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Original Research Article

Depression, anxiety and burden of care in caregivers of children with β-thalassemia major

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ABSTRACT

Introduction: β – thalassemia major is a chronic inherited blood disorder requiring lifelong treatment including blood transfusion, putting tremendous burden on caregivers of the affected children. Aims were to measure the burden of care, prevalence and severity of depression and anxiety, and their association with various socio-demographic and illness related factors in caregivers of children with β – thalassemia major.
Materials and Methods: A cross-sectional study was conducted on 100 caregivers of children suffering from β – thalassemia major coming to the Paediatrics department of S.S.G. Hospital, Vadodara. Study tools used were Zarit Burden Interview, General Health Questionnaire-28, Diagnostic and Statistical Manual of mental disorders (fifth edition) diagnostic criteria for depressive disorders and generalised anxiety disorder, Hamilton Depression and Anxiety Rating Scales.
Results: Forty seven (47%) caregivers had moderate to severe burden of care. Fifty four (54%) caregivers screened positive for having psychiatric morbidity out of which thirty five (35%) had depressive disorders and fourteen (14%) had generalised anxiety disorder. 24 (68.6%) and 9 (64.3%) had moderate to severe depression and anxiety respectively. Burden of care and depression were significantly associated with lower income and those requiring blood transfusions every 2 weeks or less.
Conclusion: Thalassemia has its impact not only on the patients but also on the mental health of their caregivers leading to high levels of depression, anxiety and burden of care in them. They should be routinely screened for depression and anxiety to provide adequate mental health care to these individuals.

1. Introduction

β-thalassemia is genetic disorder characterized by deficient (β^+) or absent (β^0) synthesis of the β-globin subunit of haemoglobin molecule.[1,2] Children with β – thalassemia major require blood transfusions for their survival along with iron chelation therapy to prevent iron overload in tissues needing lifelong treatment with no permanent cure[3] and have been found to be having psychosocial problems such as lower self-esteem & social isolation, financial issues, psychiatric disorders, limitation of physical activity, behavioural and school performance problems, factors of maturation and complications of thalassemia.[4]

Parents or caregivers of such children may also have psychological effects as they not only worry regarding their children's standard of life, goals and their expectations, but also the influence on family dynamics and the family's financial, psychological and social stability due to the

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constant realization of disease and frequent visits to the morbid hospital environment.[5] If they are not able to cope up, this may lead to hopelessness, emotional burden and social difficulties, adverse thoughts about their life, heightened anxiety, guilt and lessened self-esteem.[6]

The aims of this study were to measure the burden of care, prevalence and severity of depression and anxiety, and their association with various socio-demographic and illness related factors in caregivers of children with β – thalassemia major.

2. Material and Methods

2.1. Study design

This is an observational cross-sectional study conducted on caregivers of children suffering from β – thalassemia major coming to the Paediatrics department of S.S.G. Hospital, Vadodara. Minimum 96 caregivers were required to estimate psychiatric morbidity and burden of care among caregivers by 50% with 20% relative precision and 95% confidence.[7] 100 caregivers were recruited for the study after getting written approval from the Institutional Ethics Committee for Human Research (EC Reg No: ECR/85/Inst/GJ/2013/RR-16).

2.2. Inclusion criteria

Men and women aged ≥18 years coming to Paediatrics department of S.S.G. Hospital, Vadodara, who are caregivers of β – thalassemia major children, including parent and guardian and gave written informed consent. Only those persons who generally take care of the β – thalassemia major children at home were included. Those who were having any behavioural disturbance or suffering from psychotic disorder were excluded from the study.

2.3. Data collection

Caregivers of children with β - thalassemia major coming to Paediatrics department of S.S.G. Hospital, Vadodara, were referred for inclusion in this study and if they met the inclusion criteria, they were enrolled in the study after taking written informed consent. Interview was conducted using questionnaire involving socio-demographic and illness related characteristics.

2.4. The study tools used were

Zarit Burden Interview (ZBI-22)[8] - ZBI-22 is a standard, validated tool used to assess the burden on family caregivers. It is a 5-point (0-4; a higher score denotes higher burden), 22-item Likert scale, which assesses five main domains of burden namely health, psychological well-being, finances, social life and relationship with the patient. The final scores range from 0 to 88. It is further stratified into four categories, that is, a score of 0 -20 (No or Minimal Burden), 21-40 (Mild to Moderate Burden), 41-60 (Moderate to Severe Burden) and 61-88 (Severe Burden).

General Health Questionnaire-28 (GHQ-28)[9] – for screening psychiatric morbidity. It is a validated screening tool for assessment of psychiatric conditions and consists of four subscales: somatic symptoms, anxiety and insomnia, social dysfunction and severe depression. In GHQ scoring method (0-0-1-1), total score is 0 to 28. In the present study, GHQ-28 score greater than 4 was considered as screened positive for psychiatric morbidity.

Diagnostic and Statistical Manual of mental disorders, fifth edition (DSM-5)[10] - diagnostic criteria for depressive disorders and generalised anxiety disorder.

Hamilton Depression Rating Scale (HAMD-17)[11] – for measuring severity of depressive symptoms. It contains 17 items pertaining to symptoms of depression experienced over the past week. Sum of the scores from the 17 items are classified as 0 - 7 (Normal), 8-13 (Mild), 14-18 (Moderate), 19-22 (Severe) and ≥ 23 (Very Severe).

Hamilton Anxiety Rating Scale (HAM-A)[12] – for measuring severity of anxiety symptoms. The scale consists of 14 items, each defined by a series of symptoms, and measures both psychic anxiety (mental agitation and psychological distress) and somatic anxiety (physical complaints related to anxiety). Sum of the scores from all the parameters are classified as 14-17 (Mild), 18-24 (Moderate) and 25-30 (Severe).

2.5. Statistical analysis

Data was entered in excel sheet and statistical descriptive analysis was carried out, i.e., frequency, percentage, mean and standard deviation using Medcalc version 14.8.1. Statistical associations were tested using Chi square test.

3. Results

The study population consists of a total of 100 caregivers of children with β – thalassemia major which were selected from Paediatric ward and OPD.

3.1. Description of study population

Table 1 The mean age of caregivers was found to be 34.13 years with a standard deviation of 5.65 years.

3.2. Burden of care

Table 2 53% caregivers had no or minimal to mild burden of care and 47% caregivers had moderate to severe burden of care. Mean of burden of care (ZBI Score) was 44.64 with standard deviation 3.4.

3.3. Psychiatric morbidity, depression and anxiety

54 out of 100 caregivers screened positive for psychiatric morbidity (i.e. GHQ-28 score > 4). From those, 35 and 14 caregivers were diagnosed with depressive disorders and generalised anxiety disorder respectively.

Table 3 Out of 35 caregivers with depressive disorders, 24 (68.6%) were in moderate to very severe range of HAM-D scale. Mean HAM-D score was 15.28 with standard deviation 3.3.

Table 4 Out of 14 caregivers with generalised anxiety disorder,9 (64.3%) belonged to moderate to severe range of HAM-A scale. Mean HAM-A score was 19.14 with standard deviation 2.9.

Table 5 29 caregivers (82.8%) with depressive disorders and 11 caregivers (78.5%) with generalised anxiety disorder had moderate to severe range of burden of care.

3.4. Association of socio-demographic and illness related characteristics with depression and anxiety

Table 6 Mean HAM-D scores were higher in caregivers aged more than 40 years, females, living in rural areas, literate, unemployed, total monthly family income less than Rs.5000/-, affected child diagnosed as having β – thalassemia major more than 5 years ago and requiring blood transfusion every 15 days or less. However, statistically significant associations were established only with income and frequency of blood transfusions.

Higher mean HAM-A scores were found in caregivers aged between 18 to 29 years, females, living in rural areas, illiterate, employed, total monthly family income more than Rs.5000/-, affected child diagnosed as having beta-thalassemia major less than 5 years ago and requiring blood transfusion every 15 days or less. However, no statistically significant association could be established between any of the socio-demographic or illness related characteristics with anxiety in the study population.

3.5. Association between socio-demographic characteristics and illness related characteristics with burden of care

Table 7 Mean scores of burden of care were higher in caregivers aged 18-29 and more than 40 years, females, living in urban areas, literate, unemployed, total monthly family income less than Rs.5000/-, affected child diagnosed as having β – thalassemia major more than 5 years ago and requiring blood transfusion every 15 days or less. However, statistically significant associations were established only with income and frequency of blood transfusions.

4. Discussion

In the present study, 47% caregivers had moderate to severe and 53% caregivers had no or minimal to mild burden of care. Pruthi et al. found that psychosocial burden was greater in caregivers of thalassemia children as compared to the control group.[13] Mashayekhi et al. noted that 20%, 29% and 51% of mothers reported high, moderate and low level of burden respectively.[14]

In the present study, 54% of caregivers of children with β – thalassemia major had psychiatric morbidity. Prevalence of depressive disorders was 35% and generalised anxiety disorder was 14% which were similar to the findings of Shaligram et al. (57% psychiatric morbidity,

Table 1: Socio-demographic and illness related characteristics (N=100)

Variable		Frequency (%)
Age	18-29	21
	30-39	58
	>40	21
Gender	Male	36
	Female	64
Area	Rural	41
	Urban	59
Education	Illiterate	21
	Literate	79
Occupation	Unemployed	33
	Employed	67
Income (monthly)	≤5000	39
	>5000	61
Duration of diagnosed thalassemia	=<5 years	17
	>5 years	83
Frequency of blood transfusion	<16 days	16
	Between 16 to 30 days	72
	>30 days	12

Table 2: Distribution of caregivers on ZBI score level (N=100)

ZBI Score Level	Frequency (%)
No or Minimal Burden (0 – 20)	17
Mild Burden (21 – 40)	36
Moderate Burden (41 – 60)	27
Severe Burden (61 – 80)	20

Table 3: Severity of Depressive Disorders assessed by HAM-D scale (N=35)

HAM-D Scale Score	Frequency (%)
Mild Depression (8-13)	11 (31.4%)
Moderate Depression (14-18)	17 (48.5%)
Severe Depression (19-22)	6 (17.1%)
Very Severe Depression (≥ 23)	1 (2.8%)

Table 4: Severity of Generalised Anxiety Disorder assessed by HAM-A scale (N=14)

HAM-A Score	Frequency	Percentage
Mild Anxiety (14-17)	5	35.7
Moderate Anxiety (18-24)	8	57.1
Severe Anxiety (25-30)	1	7.1

Table 5: Relationship of depression, anxiety and burden of care in caregivers

Burden of care score	**No or Minimal**	**Mild**	**Moderate**	**Severe**
Total number of patients in this score (N=100)	17	36	27	20
Number of patients with depressive disorders in this score (N=35)	1 (2.8%)	5 (14.2%)	14 (40%)	15 (42.8%)
Number of patients with generalised anxiety disorder in this score (N=14)	1 (7.1%)	2 (14.2%)	8 (57.1%)	3 (21.4%)

Table 6: Depressive and anxiety symptoms and its association with socio–demographic and illness related characteristics

Variable		**N**	**Depression**					**Anxiety**				
			Present	**Absent**	**Mean ±SD**	**Chi square χ^2**	**P value**	**Present**	**Absent**	**Mean ±SD**	**Chi square $\chi 2$**	**P value**
Age	18-29	21	6	15	14.6±1.9	2.58	0.27	4	17	20.5 ±2.2	1.53	0.46
	30-39	58	24	34	14.9±3.7			6	52	17.8 ±2.3		
	≥40	21	5	16	17.8±2.3			4	17	20.0 ±4.3		
Gender	Male	36	9	27	13.7±3.4	1.83	0.17	6	30	18.8 ±2.1	0.07	0.78
	Female	64	26	38	15.8±3.3			8	56	19.3 ±3.5		
Area	Rural	41	10	31	15.4±3.5	2.27	0.10	7	34	19.7 ±3.4	0.19	0.65
	Urban	59	25	34	15.2±3.4			7	52	18.5 ±2.5		
Education	Illiterate	21	7	14	14.4±3.5	0.005	0.93	2	19	21.0 ±7.0	0.096	0.75
	Literate	79	28	51	15.5±3.4			12	67	18.8 ±2.2		
Occupation	Unemployed	33	16	17	16.7±3.4	3.10	0.07	5	28	18.5 ±2.6	0.0002	0.99
	Employed	67	19	48	14.0±2.9			9	58	19.7 ±3.3		
Income (monthly in Rs.)	≤5000	39	19	20	16.1±3.1	4.35	0.03	9	30	18.6±2.3	3.22	0.07
	>5000	61	16	45	14.2±2.9			5	56	20.0 ±3.9		
Duration of diagnosis	≤5 years	17	3	14	13.0±1.0	1.87	0.17	3	14	19.5 ±5.0	0.008	0.92
	>5 years	83	32	51	15.5±3.4			11	72	19.0 ±1.9		
Frequency of blood transfusion	≤15days	16	9	7	18.6±3.2	6.93	0.03	4	12	20.2 ±2.2	2.19	0.33
	16 to 30 days	72	25	47	14.0±2.6			9	63	19.1 ±3.0		
	>30 days	12	1	11	15			1	11	15.0 ±0.0		

(Statistically significant P value < 0.05)

Table 7: Burden of Care and its association with socio-demographic and illness related characteristics

Variable		**N**	**Burden of care**				**Mean± SD**	**Chi square χ^2**	**P value**
			No or Minimal	**Mild**	**Moderate**	**Severe**			
Age	18-29	21	2	8	7	4	43.7±15.9	3.65	0.724
	30-39	58	11	20	17	10	41.5±17.6		
	≥40	21	4	8	3	6	43.0±18.1		
Gender	Male	36	8	15	8	5	38.2±16.8	2.93	0.402
	Female	64	9	21	19	15	44.6±17.4		
Area	Rural	41	9	15	11	6	39.6±17.5	2.01	0.570
	Urban	59	8	21	16	14	44.2±17.2		
Education	Illiterate	21	5	6	5	5	40.9±18.5	1.42	0.699
	Literate	79	12	30	22	15	42.6±17.1		
Occupation	Unemployed	33	4	9	10	10	47.7±17.1	4.53	0.103
	Employed	67	13	27	17	10	39.6±17.0		
Income (monthly in Rs.)	≤5000	39	7	8	11	14	46.6±19.4	12.2	0.006
	>5000	61	10	28	16	6	39.8±15.6		
Duration of diagnosis	≤5 years	17	6	5	3	3	36.8±19.0	0.63	0.426
	>5 years	83	11	31	24	17	43.4±16.9		
Frequency of blood transfusion	≤15days	16	0	3	3	10	59.9±12.1	26.21	0.0002
	16 to 30 days	72	13	28	23	8	39.9±15.9		
	>30 days	12	4	5	1	2	33.2±17.3		

45% depression),[7] Khairkar et al. (33.3% depression, 10% anxiety),[15] Aziz et al. (29% depression)[16] and Pineda-Frutos et al. (22.7% depression).[17] Prevalence of depression and anxiety in the general population has been found to be 5-17% (average 12%) and 3-8% (average 5%) respectively.[18] Thus, the prevalence of depression and anxiety in the present study was about three times than in the general population. Caregivers with depressive and anxiety disorders in moderate to severe range were 68.6% and 64.3% respectively, which was similar to the findings of Ashrafizadeh H et al (44.3% moderate to severe depression and 71.1% moderate to severe anxiety).[19] Mirbehbahani et al. showed majority of depressed mothers with children having β – thalassemia major had moderate severity of depression (33.4%).[20] Khanna et al. found 38% moderate to severe depressive symptoms, and 17% moderate to severe anxiety symptoms in caregivers of children with chronic illness.[21]

In the present study, significant association of burden of care and depression was established with total monthly family income less than Rs. 5000/- and frequency of blood transfusion every 15 days or less; whereas significant association could not be established between any of the socio-demographic or illness related characteristics with anxiety. Ashrafizadeh et al. also noted the significance of duration of child's hospitalization on level of depression and anxiety of parents.[19] Aziz et al. observed a significant relationship between parent education and depression.[22] Ashkani et al. observed that parents belonging to lower socioeconomic class and with lower education level had a higher level of depression.[23]

Hence, findings of the present study were in line with the results of most of these previously conducted studies. Differences observed from a few studies may be due to demographic and sample size variations, different tools and methodology used.

Limitations of the present study were that it was a cross sectional study, some of the information collected was subjective which may lead to social desirability bias, and majority of the sample size was from a particular age group so it may not be representative of caregivers. A longitudinal study with larger sample size and control group is recommended which would give more power to the findings and may produce more significant results and further exploration of impact of caregiver mental health and burden of care on compliance.

5. Conclusion

Thus, it was concluded that β-thalassemia major affects not only children but also caregiver's mental health and also creates burden on caregivers. So, the need arises for sensitization of treating paediatricians for focusing towards the mental health aspects of caregivers while treating children with β-thalassemia major, which may help in maintaining compliance and improving the quality of life of both children and their caregivers.

6. Conflicts of Interest

None.

7. Source and Funding

None.

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