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Knowledge, burden and coping strategies among caregivers of thalassemic children attending thalassemia day care centre of selected hospital, Jodhpur

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ABSTRACT

Background: Thalassemia is a blood disorder characterized by the reduction or absence in the synthesis of the globin chains of hemoglobin. Nearly 10% of children suffering from Thalassemia are being registered as new cases every year in Rajasthan. The aim of the study was to assess knowledge, burden and coping strategies among caregivers of thalassemic children.

Methods: Data were collected from 150 caregivers of thalassemic children selected by purposive sampling technique at Umaid hospital, Jodhpur, Rajasthan. Data collection tool included self-structured knowledge questionnaire, Burden scale and Structured Brief COPE scale.

Results: Equal numbers 36% and 35.33% of caregivers were having poor and good level of knowledge respectively, knowledge levels of the subjects were found to have significant association with monthly family income (p value=0.000), education (p value=0.007) and place of living (p value=0.000). 74.3% of caregivers reported moderate level of burden. Burden levels of the subjects were found to have significant association with Monthly family income (p value=0.000), and place of living (p value=0.000). Adaptive coping strategies were more evident as compare to maladaptive strategies.

Conclusions: Knowledge was significantly lacking regarding diet management, benefits of exercise, role of iron chelation therapy etc. Continuous care of children put caregivers under moderate level of burden. There is great need to plan, implement health awareness programme for these caregivers.

Keywords: Burden, Caregivers, Coping strategies, Knowledge, Thalassemia

INTRODUCTION

Thalassemia is a blood disorder characterized by the reduction or absence in the synthesis of the globin chains of hemoglobin.¹ The common signs and symptoms of thalassemia include pale skin, retarded growth and puberty, anemia, enlarged spleen, and increased susceptibility to infections.²

Approximately, 240 million people are estimated carriers for beta thalassemia throughout the world i.e. 1.5% of world population.³

The rate for β-thalassemia carrier varies from 1-17% in India with an average of 3.2%. This means that on an average 1 in every 25 Indians is a carrier of thalassemia.³

Nearly 10% of children suffering from thalassemia are being registered as new cases of the disease every year in the Rajasthan. The numbers of children with Thalassemia are constantly increasing each passing year. There are 2,000 children suffering from Thalassemia in the state.⁴

Parents suffer from physical, emotional, psychological burden because of expenses, stress and fear of death. It is possible that uneducated, poor and socially maladjusted

parents are more affected in comparison to those who are educated, economically sound, and socially well adjusted. The psychological burden can affect the quality of life of families.⁵ Burden can be of any type like physical, psychosocial, emotional, financial burden, etc. Parents of thalassemic children usually suffer from financial burden because treatment of thalassemia cost a heavy amount. Burden on caregivers can lead to social isolation, disappointment, depression, aggression etc.⁶

Children with thalassemia require lifelong blood transfusion and iron chelation therapy to reduce iron overload. It may cause social and financial burden to the caregivers. Recognition of nature of parent's burden is curtailed because it enables nurses to intervene effectively and reduce parental burden.⁷

Caregivers of thalassemic children face multiple and extreme challenges to provide high quality care to their children.⁸ Incidence of thalassemia in a family member may cause a psychological crisis in family and it requires coping strategies. Caregivers use different coping strategies to overcome their problems and caregivers difference in using coping strategies show their difference in adjustment to burden.⁹

A caregiver who has good knowledge about thalassemia and management of thalassemia can not only provide a better quality of care to his/her child but also may act as educator or informer about thalassemia to the society in which he/she lives.

Thus, it helps immensely in raising community awareness related to the Thalassemia disorder.¹⁰

In Rajasthan nearly 10% of children suffering from thalassemia are registered as new cases every year. There are only limited thalassemia day care centre in western zone of Rajasthan.⁴ In Jodhpur district there is only one thalassemia day care centre which provide blood transfusion and medications to thalassemic children.

There is no available information on coping strategies and burden among caregivers of thalassemic children and the care of thalassemic children at home in western area of Rajasthan. The aim of present study is to examine caregiver's knowledge, burden and coping strategies of thalassemic children in western area of Rajasthan.¹¹

METHODS

Study settings

This descriptive study was conducted among caregivers of thalassemic children. The study was conducted at Thalassemia day care centre of Umaid Hospital, Jodhpur. Data were collected in the month of October 2018 to December 2018.

Sample size

Sample size calculated with the help of following formula:¹²

$$m = \frac{4PQ}{L^2}$$

P= prevalence (in Rajasthan prevalence of thalassemia is 10%)⁸

Q= 1-P

L= allowance error (5%)

So,

$$\frac{4 * \left(\frac{10}{100}\right)^* \left(\frac{1-10}{100}\right)}{(0.05)^2} = 144 \text{ samples}$$

By taking 5% non-response rate the sample size estimated to be 150.

Inclusion criteria

Caregivers who were present at the time of study and willing to participate in the study. Caregivers who experienced at least 1 year of caregiving their child.

Data collection tools

Data was collected through face to face interview method. The tools for data collection were self-structured and were developed by reviewing literatures, journals, opinion of experts and consulting with guide and co-guide. It consisted of following sections.

Section A

Personal variables data sheet (age, gender, occupation, family monthly income, educational status of caregiver, relation with child, duration of illness of child, duration of treatment, place of living of family etc.).

Section B

Self-structured knowledge questionnaire to assess knowledge of caregivers regarding thalassemia consisted of total 20 MCQ related to transmission of disease, prevention, treatment and home management of thalassemia. One mark was given to right answer and zero mark was given to wrong answer. There was no negative marking.

Section C

Self- structured burden assessment scale to assess burden of caregivers of thalassemic children contained 24 items on five-point Likert's scale (strongly agree, agree, uncertain,

disagree and strongly disagree). It contained the mixture of positive and negative declarative statements regarding measuring attributes. It contained domains like physical burden, psychological burden, social burden and financial burden.

Section D

Brief COPE scale developed by Carver was used to assess coping strategies of caregivers of thalassemic children. It is 28 item Likert scale containing wide range of thoughts and acts that caregivers use to deal with the demands of stressful conditions. It permits unrestricted use, distribution, and reproduction in any medium. It contained total 14 subscales and each subscale had 2 items. Scoring was done as score 1 was for "I haven't been doing this at all", score 2 was "for I've been doing this a little bit", score 3 was for "I've been doing this a medium amount" and score 4 was given for "I've been doing this a lot".

Reliability

Self-structured knowledge questionnaire tool's internal consistency was determined by Kuder Richardson formula 20 (reliability 0.88). Which means tool was reliable as reliability range from 0.70 to 1. Reliability of the self-structured Likert's scale was determined by Cronbach's alpha (reliability 0.87) to assess internal consistency of the items. Reliability of the brief COPE scale's domains ranges from 0.53 to 0.97 for subscales as calculated in various national and international studies.¹³

Data analysis

SPSS 16 version was used for the descriptive and inferential statistical analysis. Data were represented using percentages, mean, and standard deviation and chi-square correlation was used to find the associations.

RESULTS

Table 1 Depicts that the half of caregivers (50%) were within age group of 30-40 years. 72% of children were from age group of >5 years. 83% of caregivers were the females. Most (88%) of the caregivers were Hindu by religion. Education wise nearly 33% were illiterate, 28% had studied up to primary. As per family monthly income is concerned, nearly 41.33% of caregivers had monthly income between Rs. 10,001-20,000, 32.67% of caregivers had monthly income ≤ Rs. 10,000. More than half of the caregivers (68.67%) were from rural area and (31.33%) were from urban area. 10.67% of caregivers were having the history of consanguineous marriage. 51.33% of children were diagnosed with thalassemia at the age of less than 6 months.

Figure 1 represents the family history of thalassemia among caregivers. Nearly 75% of the caregivers were not having the family history of thalassemia. As per chelation

therapy is concerned 86% of the children were on iron chelation therapy (Figure 2).

Figure 3 depicts the levels of knowledge regarding thalassemia among caregivers. Almost equal numbers 36% and 35.33% of caregivers were having poor and good level of knowledge respectively and 28.67% caregivers reported excellent level of knowledge regarding thalassemia. Mean knowledge score among caregivers was 11.83 ± 4.84 which means that average number of caregivers had good level of knowledge regarding thalassemia.

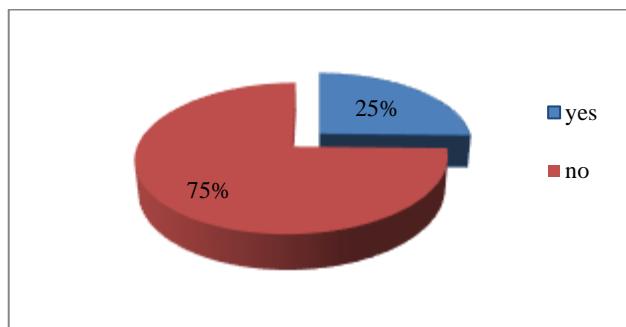


Figure 1: Family history of thalassemia (n=150).

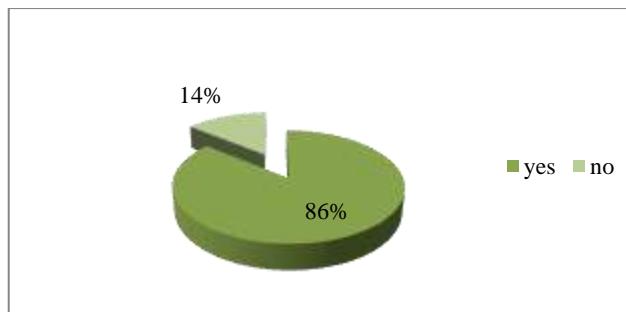


Figure 2: Children with iron chelation therapy (n=150).



Figure 3: Levels of knowledge among caregivers of thalassemic children (N=150).

As per burden levels are concerned Figure 3 shows that nearly 80% of caregivers were having moderate level of

burden, followed by 20% of caregivers with severe level of burden and only 1.33% caregivers reported mild level of burden. Mean burden score among caregivers was

82.67 ± 9.89 which infers that average no. of caregivers had moderator level of burden.

Table 1: Frequency and percentage distribution of personal variables data (n=150).

Variables	f (%)
Age of caregiver (in years)	
<30	45 (30.00)
30-40	75 (50.00)
>40	30 (20.00)
Mean age \pm SD	34.51 \pm 8.29
Age of child (in years)	
≤ 5	42 (28.00)
>5	108 (72.00)
Mean age \pm SD	8.41 \pm 4.26
Relationship with the child	
Father	62 (41.33)
Mother	77 (51.34)
Grand father	02 (1.33)
Grand mother	05 (3.33)
Others	04 (2.67)
Gender	
Male	67 (44.67)
Female	83 (55.33)
Religion	
Hindu	132 (88.00)
Muslim	18 (12.00)
Occupation	
Unemployed	77 (51.33)
Agriculture	17 (11.33)
Self-employed	43 (28.67)
Service (Private)	09 (6.00)
Service (Government)	04 (2.67)
Family monthly income (Rs.)	
$\leq 10,000$	49 (32.67)
10,001-20,000	62 (41.33)
20,001-30,000	23 (15.34)
30,001-40,000	06 (4.00)
40,001-50,000	05 (3.33)
$\geq 50,000$	05 (3.33)
Education	
Illiterate	49 (32.67)
Up to primary	42 (28)
Up to 10 th	29 (19.33)
Up to 12 th	09 (6.00)
Diploma	08 (5.33)
Graduate and above	13 (8.67)
Place of living of family	
Rural	103 (68.67)
Urban	47 (31.33)
History of consanguineous marriage	
Yes	16 (10.67)
No	134 (89.33)
Age of the child at the time of diagnosis	
0-6 months	77 (51.34)
6 months-1 year	41 (27.33)
2-4 years	23 (15.33)
5-7 years	07 (4.67)
8-10 years	02 (1.33)

Continued.

Variables	f (%)
Duration of the treatment of the child (years)	
1-6	68 (45.33)
7-12	60 (40.00)
13-18	22 (14.67)
Duration of providing care to child (years)	
1-6	68 (45.33)
7-12	60 (40.00)
13-18	22 (14.67)

Table 2: Coping strategies mean score among caregivers (n=150).

Domain	Mean±SD (Score)
Venting	4.94±1.41
Religion	4.68±1.91
Planning	4.44±1.09
Acceptance	5.55±1.15
Active coping	4.45±1.02
Use of emotional support	4.56±1.02
Use of instrumental support	5.26±1.01
Positive reframing	4.09±1.19
Self-blame	3.88±1.73
Self-distraction	4.91±0.92
Denial	3.71±1.68
Behavioral disengagement	2.9±1.15
Humor	2.04±0.23
Substance use	2.23±0.76

*Score ranged from 2 (not doing this at all) to 8 (Doing this a lot) higher score indicate increased utilization of specific strategy.

Table 2 shows the various types of coping strategies used by caregivers. Use of adaptive coping strategies is more evident as compare to maladaptive strategies. Acceptance (mean score 5.55 ± 1.15) followed by Instrumental support (mean score 5.26 ± 1.01) were the most commonly reported strategies whereas humor (mean score 2.04 ± 0.23) followed by substance use (mean score 2.23 ± 0.76) were least used strategies. Table 3 depicts the association of knowledge level with selected personal variables. Knowledge levels of the subjects were found to have significant association with Monthly family income (exact value: 49.07; p value=0.000), education (exact value: 54.68; p value=0.007) and place of living (χ^2 : 35.64; p value=0.000).

Table 4 depicts the association of burden level with selected personal variables. Burden levels of the subjects were found to have significant association with monthly family income (exact value: 22.12; p value=0.000), and Place of living (exact value: 18.40; p value=0.000).

Table 3: Association of knowledge level with selected personal variables (N=150).

Variables	Knowledge level			χ^2	Df	P value
	Poor (f)	Good (f)	Excellent (f)			
Monthly family income						
≤10,000	31	16	2			
10,001-20,000	20	25	17			
20,001-30,000	2	7	14	49.070 [#]	10	0.000*
30,001-40,000	0	3	3			
40,001-50,000	0	2	3			
≥50,001	1	0	4			
Education						
Illiterate	34	13	02			
Upto primary	12	19	11	54.68 [#]	10	0.000*
Upto 10 th	06	12	11			
Upto 12 th	0	04	05			
Diploma	01	03	04			
Degree and above	01	02	10			
Place of living						
Rural	49	39	15	35.635	2	0.000*
Urban	05	14	28			

*Significance at p level<0.05; [#]Fisher exact was used

Table 4: Association of burden level with selected personal variables (N=150).

Variables	Knowledge level			χ^2	Df	P value
	Mild (f)	Moderate (f)	Severe (f)			
Monthly family income						
≤10,000	0	33	16			
10,001-20,000	0	49	13			
20,001-30,000	2	21	0	22.122 [#]	10	0.005*
30,001-40,000	0	06	0			
40,001-50,000	0	05	0			
≥50,001	0	05	0			
Place of living						
Rural	34	13	02	18.405 [#]	2	0.000*
Urban	12	19	11			

*Significance at p level <0.05; NS: not significant at p level>0.05; [#]Fisher exact test was used.

Table 5 represent the correlation between burden score and various coping strategies. Result shows that the there is a moderate positive correlation between the burden score and venting ($r=0.484$) coping strategy followed by Denial ($r=0.401$) coping strategy and moderate negative correlation between the burden score and positive reframing ($r=-0.561$) coping strategy followed by active ($r=-0.445$) coping strategy. The findings showed that the more venting coping strategy used by caregivers had high level of burden. Caregivers using high positive reframing strategies had low level of burden.

Based on the results of study findings, a self-care module in hindi on management of thalassemia was prepared by author and validated for content by nursing, public health professionals.

This module was also validated for its language in Hindi and after this selfcare module was given to thalassemia day care unit, MS of Umaid hospital, Jodhpur and also kept in community health nursing lab, College of Nursing AIIMS Jodhpur for the future help.

Table 5: Correlation between burden score and coping strategies (n=150).

Coping Strategies	Burden score (r)
Self-distraction	-0.183
Active coping	-0.445
Denial	0.401
Substance use	0.024
Use of emotional support	-0.211
Behavioral disengagement	0.299
Venting	0.484
Use of instrumental support	-0.208
Positive reframing	-0.561
Self-blame	0.259
Planning	-0.316
Humor	0.033
Acceptance	0.353
Religion	0.350

DISCUSSION

Thalassemia is a genetic disease and its result in anemia. Children with thalassemia major require regular blood transfusion. The burden of hemoglobinopathies in India is high with nearly 12,000 infants being born every year with a severe disorder.⁴

In current study, 83% of caregivers were the female. 88% of the caregivers were Hindu by religion. 25.33% of the caregivers were having the family history of thalassemia. Contrary results were shown in the study done by Ahmed et al and Goyal et al where 5% and 8.1% of patients with thalassemia were having a family history of thalassemia respectively.^{14,15}

Knowledge of the caregivers depends on their literacy, awareness, duration of providing care to their thalassemic children and availability of mass media in that particular area. Awareness regarding thalassemia is an important factor to providing effective and efficient care to thalassemic children.² In current study the mean knowledge score of the study subjects were 11.83 ± 4.84 and 36% of caregivers had poor knowledge level. Study conducted by Maheen et al had reported similar results.¹⁶ Contrary result were shown in Dehkordi, Heydarnejad study where 66.8% of parents had no knowledge of thalassemia before the first affected child.¹⁷

Continuous care of thalassemic children leads to burden among caregivers of thalassemic children. It can be physical, psychological, financial burden etc. Evidence suggests that uneducated, poor and socially maladjusted caregivers are more affected in comparison to those who are educated, economically sound and socially well adjusted.¹⁶ In the present study 79.33% had moderate level of burden whereas in a study conducted at Jiroft Thalassemic Center (JTC) in southeast of Iran 20%, 29% and 51% of mothers reported high, moderate and low level of burden, respectively.⁶ Study conducted by Shanmugam et al reported that nearly-73% of caregivers experienced moderate to low level of burden.¹⁸ Contrary result were shown in a study done by Hisam et al where 27.1% were having moderate stress/burden.¹⁹

Burden among caregivers can be reduced by using more adaptive coping strategies than maladaptive coping strategies. Caregivers use different kind of coping strategies to relieve their internal conflict of thoughts and burden felt due to continuous providing care to their thalassemic children.¹⁴ In the present study adaptive coping strategies were more evident as compare to maladaptive strategies. Acceptance followed by Instrumental support were the most commonly reported strategies whereas humor followed by substance use were least used strategies. Similar study conducted at Rawalpindi, Pakistan also showed that most frequently used coping strategies by parents were active coping (97.5%) and least used coping strategies were humor (15%) and substance abuse (7.5%).¹⁷

Lack of awareness is influenced by societal factors, literacy rate, cultural boundaries etc. Knowledge among caregivers depends on many other factors like education, duration of providing care, place of living etc.⁴ As per the association of knowledge level with personal variables is concerned, only three demographic variables i.e. monthly family income, education level and area of living had significant association with level of knowledge in this study. Similar study was conducted at IPGME&R and SSKM Hospital, Kolkata wherein significant association of knowledge level with gender (male), residence (urban), marital status (married), education level (higher secondary & above), occupation (students & service holders), and PCMI (high socio-economic scale) were found.²⁰

Level of burden among caregivers depends on many factors like awareness regarding thalassemia and its management, using of adaptive or maladaptive coping strategies, accessibility of health care system, financial condition, social support, place of living, numbers of children with thalassemia in a family, availability of Information, education and communication etc. In current study as per the association of burden level with personal variables is concerned, only two demographic variables i.e. Monthly family income and area of living had significant association with level of burden. One of the study conducted by Aziz et al showed significant association of burden level with levels of education, occupations, residential areas.¹⁹

Using of effective coping strategies or mechanism depends on burden level among caregivers. Evidences say that caregivers feel less burden if they use effective coping strategies. Moderate positive correlation was found between the burden score and venting ($r=0.484$) coping strategy followed by Denial ($r=0.401$) coping strategy and Moderate negative correlation was found between the burden score and Positive reframing ($r=-0.561$) coping strategy followed by active ($r=-0.445$) coping strategy. The findings showed that the more venting coping strategy used by caregivers showed high level of burden and caregivers with high positive reframing strategies had low level of burden. Similar study conducted by Saldanha et al

in Bangalore showed significant correlation ($r=0.41$) between the stress score and problem oriented was found.⁸

CONCLUSION

Thalassemia is a blood disorder characterized by the reduction or absence in the synthesis of the globin chains of hemoglobin. Nearly 10% of children suffering from thalassaemia are being registered as new cases every year in Rajasthan. Almost equal numbers of the caregivers of thalassemic children had poor and good level of knowledge; knowledge was significantly lacking regarding diet management, benefits of exercise, Prevention of thalassemia, role of iron chelation therapy etc. Continuous care of children put caregivers under moderate level of burden. Adaptive coping strategies were more evident as compare to maladaptive strategies. Like for other disease conditions there are many national or internal health programmes for their management so, same for thalassemia there should be health programme on prevention and management of thalassemia. There is great need to plan, implement health awareness programme for these caregivers.

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