EFFECTIVENESS OF HEALTH CARE PACKAGE ON CARE OF THALASSEMIC CHILDREN AMONG PARENTS

By: Shalini*

***Lecturer, Kurji Holy Family Hospital College of Nursing, Patna, Bihar, India.**

ABSTRACT

The present study was to (1) assess the quality of life of children with thalassaemia (2) identify the factors associated with quality of life with thalassaemia - general health, physical functioning, behavioural functioning, social and family functioning, emotional functioning, cognitive functioning (3) seek the relationship between selected demographic factors and quality of life with thalassaemia – age ,sex, educational status of children, duration of illness of children, type of family, area of habitation, number of transfusions, number of affected siblings, Hb % level, parents occupation, parents income (4) develop health care package for parents on care of children with thalassaemia (5) assess the effectiveness of health care package for parents on care of children with thalassaemia before and after pre-test and post-test.

Key Words: Thalassemic Children, Blood disorder, Health care.

About Author:

The author Mrs Shalini is working as Lecturer in Kurji Holy Family Hospital College of Nursing, Patna, Bihar, India.

INTRODUCTION

Thalassaemia is a group of inherited blood disorders. "Inherited" means that the disorder is passed from parents to children through genes. Thalassaemia causes the body to make fewer healthy red blood cells and less haemoglobin than normal. Treatments for thalassaemia have improved over the years. People who have moderate or severe thalassaemia are now living longer and have better quality of life. However, complications from thalassaemia and their treatments are frequent. People who have moderate or severe thalassaemia must closely follow their treatment plans. They need to take care of themselves to remain as healthy as possible.

REVIEW OF LITERATURE

Neeraj (2010) conducted a cross sectional study on 142 children with beta thalassaemia of three years or more receiving regular blood transfusions at a transfusion centre in western India. Out of 142 children 68 faired poorly in their physical health, 30 children had poor quality of life in psychological domain, 20 children had poor environment and 28 had social factors.

Afshin (2008) conducted a cross sectional study on 80 children with thalassaemia of the age group between 5 to 17 years. This study was conducted in Tehran University. This study was done with the help of Short Form 36 scale .The study found that more than 50% of children had poor quality of life.

Kaheni S, Yaghobian M et.al (2013) conducted a cross sectional study on Quality of Life in Children with β-Thalassaemia Major, at Centre for Special Diseases. This study was conducted on 40 children of over 7 years of age with thalassaemia major. According to the results, quality of life of the children with thalassaemia was above average in three dimensions - physical health, psychological health and environmental health, and in order to improve quality of life in these children, appropriate programmes should be implemented to support them physically, mentally and socially, and improve the relationship of the children with thalassaemia with the Centre for Special Diseases.

Ismail (2006) a comparative study was done for 96 children with thalassaemia and 235 normal children in Kuala Lumpur. The mean age of these children with thalassaemia was 11.9 and that of normal healthy children was 13.2 years. The instrument used for the study was Paediatric Quality Of Life 4.0 generic scale. Physical, emotional, social and school functioning assessment were done for the children and indicated that the children with thalassaemia had a lower quality of life than healthy children.

METHODOLOGY

Research Approach

Phase-I

The study has been done in two phases.

Since the study intends to assess the quality of life of children with thalassaemia, the survey approach method was used for the first phase of the study.

Phase-II

In the second phase, to evaluate the effectiveness of the health care package on care of children with thalassaemia an evaluative experimental research approach was considered to be the most appropriate to accomplish the objectives of the study.

In the present study the research design selected for the two phases were:

Phase I: Descriptive Survey

Phase II: One group pre- test and post-test design to measure the effectiveness of health care package

Table 1: Symbolic Representation of PHASE II Research Design

Group	Pre Test (Day 1) Dependent Variable	Treatment Independent Variable	Post Test (Day 7) Dependent Variable
E	OK_1	X	OK_2

The interpretation of symbols is as follows:

E- Experimental group, parents of children with thalassaemia

OK_1 - Knowledge test before the administration of Health Care Package

X - Intervention (Administration of Health Care Package)

OK_2- Knowledge test after the administration of Health Care Package

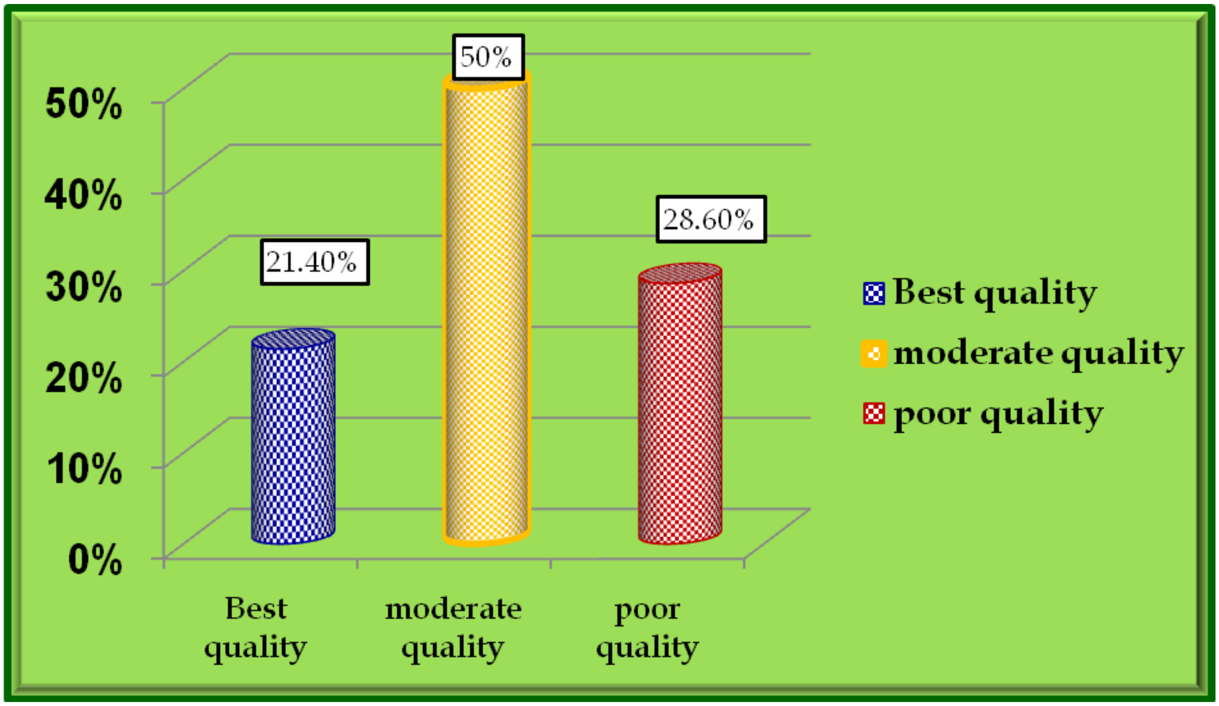
THE MAJOR FINDINGS

1. Findings related to sample characteristics of Phase 1

- Majority (74.23%) children were of age group 12 years and above followed by the children of age group of 10 to 11 years with (14.23%) and (11.43%) with the age group of 8-9 years.
- Majority were males (57.14%) and the remaining (42.86%) were females. In respect of educational status, (75.71%) were of between 11th–12th standard and (24.28%) of children were of below 10th standard.
- Regarding duration of illness, (81.43%) were having illness since 6 month-1 year and rest (15.71%) were having disease since 1 ½-2 years and (2.86%) were knowing about the disease more than 2 ½ years.
- (87.14%) of children belonged to nuclear family and rest (12.86%) of children were from joint family and also (95.14%) were from urban area and rest (4.28%) were from rural area, in the age group of 8-9 years.
- In number of transfusion/s per month (98%) of children were having once in month and (2%) of children were having twice in a month. Haemoglobin level of children with thalassaemia showed that (87.14%) of children were having haemoglobin level between 8-10gm% and (12.86%) of children were having haemoglobin level between 5-7gm%. in the age group of 8-9 years.
- As regards Parent’s occupation (40%) of the parents were in private job, (28.57%) of the parents were in government service, (28.57%) of parents were doing business and (2.85%) were unemployed. The income status of the parents indicated they were earning between Rs.5000 to 10,000 per month and rest of parents had an income between Rs.10,001 and above. This section describes the sample characteristics of 70 children with thalassaemia to assess their quality of life scale by means of frequency and distribution in the age group of 8-9 years.

2. Findings related to assessment of QOL of children with thalassaemia according to different dimensions -

Table 2: Frequency and distribution of sample characteristics



- Assessment of Quality of Life (QOL) indicates that total (21.4%) of children were having best QOL, (50%) of children were having moderate QOL and (28.6%) of children were having poor QOL.

3. Findings related to evaluation of the effectiveness of health care package in terms of knowledge of parents on care of children with thalassaemia -

Table 4

N= 60

Knowledge Test	Mean	Median	SD
Pre-Test	**20.7**	**20.5**	**4.72**
Post- Test	**27.5**	**28.0**	**3.33**

The data given in the table (4) shows that the mean post-test knowledge score (27.5) of parents of children with thalassaemia was higher than the mean pre-test knowledge score (20.7). The median of the post-test score (28) was higher than the median of the pre-test knowledge score (20.5). The data also revealed that standard deviation of the pre-test knowledge score (4.72) was more than the standard deviation of the post-test knowledge score (3.33), which indicates that health care package was effective in making the group more homogenous.

Figure 3: Line graph showing the mean , median and SD of pre-test and post-test knowledge scores of parents on care of children with thalassaemia

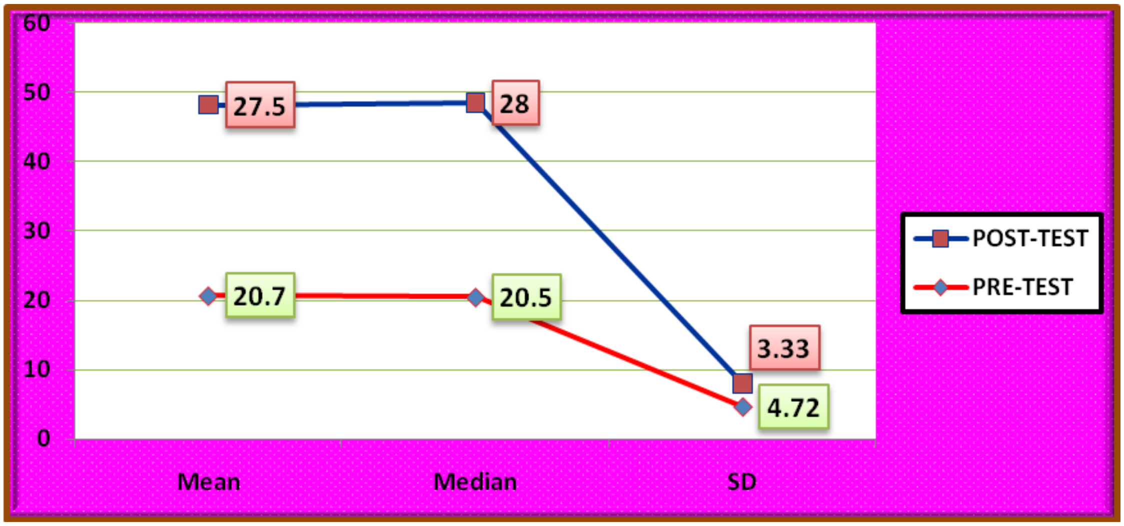
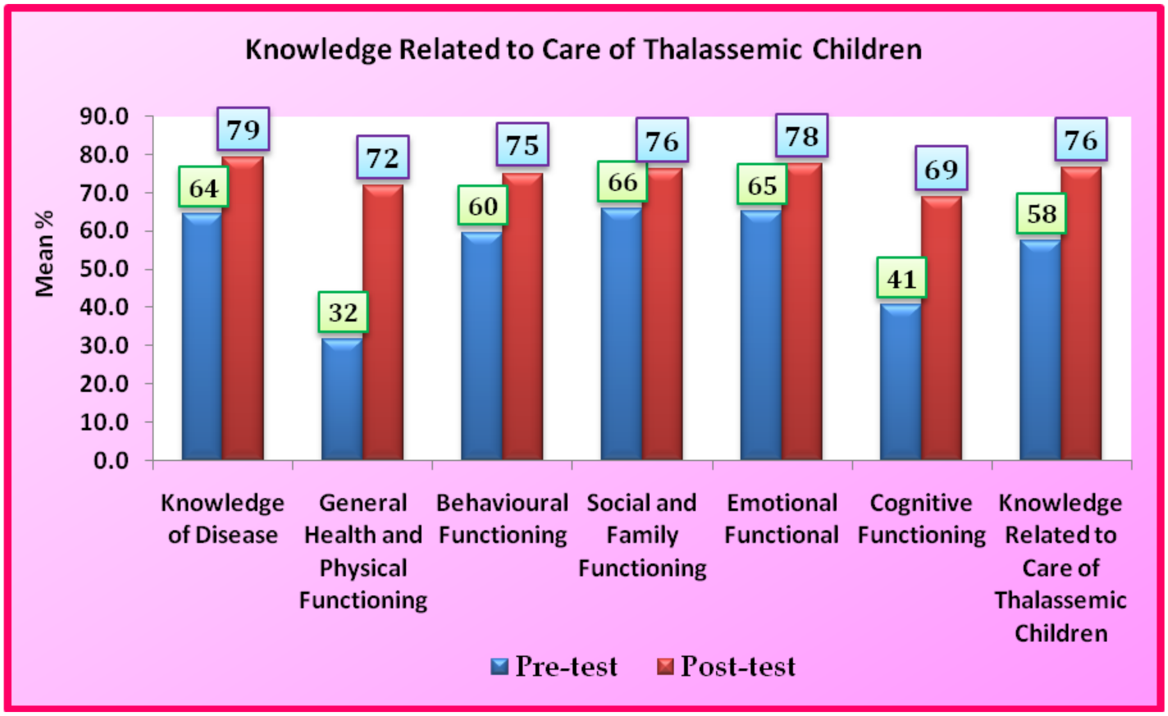


Figure 2: Bar graph shows percentage of pre-test and post-test knowledge of the sample on care of children with thalassaemia. So the mean percentage of overall knowledge on care of children with thalassaemia as compared to the pre-test is high i.e. 76.4%.



This shows that the Health care package is effective for the parents on care of children with thalassaemia.

SUMMARY

The quality of life of children with thalassaemia is affected by multiple factors such as family income, family history of thalassaemia, behavioural functioning, physical functioning, emotional functioning, social and cognitive functioning etc. Proper Education Programme, screening and counselling and supportive measures will improve the quality of life of children with thalassaemia. These children and their parents need life long psychological support to accept the challenges in their life and also the support system will help the parents to provide better quality of life to their children.

The present study was conducted as an attempt to assess the QOL of children with thalassaemia (aged 6-18 yrs) and to seek its association with selected factors with a view to develop and evaluate the effectiveness of health care package in terms of knowledge for the parents on care of children with thalassaemia in selected hospital of Delhi.

BIBLIOGRAPHY

Books

1. Hockenberry. J. M, Wilson.D.(2009). Wong's Essentials of Pediatric Nursing (8th edition) Elsevier publishers, Pg-923-924.
2. Beevi A. (2009). Textbook of Pediatric Nursing. Elsevier, Pg 292-294
3. Marlow. R. D. (2008). Textbook of Pediatric Nursing (6th edition). An imprint of Elsevier.Pg 659-600
4. Garret, H.E. (2009).Statistics in Psychology and Education (12th edition). New Delhi: Paargon International Publishers.

Journals

5. Shaligram D, Girimaji S.C.(2007). Psychological problems and Quality of life in children with thalassemia.***Indian Journal OfPediatrics***.Vol. 74(8), Pg- 727-730.
6. Telfer P et.al.(2005). Quality of life in Thalassemia, ***Annals of the New York Academy of Sciences***.Vol. 1054, Pg-273-282.
7. Torcharus.K, Indaratna K et.al.(2010). Factors affecting quality of life in Thai children with Thalassemia .**BMC Blood Disorder**, Vol. 10(1), Pg 1471-2326.
8. Pakbaz. Z, Treadwell. M (2006). Quality of life in patients with Thalassemia Intermedia compared to Thalassemia major, Vol. 1054 (8), Pg- 457-461.

Published/ Unpublished Thesis

9. Jose. D.Reshmi**"A Study To Identify the Psychological Problems Of Adults With Locomotor Disability And To Seek It's Association With Selected Factors With A View To Develop And Evaluate The Effectiveness Of An Information in terms of Knowledge Regarding Coping Strategies in a selected hospital of U.P."**Unpublished Master of Nursing thesis, University of Delhi, 2013.

Internet Links

10. www.socialstyrelsen.se/rarediseases/thalassemia
11. www.Thalassemia.com
12. evichinsky@mail.cho.org
13. www.nhlbi.nih.gov
14. health.india.com