ISSN: 0975-833X

Available online at http://www.journalcra.com

International Journal of Current Research
Vol. 10, Issue, 12, pp.76268-76272, December, 2018
DOI: https://doi.org/10.24941/ijcr.33722.12.2018

INTERNATIONAL JOURNAL
OF CURRENT RESEARCH

RESEARCH ARTICLE

PSYCHOSOCIAL AND FINANCIAL BURDEN ON PARENTS OF CHILDREN WITH THALASSEMIA

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ARTICLE INFO

Article History:
Received 26th September, 2018
Received in revised form
20th October, 2018
Accepted 29th November, 2018
Published online 31st December, 2018

Key Words:
Thalassemia,
Psychosocial problems,
Financial problems

ABSTRACT

Thalassemia are forms of inherited autosomal recessive blood disorders, characterized by abnormal production of hemoglobin and associated with low hemoglobin production and excessive destruction of red blood cells. Parents of thalassemic children have concerns regarding treatment for their children. There is a significant psychological impact on parents like emotional burden, hopelessness, and difficulty with social integration. They experience negative thoughts about their life, guilt, increased anxiety and low self-esteem. The immense medical cost makes a huge financial burden on the families of thalassemic children, which is of a major concern for the poor families. An exploratory study was conducted on 60 parents of 1-18 years old thalassemic children visiting thalassemia unit of DMC & Hospital, Ludhiana for treatment. An interview schedule was used to collect data. Results revealed that 35.0% of children were between age group 1-6 years. More than half of the children i.e. 57.7% were males, 58.34% of the parents had mild psychosocial burden, and Majority i.e., 70.00% of parents of thalassemic children feel some difficulties meeting the expenditure on their child's treatment.

***Citation: Navjot Kaur.* 2018.** "Psychosocial and financial burden on parents of children with thalassemia", *International Journal of Current Research*, 10, (12), 76268-76272.

INTRODUCTION

Thalassemia are forms of inherited autosomal recessive blood disorders that originated in the Mediterranean region. It is characterized by abnormal production of hemoglobin and associated with low hemoglobin production and excessive destruction of red blood cells. The symptoms of thalassemia most often begin within 3-6 months of birth such as anemia which may be mild, moderate or severe, jaundice , enlarged spleen, fatigue, listlessness, reduced appetite, growth problem, hormone problems, thyroid problems, heart failure and liver problems (Ghai, 2005). Studies have suggested that low income status and lack of awareness are also contributing increasing the frequency of this disease (Cohen et al., 2008). Treatment of thalassemia is transfusion of red blood cells. Regular blood transfusion can lead to buildupof iron in body. This iron overload may be treated with chelation therapy, Defeuoxamine, Deferiprone and Deferasirox are the most widely used iron chelating agents (Kashif, 2012). Parents of thalassemic children have concerns regarding the appearance of their child, bone deformities, short stature, poor self-image, frequent hospital visits for transfusion, delayed or absent sexual development and impaired fertility and other associated complications such as heart disease, bone disease, diabetes infections etc. A significant psychological impact, causing emotional burden, hopelessness, and difficulty with social integration. They experience negative thoughts about their life, guilt, increased anxiety and low self-esteem (Shazia Ali, 2012). Also parents feel so inability and weakness while watching their child's suffering from pain and body condition change. It's very hard and tensional for them to make decision about their child situation (Monireh Asadi, 2011). Prasomsuk S *et al.* (2007) did a qualitative research study was on 15 mothers of thalassemic children aged 2-14years to explore the life experiences of these families The study concluded that the mothers had lack of knowledge regarding disease, they were suffered from psychosocial and financial difficulties. They were worried for the future of their child (Prosomsuk, 2007).

Patients require lifelong blood transfusion, usually started within 6 to 12 months of birth of patient, which on other hand has its own complications. It is a chronic disease that manifests so early in life that it leads to psychological and social problems for parents (Ya-Ling Lee, 2009). S Karanjit *et al.* (2013) conducted a retrospective study on 59 regularly transfused thalassemic children to estimate the monthly expenditure and financial burden on their families .The result revealed that Medical cost makes a huge financial burden on the families of thalassemic children (Karanjit Singh, 2013). Prevalence of hepatitis B, C and HIV is very high in thalassemic patients because of repeated blood transfusions (Alan, 2008). There are specialized non-govt. organizations (NGOs) that manage these disorders specifically and, therefore, can devote more effort on the very important preventive counselling aspect of these disorders apart from therapeutic interventions (Bhaswati Bandyopadhyay, 2003).

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MATERIALS AND METHODS

It was an exploratory study, conducted on 60 parents of 1-18 years old thalassemic children visiting thalassemia unit of DMC & Hospital, Ludhiana for treatment.

An interview schedule was divided into 3 parts:

- **Part A:** A questionnaire to assess socio-demographic data of the thalassemic children and their parents.
- **Part B:** A rating scale to assess the psychosocial problems among parents of thalassemic children.
- **Part C:** A checklist to assess the financial problems among parents of thalassemic children.

Data was collected after seeking written permission for conducting the study from the Professor & Incharge, Hemato-oncology, Dept. of Paediatrics, Principal, College of Nursing. Nursing sister incharge of thalassemic unit was informed about the purpose of the study. Collected data was analyzed and some of the findings are presented here.

Table 1. Frequency and percentage distribution of parents of thalassemic children as per their psychosocial burden

N=60

SrNo.	Psychosocial Burden	n	f (%)
1.	Mild psychosocial burden	35	58.34
2.	Moderate psychosocial burden	24	40.00
3.	Severe psychosocial burden	01	01.66

Table 2. Frequency and percentage distribution of parents of thalassemic children as per their psychosocial problems

N=60

Rank order	Psychosocial problems	f (%)
1.	Not concentrated on day to day work	31 (51.66)
2.	Felt tired or had less energy	30 (50.00)
3.	Spend most of the time alone	26 (43.33)
4.	Felt lack of confidence	25 (41.66)
5.	Lost interest or pleasure in doing things	24 (40.00)
6.	Found difficulty to solve problems in daily life	24 (40.00)
7.	Felt angry, irritable or had difficulty in controlling temper	23 (38.33)
8.	Didn't attended social gatherings	22 (36.66)
9.	Experienced difficulty to recall the things in daily life.	21 (35.00)
10.	Felt that child's illness affect their eating pattern	21 (35.00)
11.	Found difficulty in initiation of household activities	19 (31.66)
12.	Not supported by their family members	19 (31.66)
13.	Experienced trouble concentrating on things like reading newspaper or watching television	19 (31.66)
14.	Felt down, depressed or hopeless	17 (28.33)
15.	Felt that child's illness affect their sleep patterns	17 (28.33)
16.	Thought that child's present problem is a punishment for them.	14 (23.33)
17.	Blamed themselves for their child's illness	13 (21.66)
18.	Taken drug or stimulant to relieve tension	10 (16.66)
19.	Had thought that they would better off dead or off hurting yourself in some way	06 (10.00)
20.	Felt they are being downgraded by their relatives	03 (05.00)

RESULTS

Frequency and percentage distribution of thalassemic children and their parents as per their socio demographic characteristics states that slightly more than one third of children i.e. 21 (35.0%) were between age group 1-6 years whereas less than one third of children i.e.18 (30.0%) were between age group of >12-18 years. Approximately, more than half of the children i.e.34 (57.7%) were males. Majority of children 47(78.3%) were living in urban area. Less than two third of children i.e. 36(60%) belongs to joint family. However more than one third i.e.25 (41.6%) of father are educated up to elementary and slightly less than one third i.e.19 (31.6%) were graduated and above. Slightly less than half of mothers i.e. 29(48.3%) were educated upto graduation & above and only 1(01.6%) of mother was illiterate. Almost i.e.59 (98.3%) of parents had non consanguineous marriage. Table 1: depicts that slightly more than half i.e. 35(58.34%) of the parents had mild psychosocial burden whereas 24(40%) had moderate psychosocial burden and only 01(1.66%) had severe psychosocial burden. Table 2: depicts that slightly more than half i.e.31(51.6%) parents were not able to concentrate on their day to day work More than one third i.e.21(35%)of parents felt that child's illness affect their eating pattern and slightly less than one third i.e.17 (28.3%) of parents felt that child illness affect their sleep patterns. Slightly less than half i.e.24 (40%) of parents lost their interest and pleasure in doing things. Slightly less than one third i.e. 17(28.3%) of parents felt down, depressed or hopeless. Less than one third i.e. 13(21.6%) of parents blamed themselves for their child's illness. Slightly more than one third i.e. 23(38.3%) of parents felt angry, irritable or had difficulty in controlling temper and 24(40%) found difficulty to solve problems in daily life. The figure shows that majority i.e. 42 (70.00%) of parents of thalassemic children feel some difficulties meeting the expenditure on their child's treatment.

Slightly more than two third i.e. 41 (68.33%) feel they were able to meet finance themselves. One third of parents i.e. 20(33.30%) got financial support from any extended family member and slightly less than one third of parents 19 (31.67%) got financial support from non-government agency and 06(10.00%) got financial support from government agency. Only 09(15.00%) of parents have sold their valuable items and property for their child's treatment. Only 04(6.70%) have insurance which is helping in meeting this expenditureand only 01(01.66%) have taken loan for the treatment for their child. Table 3: depicts the association of psychosocial problems among parents of thalassemic children with selected socio-demographic characteristics.

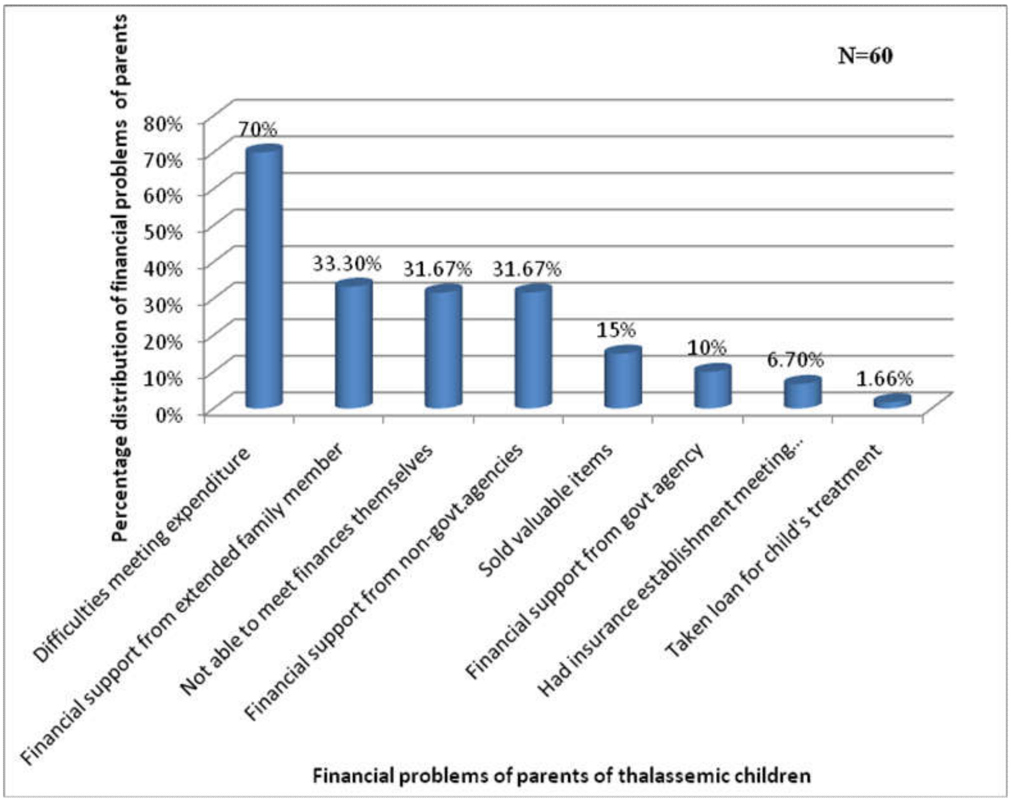

Fig. 1. Percentage distribution of financial problems of parents of thalassemic children

Table 3. Association of psychosocial problems of parents ofthalassemic children with their socio demographic characteristics N=60

Variables	n	Psychosocial problems Mean ± SD	f/t	p
Age of child (in years)				
01-06	21	23.81± 9.98	0.93	0.39^{NS}
06-12	21	27.35±10.95		
13-18	18	27.94±10.07		
Occupation of father				
Business	25	23.16±10.50	1.36	0.26^{NS}
Shopkeeper	21	27.38±12.21		
Job	13	29.69±05.29		
Farmer	01	22.00±0		
Occupation of mother				
Business	01	29.00±0	0.72	0.54^{NS}
Shopkeeper	06	29.50±15.51		
Job	05	20.40±11.86		
Housewife	48	26.12±09.67		
Number of thalassemic children				
1	57	26.11±10.51	0.23	0.88^{NS}
2	03	24.67±10.26		
Receiving thalassemic treatment since (in years)				
<2	09	29.56±11.20		
2-5	12	25.83±07.54	0.61	0.54^{NS}
>5	39	25.28±11.04		
Thalassemia was detected (in months)				
<2	03	45.33±13.01		
3-5	17	26.06±09.92	6.59	0.003^{**}
>5	40	24.58±09.17		
Socio economic status				
Upper class	05	25.20±10.15	1.35	0.26^{NS}
Upper middle class	25	24.40±09.46		
Lower middle class	24	27.67±11.80		
Upper lower class	05	23.20±03.89		
Lower class	01	46.00±0		

Although the mean of psychosocial problems is higher in parents of children between the age group of 13-18 years followed by 6-12years, but this association was found to be statistically non-significant.

The mean of psychosocial problems is more in fathers who are doing job, mothers who are shopkeeper, parents having one children affected with thalassemia, but this association was found to be statistically non-significant. A statistically non-significant association was found between the psychosocial problems of parents of thalassemic children and number of years of treatment of child. The psychosocial burden was highest in the parents whose children were detected with thalassemia since less than two months, which was found to be statistically non-significant. A statistically non-significant association was found between psychosocial problems and the socio–economic status of the parents.

DISCUSSION

The study shows that slightly more than one third of children (35.0%) were between age group 1-6 years whereas less than one third of children (30.0%) were between age group of 13-18 years. Whereas slightly more than half (53.4%) of father were in age group 31-40 years and slightly more than one third (35.0%) in >40 years whereas more than half (58.3%) of mothers were in age group 31-40 years. Approximately half of the children (57.7%) were males. Less than two third of children (60%) belongs to joint family and more than one third of children (40.0%) belong to nuclear family. Ain Q U et al. (2012)a cross sectional study was carried out at hospitals of faisabad the Result demonstrated that males were significantly ($p<0.01$) more affected than female. The highest beta thalassemic patients (34.33%) were observed between 3-5 years of age groups (Ain, 2001). Almost (98.3%) of parents had non consanguineous marriage. Majority of mothers (88.33%) don't know their thalassemia status & 7 i.e. (11.67%) of mothers know their thalassemia status. Similar is for fathers. The present study revealed that out of 60 parents of thalassemic children more than half (58.34) had mild psychosocial burden, whereas (40%) had moderate and (1.66%) had severe psychosocial burden. A similar study done by Naiemeh S et al (2002) revealed that 58% of subjects experienced that psychosocial problems at moderate level and 74% of subjects were using coping strategies (Naiemeh, 2002). Another study conducted by YazdiKh, et al in 2007 at clinics of Gorgan's universityrevealed that 81.8% of parents were seen in stress, 33.8% of parents had social problems and 63.8% of parents were seen in financial problems (Yazdikh, 2007). In present study, slightly more than half (51.6%) parents were not able to concentrate on their day to day work slightly more than one third (43.3%) spend most of time alone.

More than one third (41.6%) of parents felt lack of confidence. Slightly less than half (40%)of parents lost their interest and pleasure in doing things and Slightly more than one third (38.3%) of parents felt angry, irritable or had difficulty in controlling temper and (36.6%) of parents didn't attended social gathering. More than one third (35%) of parents felt that child's illness affect their eating pattern and (35%) experienced difficulty to recall the things in daily life. Slightly less than one third (28.3%) of parents felt that child illness affect their sleeppatterns and (28.3%) of parents felt down, depressed or hopeless. Less than one third (23.3%) of parents thought the child's present problem is punishment for them. Less than one third (21.6%) of parents blamed themselves for their child's illness. A similar study done by KashifA et al (2011) on Pakistani parents revealed that 29% of parents had severe depression, 16% had sleep disturbances and56% were downgraded by relatives (Kashi, 2012). The present study, Majority (70.00%) of parents of thalassemic children feels some difficulties meeting the expenditure on their child's treatment. One third of parents (33.30%) got financial support from any extended family member and slightly less than one third of parents (31.67%) got financial support from non-government agency. Also, slightly less than one third (31.67%) were not able to meet finances themselves. Only (15.00%) of parents have sold their valuable items and property for their child's treatment and (10.00%) got financial support from government agency. Only (6.70%) have insurance which is helping in meeting this expenditure and only (01.66%) have taken loan for the treatment of their child. Pruthi et al (2009) did a comparative study on psychological burden and quality of life in parents of children with thalassemia and cerebral palsy. Results indicated that psychosocial burden was greater in Thalassemic group participants, followed by Cerebral Palsy group, as compared to the control group (Pruthi, Kaur, 2010). A statistically non-significant association was found between various socio-demographic variables and psychosocial problems among parents of thalassemic children.

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