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Burden of Caregivers Care for Children with Thalassemia at Babylon Child and Maternity Teaching Hospital / Babylon Governorate / Iraq

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Abstract : Objectives : *to assess the psychological burden of caregivers of thalassemia children, the social burden of caregivers of thalassemia children, and to find out the association between psychological and social variables with the demographic characters of caregivers like age , level of education, occupation , and residential area.*

Methodology : *Descriptive design study ,purposive sample of (100) caregivers who attending the Babylon Pediatric and Maternity Teaching Hospital . Questionnaire was used to collect the data for the period from 26th march to 27th may 2013, data were analyzed by using descriptive statistical (percentage , frequency and mean score) and inferential (chi-square).*

Result: *the study presents that(55%) of caregivers are mothers and (34%) are relatives, (82%) of caregivers are feeling fear of future ,while (66%) of them have no pleasure in life, Also the results show that (82%) are hoping to treat their children in private hospital .*

Conclusion :The majority of caregivers are hoping to treat their children in private hospitals and this makes them feel guilty toward their children .

Recommendation : Further studies with larger sample size or multicentre studies with longer period of follow up.

Keywords: *Burdens, caregivers, children with thalassemia*

I. Introduction

Thalassemia at present is considered as one of the most challenging hematological disorder with no permanent cure (1). It refers to a group of genetic disorders, characterized by insufficient production of hemoglobin (2). Thalassemia is a disorder characterized by defective production of hemoglobin and excessive destruction of red blood cells. This defect causes an abnormal development of red blood cells and ultimately anemia, which is the main characteristic symptom of the thalassemia (3).

Children with thalassemia need regular blood transfusions in order to live. The usual treatment consists of periodic blood transfusions that can cause iron overload within tissues; the resulting iron overload also requires chelating therapy (2).

Although optimal medical managements have reduced the difficulties faced by thalassemia, the psychosocial problems faced by the family are now of primary importance. The clinical burden caused by thalassemia is overwhelming to whole family and this may include psychological as well as social burden (4). They have to cope up with the psychosocial aspects along with their regular visits to the thalassemia centers for blood tests and blood transfusion with iron chelation therapy and their determination to fulfill the treatment steps. This creates a lot of burden on the families due to many causes like being chronic, treatment modalities, morbidities and the expectation of early death adding to complications which may result. All the later, may lead and arouse the psychosocial burden upon parents due to their inability to cope with painful situation and leads to worsen the relationship among family members (3) .Present study was designed to study the psychosocial and social burdens among parents having children with Thalassemia.

II. Objectives of the study

1. To assess the psychological burden of caregivers of thalassemia children
2. To assess the social burden of caregivers of thalassemia children
3. To find out association between psychological and social burdens with the demographic characteristics of caregivers like age , level of education, occupation , residential area and

III. Methodology:

1. Design of the study: descriptive study.
2. Setting of the study: The study was carried out at Pediatric and Maternity Teaching Babylon Hospital, Thalassemia Center for the period from 26th march to 27th may 2013.
3. The sample of study: The purposive non-probability sample selected from Thalassemia Centre at Pediatric and Maternity Babylon Hospital. The sample consisted of (100) caregivers having children with thalassemia. The criteria of the sample selection: caregivers who have children whom diagnosed with thalassemia major.

The questionnaire was used as a mean of data collection. The data collection was carried out at Pediatric and Maternity Babylon Hospital for the period from 26th of march to 27th of may 2013. Questionnaire was designed to assess the psychological and social burdens of caregivers. It comprised of(10) items for psychological burdens and (8) items for social burdens. The items were rated according to 3 points type rating scale as (always, sometimes and never) and levels of scale were scored as (3 for always , 2 for sometimes and 1 for never).

4. Ethical consideration: Data collection is carried out by researcher who kept the confidentiality and anonymity of the data. The form for data collection was applied without mentioning the name of caregiver, their address, or any other information and adding to that a verbal agreement was obtained from participants in the study.
5. Statistical Analysis: Data were analyzed through the measurement of descriptive tools(frequencies, percentage) and inferential (chi- Square), the test used to determine the significant relation of caregiver's psychological and social burden and the relation - Demographic characteristics at p value< 0.05

IV. Results:

Table 1. Demographic characteristics of care givers

Characteristics	**No**	**%**
Care givers		
Mothers	55	55
Fathers	5	5
Parents	34	34
Total	100	100
Age of caregivers		
18-24	3	3
25-31	23	23
32-38	68	68
39-45	6	6
More than 45 years	-	-
Total	100	100
Level of caregivers education		
Illiterate	2	2
Read and write	30	30
Primary school	38	38
Secondary school	11	11
Institute and college	10	10
Total	100	100
caregivers occupation		
Employee	30	30
Unemployed	70	70
Total	100	100
Residual area Urban area	73	73
Rural area	27	27
Total	100	100

Table (1) shows that (55%) 0f caregivers were mothers and (34%) were relatives. Also the table indicated that (68%) of caregivers age is between (32-38years) while (23%) of them their age ranging between (25-31years). The table also stated that (38%) of caregivers' level of education were primary and (30%) of caregivers were read and write ,regarding to the occupation of caregivers (70%) of them were employee and (30%) were unemployed, also table (1) stated that (73%) of caregivers from urban area.

Table 2. Assessment of psychological burden of caregivers of children with thalassemia

Psychological burden	Always		Some time		Never		M.s	Level
	f	%	f	%	f	%		
1. I am frustrated since diagnosis of the disease	53	53%	27	27%	20	20%	2.33	ML
2.. I Feel sad	33	33%	43	43%	24	24%	2.09	ML
3. .I feel guilty	53	53%	44	44%	3	3%	2.5	ML
4. I want to cry	42	42%	45	45%	13	13%	2.29	ML
5. lost appetite for food	51	51%	44	44%	5	5%	2.46	HL
6. loss pleasure in life	66	66%	28	28%	6	6%	2.6	HL
7. I feel shivering in hands	34	34%	36	36%	30	30%	2.04	ML
8. I feel dryness in my mouth	42	42%	38	38%	20	20%	2.32	ML
9. I feel the fear of the future	82	82%	16	16%	2	2%	2.8	HL
10. I feel despair of life	73	73%	23	23%	4	4%	2.69	HL

*ML: medium level*HL: high level*: LL: low level

Table (2) stated that(82) of caregivers were feeling scared from the future while(66%) of them lost pleasure in life , and(53%) of them were feeling guilty ,also(53%) of caregivers frustrated since diagnosis of the disease and(42%) of caregivers were having the feeling to cry . Also the table indicated that (73%) of them feel despair of life.

Table 3. Assessment of social burden of caregivers of children with thalassemia

Social burden	Always		Sometime		Never		Mean score	Level
1.I spend most of my time with my child	54	54%	42	42%	4	4%	2.5	ML
2. My relationships with others have been affected	56	56%	32	32%	12	12%	2.44	ML
3. I am ashamed because of my son's illness	31	31%	49	49%	30	30%	2.21	ML
4. I feel that I m rejected by society because of my son	29	29%	51	51%	20	20%	2.09	ML
5. Care of my child is lord satisfy	56	56%	14	14%	30	30%	2.26	ML
6. Ignoring my other children	15	15%	53	53%	32	32%	1.83	LL
7. Care at the hospital is not enough	10	10%	37	37%	53	53%	1.87	LL
8. I hope that my son can be treated in private hospital	82	82%	37	37%	53	53%	2.79	HL

*

ML: medium level*HL: high level*: LL: low level

Table(3) stated that(82%) of the sample were not satisfied with services in hospital and hoping that to treat their children in the private hospital and (56%) of them stated that, their relationships have been affected due to the child sickness and(56%) of caregivers were handling the care of their children to the lord,also(54%) of them spend most of their time with sick child and ignore the rest.

Table 4. Association between ages of mothers with psychology burden

Item	Always		Sometime		Never		Total	
	f	%	f	%	f	%	f	%
Age								
18-24 years	3	3	0	0	0	0	3	3
25-31years	12	12	3	3	8	8	23	23
32-38 years	44	44	13	13	11	11	68	68
39-45 years	5	5	1	1	0	0	6	6
More than 45 years	0	0	0	0	0	0	0	0
Total	64	64	17	17	19	19	100	100

Chi-square 7.378 , df. 6 P.0.28729933 Significant

This table shows that there is significant relation between the ages of caregivers with psychological burden at p≤ o.5

Table 5. Association between ages of caregivers with social burden

Item	Always		Some time		Never		Total	
	f	%	f	%	f	%	f	%
Age								
18-24 years	3	3	0	0	0	0	3	3
25-31years	15	15	6	6	8	2	23	23
32-38 years	38	38	13	13	11	17	68	68
39-45 years	3	3	2	2	0	1	6	6
More than 45 years	-	-	0	0	0	0	0	0
Total	59	59	21	21	19	19	100	100

Chi-square 5. 615 , df . 6 P.0.46766779 Significant

This table shows that there is signification relation between the ages of caregivers with social burden at p≤ o.5

Table 6. Association between levels of education caregivers with psychology burden

Item	Always		Some time		Never		Total	
	f	%	f	%	f	%	f	%
Illiterate	9	9	1	1	1	1	11	11
Read & write	21	21	5	5	4	4	30	30
Primary school	30	30	4	4	4	4	38	38
Secondary school	6	6	4	4	1	1	11	11
Institute &college	1	1	5	5	4	4	10	10
Total	67	67	19	19	14	14	100	100

Chi-square= 20.753 df=8 p. value= 0.00078333 Significant

This table shows that there is signification relation between levels of education with psychology burden at p≤ o.5

Table 7. Association between levels of education caregivers with social burden

Item	Always		Not agree		Strong not agree		Total 1	
	f	%	f	%	f	%	f	%
Illiterate	4	4	3	3	4	4	11	11
Read & write	18	18	8	8	4	4	30	30
Primary school	33	33	2	2	3	3	38	38
Secondary school	10	10	1	1	1	1	11	11
Institute &college	5	5	4	4	2	2	10	10
Total	70	70	17	17	13	13	100	100

Chi-square= 19.005 df=8 p. value= 0. 0.1566388 Significant

This table shows that there is signification relation between levels of education with social burden at p≤ o.5

Table 8. Association between caregivers care with psychology burden

Item	Always		Sometime		Never		Total	
Caregivers care	f	%	f	%	f	%	f	%
Fathers	38	38	10	10	4	4	52	52
Mothers	17	17	3	3	2	2	22	22
Grandmothers	10	10	11	11	5	5	26	26
Total	65	65	24	24	11	11	100	100

Chi .square= 11. 149 df= 4 P.Value = 0.02493952

This table shows that there is signification relation between care givers with psychology burden at p≤ o.5

Table 9. Association between caregivers care with social burden

Item	Always		Sometime		Never		Total	
Caregivers care	f	%	f	%	f	%	f	%
Fathers	45	45	5	5	2	2	52	52
Mothers	10	10	8	8	4	4	22	22
Grandmothers	22	22	3	3	1	1	26	26
Total	77	77	16	16	7	7	100	100

Chi .square= 16. 041 df= 4 P.Value = 0.00296464

This table shows that there is signification relation between care givers with social burden at p≤ o.5

Table 10. Association between occupations of caregivers with psychology burden

Item	Always		Sometime		Never		Total	
occupation	f	%	f	%	f	%	f	%
Employer	10	10	12	12	8	8	30	30
Employer	31	31	23	23	16	16	70	70
Total	41	41	35	35	24	24	100	100

Chi-square = 1.048 df= 2 P.Value= 0.59214722

This table shows that there is signification relation between occupations of care givers with psychology burden at p≤ o.5

Table 11. Association between occupations of caregivers with social burden

Item	Always		Sometime		Never		Total	
occupation	f	%	f	%	f	%	f	%
Employer	22	22	7	7	1	1	30	
Employer	54	54	13	13	3	3	70	
Total	76	76	20	20	4	4	100	

Chi-square = 0.326 df= 2 P.Value= 0. 0.89959119

This table shows that there is signification relation between occupations of care givers with social burden at p≤ o.5

Table 12. Association between Residential of caregivers with psychology burden

Item	Always		Some time		Never		Total	
Residual area	f	%	f	%	f	%	f	%
Urban area	43	43	23	23	7	7	73	73
Rural area	18	18	7	7	2	2	27	27
Total	55	55	30	30	9	9	100	100

Chi-square = 0.504 df= 2 p.Value= 0. 0. 777244

This table shows that there is signification relation between residential areas of care givers with psychology burden at p≤ o.5

Table 13. Association between Residential of caregivers with Social burden

Item	Always		Some time		Never		Total	
Residual	f	%	f	%	f	%	f	%
Urban area	55	55	8	8	10	10	73	73
Rural area	21	21	4	4	2	2	27	27
Total	76	76	12	12	12	12	100	100

Chi-square = 0. 91 df= 2 p.Value= 0. 063444797.

This table shows that there is signification relation between residential areas of care givers with social burden at p≤ o.5

V. Discussion

The result of this study indicated that (55%) 0f caregivers were mothers and (34%) were relatives. This may be explained by the women still outnumber men when it comes to family caregivers, men are less likely to have background in performing care (5). Majority of the respondents were found females in studies done by (6 &7). Also the result stated that(68%) of caregivers ages are between (32-38) years, while(23%) of them are at age ranging between (25-31) years. This is the age of motherhood which agreed upon by many studies (8 &9) who mentioned that highest percentage of the caregiver age between 30-39 years. The result also stated that (38%) of caregivers' level of education was primary and (30%) was read and write. Also, in regard to the occupation of caregivers (70%) of them were unemployed and (30%) were employers. And lastly (73%) of caregivers from urban areas.

According to psychological burden the result stated that (82 %) of caregivers were feel fear of future while (66%) of them were loss pleasure in life , and (53%) of them were feel guilty ,also(53%) of caregivers frustrate since the diagnosis of disease is confirmed and(42%) of caregivers were feel to cry(Table 2).There results are supported by (1,2) who reported that psychological problems were very high (74%) strikingly high percentage (44%) of families had perceived severe burden due to illness of their children. and (68 %) reported that the family being more stressed, embarrassed and afraid of their child’s future. Probably related to the fear for future complications (5). Similar results were reported in studies held by (4,6), who studied 45 caregivers, having children with thalassemia, with the aim of assessing the psychological burden .The results indicated that (57%) of the caregivers had psychological problems, with depressive disorders in (50%).According to social burden the results showed that (82%) of the sample have a hope to treat their children in the private hospitals and(56%) of them their social relation affected because of the care of their children. (54%) of the sample spend most of their time with their sick children as sported by (10) who mentioned that mothers of children with thalassemia reported having physical problems and feelings of meaninglessness and dissatisfied with their life.
Most of the sick adolescents (80%) reported that thalassemia had affected their social life. Going out and share in social life were dicreased. (11). The adolescents worried about their disease and its complications. On being questioned about their worries (12), they responded that they were mainly concerned about the future of their health (56%) and education (34%). Patients belonging to the lower socio-economic stratus had additional worries related to the financial ramifications of their therapy.

VI. Recommendation

1- Further studies with larger sample size or multicentre studies with longer period of follow-up.
2- Psychological disturbances of families having children with thalassemia is a major issue which indicate that approaches need to be more family-centered than patient centered.
3. Caregivers should be encouraged to attend specific meetings, programs, workshops and seminars which set by Ministry of Health in concerning thalassemia and needs of children with this issue to be acquainted with the most recent, advances and skills in the field .

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