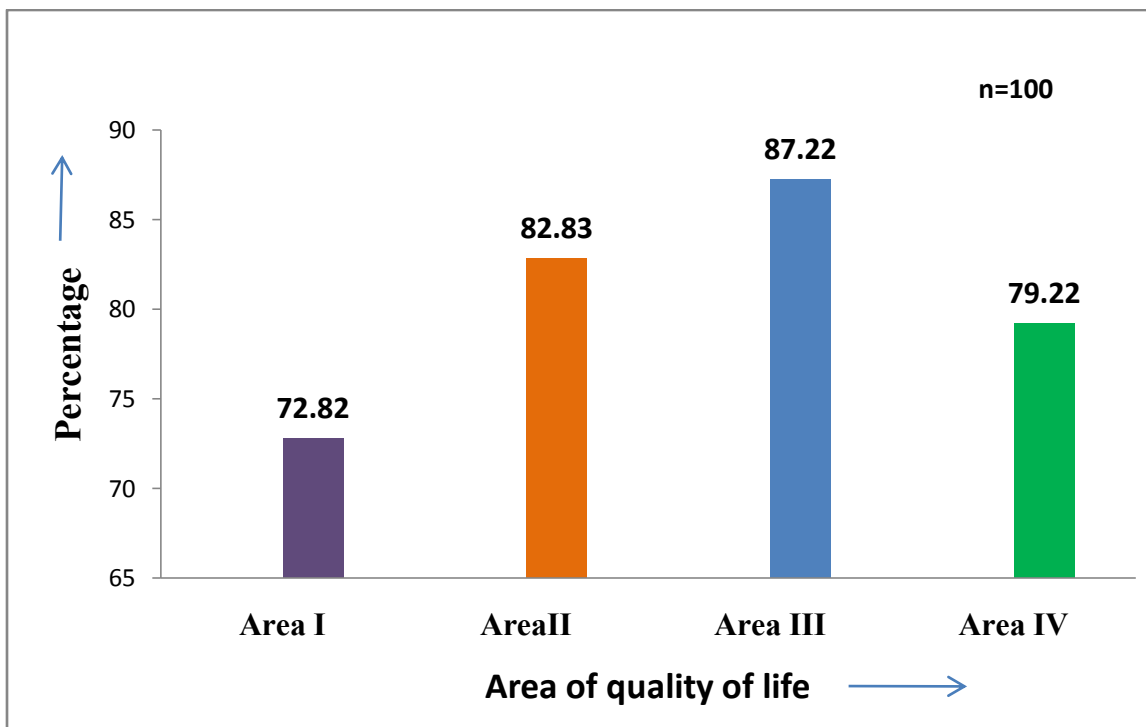


Fig 5:- Bar diagram showing the mean percentage of four aspect of quality of life among children suffering from thalassemia.

Key:

Area – I Physical wellbeing, Area – II Psychological wellbeing, Area III – Social wellbeing, Area – IV Environmental wellbeing.

The data presented in the figure 5 showed The quality of life is highest (87.22%) in the area of social wellbeing and lowest (72.82%) in the area of physical wellbeing.

Section III -

Association with quality of life of children suffering from thalassemia and selected variables

To find the association of Quality of Life and selected variables, chi square was computed. The obtained chi values (0.88), (2.54), (3.11), (2.31), (0.07), (4), (2.26), (3.69) were less than the table value for the variables- gender, educational status of child, employment status of father, employment status of mother, type of therapy received, frequency of blood transfusion, monthly family income, presence of siblings. So, it can be interpreted that these variables were not associated to quality of life of children suffering from thalassemia. The obtained chi values (7.97), (3.89), (12.19), (14.16), (10.19), (14.76) were more than the table value for the variables- age, religion, educational status of mother, educational status of father, age of detection of thalassemia, age of starting blood transfusion. So, it can be interpreted that that quality of life of children suffering from thalassemia was associated with the selected variables- age, religion, educational status of mother, educational status of father, age of detection of thalassemia, age of starting blood transfusion.

Discussion:-

The present study findings revealed that the mean, median and standard deviation of quality of life of children suffering from thalassemia was 137.60, 137.60 and 8.91 respectively. It also showed that out of 100 children suffering from thalassemia, 86 (86%) had good quality of life and rest 14(14%) had satisfactory quality of life and none of them had poor quality of life. The quality of life of children suffering from thalassemia was associated with

the selected variables- age, religion, educational status of mother, educational status of father, age of detection of thalassemia, age of starting blood transfusion.

Conclusion:-

From the study findings it could be concluded that the quality of life of the children suffering from thalassemia was affected in all aspect of wellbeing and was associated with the selected variables- age, religion, educational status of parents, age of detection of thalassemia, age of starting blood transfusion .

Reference:-

1. Bagga A, Ghai OP, Paul K Vinod. Essential Pediatrics.7th ed. New Delhi:CBS Publishers and distributors Private Limited ; 2010.p. 307.
2. Modell B , Darlison M, Global epidemiology of haemoglobin disorders and derived service indicators. Bulletin of the World Health Organization.2008; 86:417-96. Available from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2647473>.
3. Nicosia, Cyprus. Report of joint WHO-TIF meeting. Management of Haemoglobin Disorders. World Health Organisation; 2008.
4. Madan N, Sharma S, Sood SK, Colah R, Bhatia LH. Frequency of β -thalassemia trait and other hemoglobinopathies in northern and western India. Indian J Hum Genet [Internet]. 2010; 16:16-25. Available from <http://www.bioline.org.br>.
5. M Sengupta. Thalassemia among the tribal communities of India. IJBA [Internet]. 2007;1: Available from <http://ispub.com/IJBA/1/2/5492>.
6. Marlow R D, Redding A B. Textbook of Pediatric Nursing. 6th ed. New Delhi: Elsevier; 2013. P. 530.
7. Hockenberry J M , Wilson David. Wong's Essential of Pediatric Nursing.8th ed. St Louis, Missouri: Elsevier ; 2009.p. 923-4.