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Original Research Article

Effectiveness of an information booklet regarding home based management on knowledge of caregivers of children with thalassemia

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ABSTRACT

Background: Thalassemia is one of the most common inherited diseases worldwide. It is (mediterranean anemia, cooley's anemia) inborn hemolytic anemia characterized by a drop in the synthesis of hemoglobin. It produces hypochromic microcytic anemia due to imperfect hemoglobinization of RBCs, hemolysis, and futile erythropoiesis. It is due to mutations on chromosome 11 which leads to the synthesis of abnormal or absent beta globin chains. Recently there has been increasing cases of thalassemia worldwide. Hence, current study was planned to assess the knowledge of caregivers regarding homebased management of children with thalassemia.
Methods: We assessed caregivers' knowledge regarding home-based management of children with thalassemia in thalassemia day care department of pediatric KGMU Lucknow, using a self structured questionnaire. Statistical analysis was performed using SPSS software version 24.
Results: The level of knowledge regarding pretest and posttest mean scores is 9.50 and 14.17 respectively. Paired t test calculated value was -9.808 which was much higher than the table value at $p<0.05$ level of significance.
Conclusions: The study concluded that information booklet teaching was effective in improving the knowledge level of caregivers of children with thalassemia. More studies need to be done with larger sample size to empower cargivers regarding thalassemia.

Keywords: Assess, Knowledge, Caregivers, Thalassemia, Information booklet, Effectiveness

INTRODUCTION

The word thalassemia is evolved from the Greek word 'thalassa' means the great sea. It was foremost expressed by Cooley in 1925. It was first observed in patients who came from the sea coast countries of the Mediterranean Sea. It is characterized by a drop in the synthesis of haemoglobin. It produces hypochromic microcytic anaemia due to imperfect hemoglobinization of RBCs, haemolysis, and futile erythropoiesis. Thalassemia can be considered as hyperproliferative and haemolytic anaemia associated with abnormal haemoglobin. Nowadays thalassemia has been found in various provinces whole over the world. The popularity of the disease in India is far above the ground among Gujaratis, Sindhis, and Punjabis. There are millions of people as carriers of the thalassemia gene. The fundamental defect in the hereditary inability to produce a globin polypeptide chain. Certain communities in India, such as Kutchis, Bhanushali's, Mahar's, Neobuddhist's, Koli's and Agri's from Maharashtra, Sindhis and Punjabis, Gowda's and Lingayat's from Karnataka and Lohana's from Gujarat, etc. have a higher transporter pace.[1]

Clinical features of thalassemia minor include haemolytic facies (bossing of skull, frontal prominence, hypertrophied maxilla with malar prominence, depressed nasal bridge) develop in the second year of life.[2] They develop progressive enlargement of 3 the liver and spleen.[2] The transfusion requirements increase with time and they develop iron overload for which they require chelation (oral or subcutaneous). These patients are usually short and have delayed sexual maturity. They become predisposed to infections and death can occur due to severe anemia, cardiac failure, or liver failure.[3]

A descriptive cross-sectional study carried out in a tertiary teaching hospital in Kolkata, among 428 study population using a pre-tested structured schedule by interview method. Study result revealed that about 57.94% of the study population had adequate knowledge; 83.88% had a positive attitude and only 14.02% had good practice about thalassemia. The significant contributing factors of thalassemia knowledge and attitude were age (middle age), gender (male), residence (urban), marital status (married), an education level (bachelor degree), occupation (students and service holders), and per capita monthly income (high SE scale). The research concluded that the general public doesn’t have much knowledge; their attitude was good but the practice was very poor; and they need a high level of information.[4]

The delivery of thalassemic child places considerable strain not only on affected child and family but on society at large. Therefore there is an emphasis on shift from treatment to prevention of birth of such children in the future. This can be achieved by population education, mass screening of high-risk communities and prenatal diagnosis.

Prevention and counseling screening for thalassemia carrier is possible using NESTROF (naked eye single tube red cell osmotic fragility) test or various red cell indices (MCV, RBC count, Mentzer index, RDW, etc). Confirmation of carrier status comes from the demonstration of elevated HBA2 on electrophoresis. There are 25% chances of the disease in the offsprings if both parents are carriers. Antenatal diagnosis of thalassemia through analysis of fetal blood is now possible by fetoscopy at, amniocentesis or chorionic villous sampling during the first trimester.[5]

Objectives

The objectives of the current study were; to assess knowledge of caregivers regarding home-based management of children with thalassemia before administration of information booklet, to assess the effectiveness of an information booklet regarding home-based management on knowledge of caregivers of children with thalassemia and to find out the association between the post-test knowledge score of caregivers regarding home-based management of children with thalassemia with their socio-demographic variables.

METHODS

Study design

Presented study is a quasi experimental study (one group pretest posttest design) which was conducted at the King George’s medical university, college of nursing, Lucknow, Uttar Pradesh during the period, November 2019 to January 2020.

Study population

Caregivers (mother or father or grandparents or uncle or aunts or elder brother or elder sister) of children with thalassemia between age group 1-15 years who was available during the study in thalassemia day care, department of paediatric KGMU Lucknow.

Study settings

The setting of the study was thalassemia day care department of paediatrics KGMU Lucknow, the hospital is a well-reputed medical college of India.

Sample size

A total of 46 care givers of children with thalassemia was included in this study as a sample. Sample size was calculated using below mentioned formula which is for one group pre and post test;

$$n = \frac{z\alpha \times 2pq}{d2}$$

Where; Zα=95% confidence interval, p=expected %, q=(100-p), d=minimum difference in p. With 95% confidence interval level and 90% power, the minimum sample size was found to be n=46.

Sampling technique

46 samples were selected by using convenient sampling technique.

Inclusion criteria

Inclusion criteria for current study were; care givers of 1-15 years children, care givers who are available at the time of data collection and care givers who are able to read and write.

Exclusion criteria

Exclusion criteria for current study were; care givers who were not willing to participate in the study, care givers who was having a physical or mental disability and care givers who had attended a similar Programme within 3 months.

Development of tools

The following steps were adopted to develop the information booklet; development of the blueprint, preparation of information booklet, preparation of the content validity of information booklet, translation of information booklet in English to the Hindi languages.

Description of the tools used in the study

A structured questionnaire was used as the research tool. After an extensive review of literature, discussion with the experts and based on personal experience a structured questionnaire was developed to elicit responses from the subjects. It consisted of 2 parts i.e. part A and part B; part A had 15 socio-demographic questions and part B had 24 well Structured knowledge questionnaire.

Table 1: Scoring criteria.

Score	Score (%)	Level of knowledge
1-8	4.1-33.33	Poor knowledge
9-16	37.5-66.66	Average knowledge
17-24	70.83-100	Good knowledge

*Each right answer and wrong answer carries 1 and 0 marks respectively.

Reliability

The reliability of the test was calculated using split half method. Correlation of the split-half test was found by using Karl Pearson correlation coefficient formula and the reliability co-efficient of the whole test was established by Spearman's prophecy formula i.e. r=2r/1+r. The calculated r value was 0.78 and the tool was found to be reliable.[6,7]

Data collection process

The study was conducted after obtaining permission from the head of department of paediatric. On day 1, 46 samples were selected by convenient sampling technique. The self-introduction and purpose of the study was explained to the caregivers after obtaining written consent. The pre-test was conducted to assess the knowledge of caregivers regarding home based management of children with thalassemia.

The information booklet was explained for 15 minutes and it will be given on the same day after pre-test. On day fifteenth, the post test was conducted to assess the effect of the information booklet by using same tool. After that the collected raw data entered into the master sheet for analysis.

Analysis

The data was entered in the MS excel and analysed using frequency, percentage, and Chi-square with the help of descriptive and inferential statistics.

RESULTS

A total of forty six care givers of children with thalassemia were studied. The following observations were made.

Section I

Baseline characteristics; in considering the age of the caregivers 3 (6.5%) belong to 18-23 years of age, 14 (30.4%) belong to 24-29 years of age, 11 (23.9%) belong to 30-35 years of age, 11 (23.9%) belongs to 36-41 years of age and 7 (15.2%) belongs to 41 and above of age. With respect to gender 30 (65.2%) were male, 16 (34.8%) were female and 0 (0%) were transgender. Concerning care giver relationship with children 22 (44%) were father, 18 (36%) were mother 5 (10%), 0% was grandmother and grandfather, 5 (10%) were elder brother/elder sister. Concerning educational status 5 (10.9%) were having profession or honor, 15 (32.6%) were graduate, 8 (17.4%) were having intermediate or diploma, 10 (21.7%) were having high school education, 2 (4.3%) were having middle-class education, 6 (13%) belonged to primary level education and 0 (0%) were illiterate. For religion**,** 31 (67.4%) were Hindu, 15 (32.6%) were Muslim and 0% were Christian and others. Considering family type 19 (41.3%) were from the nuclear family, 27 (58.7%) were from a joint family.

Table 2: Distribution of pre-test knowledge score of caregivers regarding homebased management of children with thalassemia.

Level of knowledge	N	(%)
Poor knowledge	16	34.8
Average knowledge	30	65.2
Good knowledge	0	0

Table 3: Mean and SD of the pre-test knowledge score of caregivers regarding home based management of children with thalassemia.

Level of knowledge (n=46)	Mean	SD
Pre-test	9.50	2.873

Based on occupation 9 (18%) were government employees, 8 (16%) were private employees, 16 (32%) were housewives, 0% were retired, 3 (6%) were unemployed and 14 (28%) were self-employed. Considering the marital status of caregivers 13 (26%) were single 36 (72%) were married 1 (2%) were widow/widower, 0% were divorced. Based on the residence of caregivers 15 (30%) were lived in urban places and 35 (70%) were lived in rural places. Considering the socioeconomic status of caregivers 16 (32%) belonged to the low class, 29 (58%) were middle class, and 5 (10%) were high class.

Table 4: Description of frequency and percentage distribution of socio-demographic variables of care givers of thalassemic children.

Socio demographic variables	N	%	Socio demographic variables	N	%
Age of care givers (years)			**Occupation**		
18-23	3	6.5	Government employee	9	19.6
24-29	14	30.4	Private employee	8	17.4
30-35	11	23.9	Housewife	12	26.1
36-41	11	23.9	Unemployed	3	6.5
41 and above	7	15.2	Self employed	14	30.4
Gender			**Marital status**		
Male	30	65.2	Single	4	8.7
Female	16	38.8	Married	41	89.1
Relationship			Widow/Widower	1	2.2
Father	21	45.7	**Residence**		
Mother	19	41.3	Urban	15	32.6
Uncle/aunt	3	6.5	Rural	31	67.4
Elder brother/sister	3	6.5	**Socio economic status**		
Education			Low	16	34.8
Profession /honour	5	10.9	Middle	27	58.7
Graduate	15	32.6	High	3	6.5
Intermediate/diploma	8	17.4	**Number of thalassemic child**		
High school	10	21.7	1	16	34.8
Middle school	2	4.3	2	27	58.7
Primary school	6	13.0	3	3	6.5
Religion			**Attend social gatherings**		
Hindu	31	67.4	Not at all	21	45.7
Muslim	15	32.6	Sometime	15	32.6
Family type			**Blood transfusion**		
Nuclear	19	41.3	Within a week	2	4.3
Joint	27	58.7	Within 15 days	30	65.2
Awareness about thalassemia			Within 1 month	5	10.9
Yes	16	34.8	Within 3 month	9	19.6
No	30	65.2			
Genetic counselling					
Yes	18	39.1			
No	28	60.9			

Considering the number of thalassemic children 46 (92%) having 1 thalassemic child, 3 (6%) having 2 thalassemic children, 1 (2%) having 3 thalassemic children and 0% have more than 4 thalassemic children. For the criteria, unable to attend social gathering 21(42%) were unable to attend a social gathering, 15 (30%) were sometimes able to attend a social gathering, 10 (20%) were often attend the social gathering and 4 (8%) were able to attend social gathering every time. Based on the frequency of blood transfusion 2 (4%) children need BT within a week, 30 (60%) children need BT within 15 days, 7 (14%) needs BT within 1 month, 10 (20%) needs blood transfusion within 3 months and 1 (2%) needs BT more than 3 months. Based on awareness about thalassemia 16 (32%) having awareness about thalassemia and 34 (68%) having no awareness about thalassemia. For genetic counselling done prior 19 (38%) were having genetic counselling done prior and 31 (62%) have no genetic counselling done prior.

Section II

Pre-test and post-test knowledge score; out of 46 sample in pre-test 16 (34.8%) of the respondents have poor knowledge, 30 (65.2%) have average knowledge, whereas no one has good knowledge regarding home-based management of children with thalassemia. Indeed there was a need for awareness regarding home-based management of children with thalassemia.

Out of 46 sample in post-test 11 (23.9%) of the respondents have good knowledge, 32 (69.6%) have average knowledge, and only 3 (6.5%) have poor knowledge regarding home-based management of children with thalassemia. The mean and SD of the post-test knowledge score was 14.1739, the SD was 3.03 respectively.

Table 5: Distribution of post-test knowledge score of caregivers regarding home based management of children with thalassemia.

Level of knowledge (n=46)	N	(%)
Poor	3	6.5
Average	32	69.6
Good	11	23.9

Findings related to knowledge

In pre-test 16 (34.8%) of the respondents have poor knowledge, 30 (65.2%) have average knowledge, and no one was having good knowledge regarding home-based management of children with thalassemia. Indeed there was a need for awareness about thalassemia. The mean score of the caregivers in the pre-test is 9.50 and 14.17 in the post-test. The SD was 2.87 in the pre-test and 3.03 in the post-test.

Table 6: Mean and SD of the post-test knowledge score of care givers regarding home based management of children with thalassemia.

Level of knowledge (n=46)	Mean	SD
Post-test	14.1739	3.03

Section III

Comparison of pre and post-test knowledge score; out of 46 samples in pre-test 16 (34.8%) of the respondents have poor knowledge, 30 (65.2%) have average knowledge whereas no one having good knowledge. But after administration to information booklet the values changed significantly, as 11(23.9%) have a good level of knowledge, whereas in pre-test it was zero, 32 (69.6%) have average, and only 3 (6.5%) have poor knowledge. The mean and SD in pre test score were 9.50and 2.87. The same in post-test knowledge score were 14.1739 and 3.03 respectively.

Table 7: Comparison of pre and post-test knowledge scores of caregivers to assess the effectiveness of the information booklet.

Level of knowledge (n=46)	Pre-test (%)	Post-test (%)
Poor	34.8	6.5
Average	65.2	69.6
Good	0	23.9

Table 8: Comparison of Mean and SD of the pre and post-test knowledge score.

Level of knowledge (n=46)	Pre-test		Post-test	
	Mean	**SD**	**Mean**	**SD**
Overall	9.50	2.87	14.1739	3.03

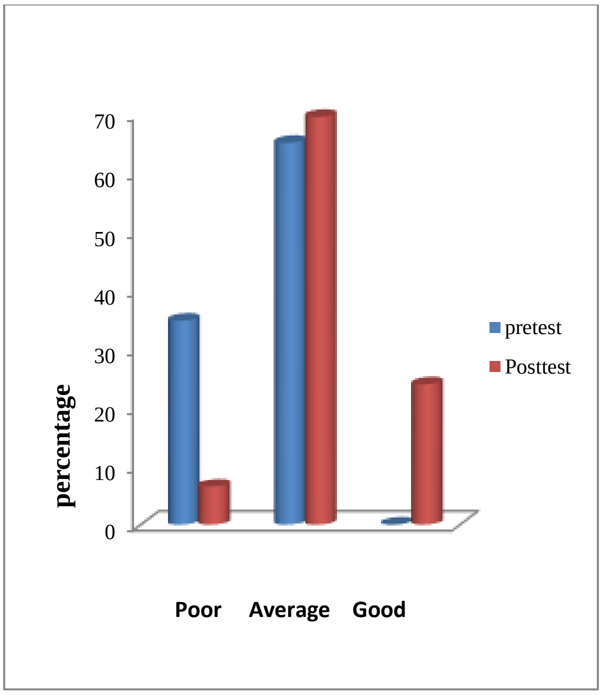

Figure 1: Comparison of pre and post-test knowledge.

Findings related to the effectiveness of information booklet

It is evident from that the calculated t values are greater than table value (t=2.011 at p<0.05) showing that there was significant difference pre-test and post test knowledge of caregivers of children with thalassemia.

Table 9: Mean difference and t value of the pre-test and post-test knowledge of care givers regarding home-based management of children with thalassemia.

	Mean	(f)	"t" value	df
Pre-test	9.50	46		45
Post-test	14.17	46	-9.808	

Findings related to the association between post-test knowledge score of caregivers with their socio-demographic variables

The result showed that there was a significant association between post-test knowledge score with socio-demographic variables such as education (X2=0.21) religion (X2=0.27), relationship (X2=0.000), marital status of caregivers (X2=0.000), the residence of caregiver (X2=0.27), socioeconomic status (X2=0.000), number of thalassemic children (X2=0.000), unable to attend social gatherings (X2=.001) frequency of blood transfusion (X2=0.000), relationship (X2=0.000) and, evidence that there was statistically association at p<0.05 level. Hence the research hypothesis (H2) is accepted.

Table 10: Chi-square test showing an association between post-test levels of knowledge with their socio-demographic variables.

Demographic variables	Level of knowledge			Chi square	df	Inference
	Good	Average	Poor			
Age of care givers (years)						
18-23	0	3	0	0.95	4	NS*
24-29	4	9	1			
30-35	0	10	1			
36-41	5	6	0			
41 and above	2	4	1			
Gender						
Male	7	24	2	0.055	1	NS*
Female	3	9	1			
Transgender	0	0	0			
Relationship						
Father	4	14	3	0.000	3	S*
Mother	6	13	0			
Uncle/aunt	0	3	0			
Grand father and mother	0	0	0			
Elder brother and sister	2	1	0			
Education status						
Professional	0	5	0	0.021	5	S*
Graduate	1	12	2			
Intermediate or diploma	1	7	0			
High school	4	4	2			
Middle	1	1	0			
Primary	4	2	0			
Illiterate	0	0	0			
Religion						
Hindu	6	24	2	0.027	2	S*
Muslim	5	8	1			
Christian	0	0	0			
Other	0	0	0			
Family type						
Nuclear	4	15	0	0.302	1	NS*
Joint	7	20	0			
Occupation						
Government employee	0	7	0	0.103	4	NS*
Private employee	3	5	0			
Housewife	3	6	3			
Retired	0	0	0			
Unemployed	2	1	0			
Self employed	1	13	0			
Marital status of care givers						
Single	0	4	0	0.000	2	S*
Married	11	27	3			
Widow/widower	0	1	0			
Divorced	0	0	0			
Residence of care giver						
Urban	1	12	2	0.027	2	S*
Rural	10	20	1			
Socioeconomic status						
Low	3	11	2	0.000	2	S*
Middle	9	17	0			
High	0	3	0			

Continued.

Demographic variables	Level of knowledge			Chi square	df	Inference
	Good	**Average**	**Poor**			
Number of thalassemic children						
1	10	29	3	0.000	2	S*
2	1	2	0			
3	0	1	0			
More than 4	0	1	0			
Unable to attend social gatherings						
Not at all	2	18	2	0.001	3	S*
Sometime	4	9	1			
Often	2	5	0			
Every time	3	0	0			
Frequency of blood transfusion						
Within a week	0	2	0	0.000	3	S*
Within 15 days	4	23	3			
Within 1 month	3	2	0			
Within 3 month	4	5	0			
More than 3 month	0	0	0			
Awareness about thalassemia						
Yes	1	14	1	0.055	1	NS*
No	10	18	2			
Genetic counselling done prior						
Yes	3	14	1	0.185	4	NS*
No	8	18	2			

*NS=not significant, S=significant

DISCUSSION

Current study was conducted to assess the knowledge of caregivers regarding home-based management of children with thalassemia.

A similar type of descriptive study was conducted in paediatric ward of a tertiary care hospital in Navi Mumbai in which parents of 40 beta thalassemia major children were enrolled. Parents were interviewed to assess their knowledge, awareness, the practices. The results revealed that 47.5% of parents were aware of thalassemia as genetic disorder. 62.5% were aware of regular blood transfusion. 23 parents were aware of the regular medications taken by their children. 90% parents followed a good practice of getting their child for regular blood transfusion. 65% of parents lacked in giving optional vaccines to the child. While only 45% knew about the antenatal detection. The study concluded that majority of parents followed good practice, though the knowledge and awareness about the disease was inadequate, and also in our study mean of pre test was very less as compared to post test so there also there was the need for providing awareness.[8]

A previous study was conducted in which 50 caregivers of chronically transfused thalassemic children were interviewed regarding their knowledge, attitude and practice towards this disease, using a self-made questionnaire. Study results revealed that despite adequate knowledge regarding every aspect of this disease, there is a lack of attitude of practice towards prevention. The study concluded that there was a need to promote an attitude of practice in prevention of the birth of thalassemic children as mere knowledge regarding the disease was not enough.[9]

A similar study was conducted to assess knowledge, attitude, and practices among 260 parents of β thalassemia children regarding thalassemia, after taking consent, a pre designed structured questionnaire was provided. Results revealed 48.4% were aware that thalassemia is a genetic disorder, 66. 1% had awareness about need of blood transfusions. 74.6% were worried about children’s education and also they are getting emotional distress about child future. 94.2% were taking their child to hospitals for regular blood transfusion, 90.3% were taking regular medications. The study concluded that age, education, socioeconomic status were significant predictors in relation to practices of caregivers and in our study also there was significant association with education of caregivers.[10]

Limitations

Limitations of the current study were; the study was limited to caregivers of 1-15 years of children having thalassemia and the data collection period was limited to 3 months.

CONCLUSION

From the findings of the study, it has been observed that the level of knowledge regarding home-based management of children with thalassemia in the post-test score was higher than the pre-test score. Thus the study finding proved that an Information booklet was effective to increase the knowledge of caregivers regarding home-based management of children with thalassemia. But mean of pre-test was very less as compared to post-test, So there is a need of providing proper information. The health care provider should provide education to improve the knowledge regarding thalassemia.

Recommendations

Similar studies can be replicated on larger samples for wider generalization mainly in the community. Similar studies can be conducted as a comparative study in rural and urban settings.

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