

Quality of Life of Thalassemic Children and the Assessment of Effectiveness of Health Care Package in Terms of Knowledge for the Parents on Care of Thalassemic Children

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Abstract

A study "To assess the quality of life of thalassemic children and to seek its association with selected factors with a view to evaluate the effectiveness of health care package in terms of knowledge for the parents on care of thalassemic children in selected hospital of Delhi".

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

Introduction

Thalassemia is inherited blood disorders. "Inherited" means that the disorder is passed from parents to children through genes. Thalassemia causes the body to make fewer healthy red blood cells and less haemoglobin than normal. Treatments for thalassemia have improved over the years. People who have moderate or severe thalassemia are now living longer and have better quality of life. However, complications from thalassemia and their treatments are frequent. People who have moderate or severe thalassemia 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 beta thalassemic children 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 faired poorly quality of life in psychological domain, 20 children had poor environment and 28 had social factor.

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

Prathama Guha¹, Arunansu Talukdar (2013) conducted a study on behavioural profile and school performance of thalassemic children in eastern India. 49 randomly selected cases and 51 age, sex and socioeconomic status matched controls were assessed. Behavioural abnormalities were present in 67.3% of cases, compared to 21.6% of controls (p=0.01). There was an overall effect with the presence of psychopathology in thalassemic children. Presence of psychopathology significantly predicted school dropout - an outcome not affected by IQ, socioeconomic status, residence, or parental education.

Methodology

Research Approach

Phase-I

The present study has been done in two phases.

Since the study intends to assess the quality of life of thalassemic children, 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 thalassemic children, 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 1- Descriptive Survey

Phase -2- 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 as follows:

E- Experimental group, parents of thalassemic children

OK₁ - Knowledge test before the administration of Health Care Package

X - Intervention (Administration of Health Care Package)

OK₂ - Knowledge test after the administration of Health Care Package

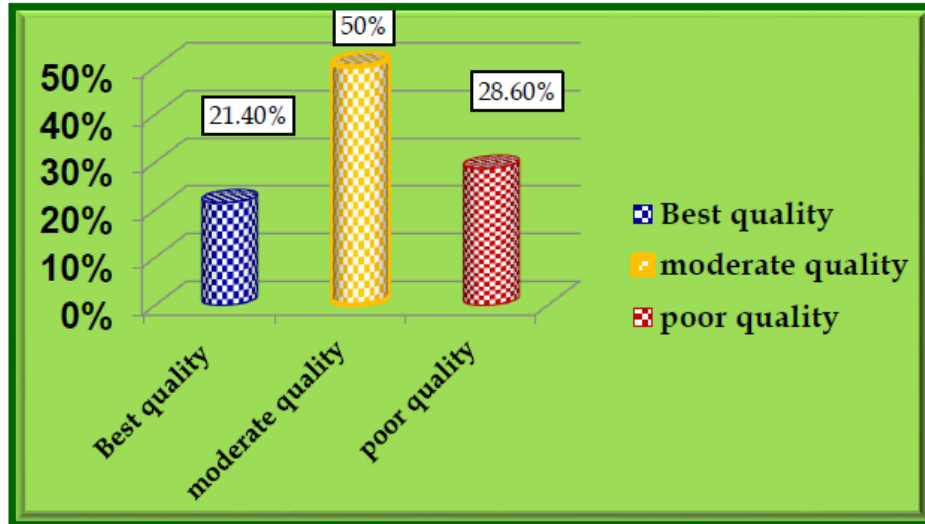
The major findings

1. Findings related to sample characteristics of Phase 1

- Majority (74.23%) children were of age group 12 years and above followed by the age group of 10 to 11 years of children with (14.23%) and (11.43%) with the age group of 8-9 years.
- Majority were male (57.14%) and the remaining (42.86%) were female. In educational status, (75.71%) were of between 11th- 12th standard and (24.28%) of children were of below 10th standard.
- For duration of illness, (81.43%) were having illness since 6mth- 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 belong 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 number of transfusions per month (98%) of children were having once in month and (2%) of children were having twice in a month. Haemoglobin level of thalassaemic children shows that (87.14%) of children were having haemoglobin level between 8- 10gm% and (12.86%) of children were having haemoglobin level between 5-7gm%.
- 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 parent's was getting between Rs. 5000 to 10,000 per month and rest of parent's were getting the income between Rs. 10, 0001 and above. This section describes the sample characteristics of 70 thalassemic children to assess their quality of life scale by means of frequency and distribution.

2. Findings related to assessment of QOL of thalassemic children according to different dimensions

- Assessment of 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.



Findings related to evaluation of the effectiveness of health care package in terms of knowledge of parents on care of thalassemic children.

Table:4
N= 60

Table 2. Frequency and distribution of sample characteristics

Knowledge Test	Mean	Median	SD
Pre-Test	20.7	20.5	4.72
Post- Test	27.5	28	3.33

The data given in the table 15 shows that the mean post- test knowledge score of parents of thalassemic children (27.5) 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.

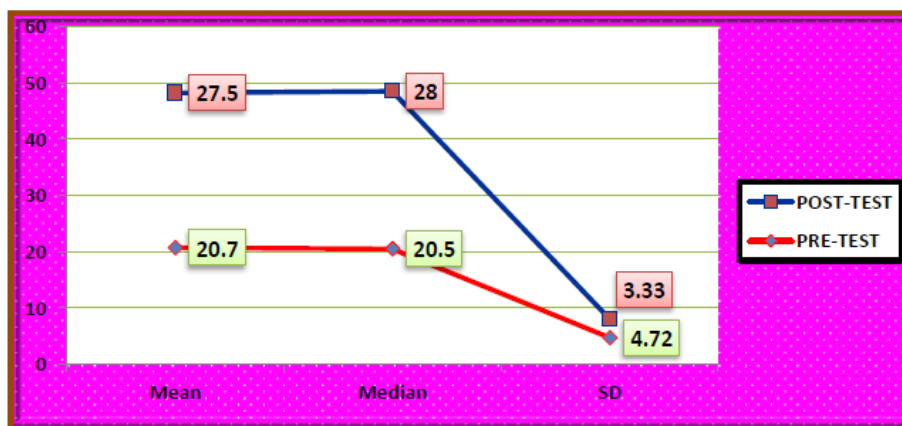


Figure 2. Line graph showing the mean, median and SD of pre-test and post-test knowledge scores of parents on care of thalassemic children

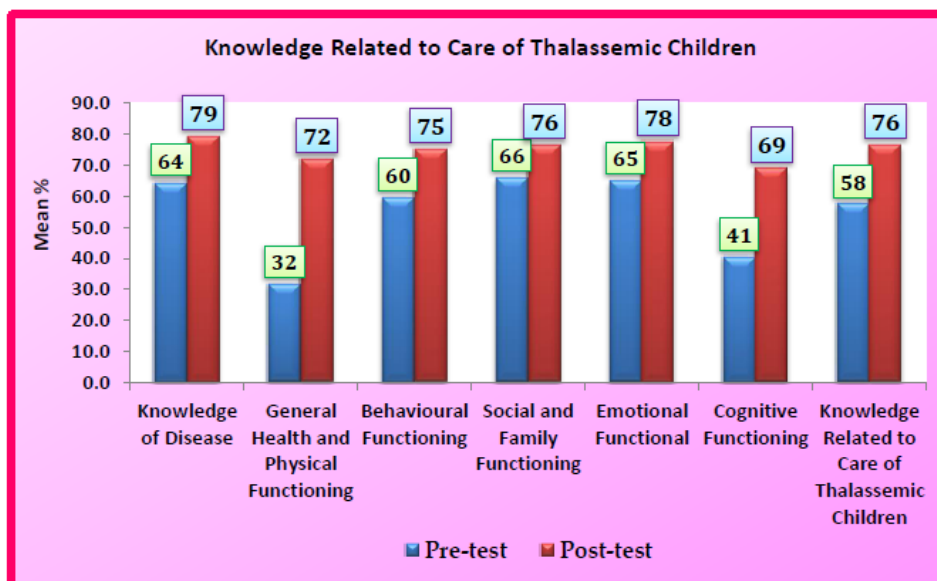


Figure 3. Bar graph showing percentage of pre-test and post-test knowledge of sample on care of thalassemic children

So, the mean percentage of overall knowledge on care of thalassemic children 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 thalassemic children.

Summary

The quality of life of thalassemic children is affected by multiple factors such as family income, family history of thalassemia, behavioral functioning, physical functioning, emotional functioning, social and cognitive functioning etc. Proper Education Program and screening and counseling and supportive measures will improve the quality of life of thalassemic children. Thalassemic children and parents needs life- long psychological support to accept the challenges in their life and also 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 thalassemic children (6-18yrs) 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 thalassemic children in selected hospital of Delhi”.

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