

ORIGINAL ARTICLE:

Frequency of Depression and Anxiety among Caregivers of Patients with Beta Thalassemia Major at Thalassemia Center of a Tertiary Care Hospital

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ABSTRACT

OBJECTIVE

To determine the frequency of anxiety and depression among the caregivers of patients with beta thalassemia major in a tertiary hospital, and to identify the gender and demographic associations.

STUDY DESIGN

Cross-sectional study

PLACE & DURATION OF STUDY

The study was conducted at Kech Thalassemia Care Center (KTCC), affiliated with the tertiary teaching hospital, Turbat, from June 2024 to February 2025.

METHOD

A total of 88 caregivers of patients with beta-thalassemia major (BTM) were enrolled. A non-probability sampling technique was used for data collection. The Hospital Anxiety and Depression scale was administered to assess the levels of anxiety and depression in caregivers. Data were analyzed using SPSS version 20.0. Chi-square test and binary logistic regression were used to evaluate associations and predictors.

RESULTS

Moderate-to-severe anxiety was observed in 50% of Caregivers of BTM patients, while 30.7% showed moderate depression. Low income ($\leq$ 50,000 PKR) was a significant predictor of depression (aOR = 4.65, p = 0.019).

CONCLUSION

Depression and Anxiety disorders are prevalent among primary caregivers of beta thalassemia major in Mekran region of Balochistan. Low household monthly income and lack of formal education were seen associated with a higher frequency of anxiety and depression. Mental health interventions are required.

KEYWORDS

Caregivers, Beta thalassemia major, Anxiety, Depression, Mekran

Introduction

Beta-thalassemia major (BTM) is an inherited blood disorder that requires lifelong blood transfusions. It is still a major public health problem in many low- and middle-income countries. It is commonly seen in South Asia, the Middle East, and some parts of Africa.¹ In Pakistan, approximately 5–7% of the population are carriers of the β -thalassemia trait. Each year, nearly 5,000 children are diagnosed with BTM.²⁻⁴ The impact of BTM extends beyond the affected child and has substantial psychological, social, and financial effects on families, especially primary caregivers.

Mekran, the southwestern region in the province of Balochistan, Pakistan, is a resource-limited area where economic hardship is widespread and awareness of genetic disorders is low. Poverty is high, while healthcare availability is limited in the Mekran region. Such conditions create an environment where caregiving responsibilities can become overwhelming, and psychological distress is significant^{5,6}

Parents and other family members are responsible for the medical management of children with BTM. In most families, the mothers accompany the children for frequent hospital visits and blood transfusions, while invariably, the fathers take on the challenge of the monetary burdens of the patients with BTM.^{7,8} Such challenges usually compromise the mental health of the parents, with anxiety and depression being the most common psychiatric outcomes. Studies from Bangladesh and other parts of Pakistan have shown that about 30 % to 70 % of caregivers suffer from anxiety and depression.^{9,10} However, research focused on caregivers of BTM is scarce in Mekran, Balochistan, an underserved and underrepresented far-flung area of Balochistan.

Limited mental health education and social stigma about psychiatric disorders contributed to the neglect of the mental health and social well-being of caregivers in this region. Family and caregivers of BTM rarely receive psychological counseling and therapeutic intervention.⁹ As a result, the quality of life of the caregivers of BTM may be adversely affected by anxiety and depression. Given the socioeconomic and healthcare inequalities, assessing the psychological effects on caregivers is necessary.¹¹

This study aimed to estimate the frequency of anxiety and depression in primary caregivers of children with BTM, thereby underscoring the need to integrate psychosocial services into thalassemia care.

Method

Participants

The present cross-sectional study was conducted at the Kech Thalassemia Care Center (KTCC), affiliated with the Teaching Hospital, Turbat, of Mekran Medical College, Kech. This study was carried out from June 2024 to February 2025. OpenEpi was used to compute the required sample size, assuming a 95% confidence level and a 10% margin of error. The expected prevalence of depression was 35%, as reported by a previous peer-reviewed study.¹² The relatively wider margin of error (10%) was selected because of the exploratory nature of the study and limited access to the dispersed population in the Mekran region. OpenEpi yielded an estimated sample size of 88 for the study. Those who visited the thalassemia clinic were enrolled using a consecutive sampling technique. Both male and female caregivers aged 18-65 years who had cared for patients for at least 6 months were selected based on the inclusion criteria. Caregivers with prior psychiatric disorders, drug addiction, or taking any psychiatric medications, and suffering from cognitive or communication impairment were excluded.

Instrument

The principal investigator and a consultant psychiatrist from the teaching hospital interviewed the caregivers using the Structured Clinical Interview for Disorders (SCID) for the Diagnostic and Statistical Manual of Mental Disorders (DSM-5).¹³ The Urdu version of the Hospital Anxiety and Depression Scale (HADS) was administered to measure the severity of anxiety and depression.¹⁴ It is a 14-item questionnaire used in non-psychiatric settings to detect states of anxiety and depression. The scale consists of two subscales: HAD-A for anxiety and HADS-D for depression, each subscale containing 7 items, with total subscale scores ranging from 0 to 21. Standard cutoff points are 0-7 Normal, 8-10 Mild, 11-14 Moderate, and 15-21 Severe.^{14,15}

Procedure

The Institutional Ethical Research Board approved the study, letter No. 1/1-R/Estt 5283, on 11th June 2024. After the detailed description of the study, informed consent was obtained from all participants. Caregivers were interviewed to complete the questionnaires. IBM SPSS 20.0 was used for data entry and statistical analysis. For age and duration of illness, the mean and standard deviation were computed. Frequencies and percentages were computed for gender, marital status, level of education, monthly income, and relationship with patients. To identify independent predictors, binary logistic regression was applied, adjusting for potential confounders.

Results

Of 88 caregivers of BTM, the mean age was 36.1 ± 11.8 years. There were 47 males (53.4%) and 41 females (46.6%) caregivers. The children with beta-thalassemia major had a mean age of 7.17 years ($SD \pm 4.37$), and the average duration since diagnosis was 1.68 years ($SD \pm 2.52$), ranging from one month to 11 years. When anxiety levels were grouped as normal ($HADS-A < 8$) versus abnormal ($HADS-A \geq 8$), 50% of caregivers had abnormal levels of anxiety. Similarly, 64.8% (57/88) of caregivers scored in the abnormal range for depression ($HADS-D \geq 8$). The chi-square test was used to assess the association between caregiver characteristics and mental health outcomes. Abnormal anxiety was more frequently observed among caregivers with lower incomes and no formal education. Monthly household income was significantly associated with anxiety ($p = 0.011$), whereas education was not statistically significant. Table 1 presents the comparison of anxiety levels with caregiver baseline characteristics.

Table 1

Comparison of HADS Anxiety Levels with Baseline Characteristics of Caregivers (n = 88)

Baseline Characteristics	Normal (n=23)	Mild (n=20)	Moderate (n=44)	Severe (n=1)	Total (n=88)	p-value
Duration since diagnosis (years) Mean $\pm$ SD*	1.41 $\pm$ 2.25	2.03 $\pm$ 2.61	1.62 $\pm$ 2.49	0.83	1.68 $\pm$ 2.52	0.497
Age (mean $\pm$ SD)	35.3 $\pm$ 11.2	39.5 $\pm$ 12.8	35.0 $\pm$ 11.7	30.0	36.1 $\pm$ 11.8	0.495
Sex						0.756
Male	13 (56.5%)	11 (55.0%)	22 (50.0%)	1 (100.0%)	47 (53.4%)	
Female	10 (43.5%)	9 (45.0%)	22 (50.0%)	0 (0.0%)	41 (46.6%)	
Marital Status						0.894
Married	22 (95.7%)	19 (95.0%)	38 (86.4%)	1 (100.0%)	80 (90.9%)	
Unmarried	1 (4.3%)	1 (5.0%)	2 (4.5%)	0 (0.0%)	4 (4.5%)	
Divorced	0 (0.0%)	0 (0.0%)	1 (2.3%)	0 (0.0%)	1 (1.1%)	
Widowed	0 (0.0%)	0 (0.0%)	3 (6.8%)	0 (0.0%)	3 (3.4%)	
Education						0.526
No formal education**	8 (34.8%)	10 (50.0%)	27 (61.4%)	1 (100.0%)	46 (52.3%)	
Primary	3 (13.0%)	4 (20.0%)	7 (15.9%)	0 (0.0%)	14 (15.9%)	
Middle-Intermediate	8 (34.8%)	5 (25.0%)	7 (15.9%)	0 (0.0%)	20 (22.7%)	
Graduate	4 (17.4%)	1 (5.0%)	3 (6.8%)	0 (0.0%)	8 (9.1%)	
Income (PKR)						0.011
Below 50,000	7 (30.4%)	10 (50.0%)	26 (59.1%)	1 (100.0%)	44 (50.0%)	

50,000–100,000	8 (34.8%)	8 (40.0%)	17 (38.6%)	0 (0.0%)	33 (37.5%)
Above 100,000	8 (34.8%)	2 (10.0%)	1 (2.3%)	0 (0.0%)	11 (12.5%)
Relation with Patient					0.107
Mother	5 (21.7%)	7 (35.0%)	27 (61.4%)	1 (100.0%)	40 (45.5%)
Father	11 (47.8%)	6 (30.0%)	8 (18.2%)	0 (0.0%)	25 (28.4%)
Grandparent	3 (13.0%)	5 (25.0%)	5 (11.4%)	0 (0.0%)	13 (14.8%)
Others***	4 (17.4%)	2 (10.0%)	4 (9.1%)	0 (0.0%)	10 (11.4%)

SD* = Standard Deviation, Other*** = Sibling, aunt, uncle, cousin, No formal education** = Unable to read and write

For depression, significant associations were observed with marital status ($p=0.010$), education level ($p=0.023$), and monthly income ($p=0.022$). Widowed caregivers and those without schooling (no education) had higher proportions of abnormal depression scores. Depression levels were distributed as follows: 31 (35.2%) normal, 24 (27.3%) mild, 27 (30.7%) moderate, and 6 (6.8%) severe. Overall, 64.8% (57/88) of caregivers had abnormal depression (HADS-D ≥ 8). This was associated with caregivers' marital status ($p=0.010$), education ($p=0.023$), and income ($p=0.022$). Notably, widowed caregivers reported the highest frequency of severe depression. There was no significant association observed with age ($p=0.835$) or sex ($p=0.310$). These results are shown in Table 2, which summarises the distribution of depression levels according to caregiver variables.

Table 2

Comparison of HADS Depression levels with baseline characteristics of caregivers (n = 88)

Baseline Characteristics	Normal (n=31)	Mild (n=24)	Moderate (n=27)	Severe (n=6)	Total (n=88)	p-value
Duration since diagnosis (years) Mean $\pm$ SD*	1.55 $\pm$ 2.35	1.42 $\pm$ 2.47	2.08 $\pm$ 2.82	2.51 $\pm$ 3.01	1.68 $\pm$ 2.52	0.426
Age (mean $\pm$ SD*)	37.6 $\pm$ 12.5	35.1 $\pm$ 9.8	35.6 $\pm$ 13.2	34.2 $\pm$ 10.9	36.1 $\pm$ 11.8	0.835
Sex						0.310
Male	18 (58.1%)	13 (54.2%)	15 (55.6%)	1 (16.7%)	47 (53.4%)	
Female	13 (41.9%)	11 (45.8%)	12 (44.4%)	5 (83.3%)	41 (46.6%)	
Marital Status						0.010
Married	30 (96.8%)	22 (91.7%)	24 (88.9%)	4 (66.7%)	80 (90.9%)	
Unmarried	1 (3.2%)	2 (8.3%)	1 (3.7%)	0 (0.0%)	4 (4.5%)	
Divorced	0 (0.0%)	0 (0.0%)	1 (3.7%)	0 (0.0%)	1 (1.1%)	
Widowed	0 (0.0%)	0 (0.0%)	1 (3.7%)	2 (33.3%)	3 (3.4%)	
Education						0.023
No formal education***	13 (41.9%)	18 (75.0%)	12 (44.4%)	3 (50.0%)	46 (52.3%)	
Primary	3 (9.7%)	0 (0.0%)	9 (33.3%)	2 (33.3%)	14 (15.9%)	
Middle-Intermediate	10 (32.3%)	5 (20.8%)	4 (14.8%)	1 (16.7%)	20 (22.7%)	
Graduate	5 (16.1%)	1 (4.2%)	2 (7.4%)	0 (0.0%)	8 (9.1%)	
Income (PKR)						0.022
Below 50,000	11 (35.5%)	12 (50.0%)	16 (59.3%)	5 (83.3%)	44 (50.0%)	
50,000–100,000	11 (35.5%)	11 (45.8%)	10 (37.0%)	1 (16.7%)	33 (37.5%)	
Above 100,000	9 (29.0%)	1 (4.2%)	1 (3.7%)	0 (0.0%)	11 (12.5%)	
Relation with Patient						0.400
Mother	8 (25.8%)	13 (54.2%)	15 (55.6%)	4 (66.7%)	40 (45.5%)	
Father	13 (41.9%)	5 (20.8%)	6 (22.2%)	1 (16.7%)	25 (28.4%)	
Grandparent	6 (19.4%)	4 (16.7%)	3 (11.1%)	0 (0.0%)	13 (14.8%)	
Others	4 (12.9%)	2 (8.3%)	3 (11.1%)	1 (16.7%)	10 (11.4%)	

SD* = Standard Deviation, Other** = Sibling, aunt, uncle, cousin, No formal education*** = Unable to read and write.

To explore these associations, binary logistic regression was used to assess depression status (normal vs. abnormal) as the outcome. After adjusting for confounders, caregivers with a monthly income of $\leq$ 50,000 PKR were found to have significantly greater odds of abnormal depression (aOR = 4.65, 95% CI: 1.29–16.76, p = 0.019). Similarly, caregivers with no formal education had increased odds of depression (aOR = 3.28, 95% CI: 1.01–10.67, p = 0.049). Though depression was more common among female and widowed

caregivers, these variables did not reach statistical significance in the adjusted model. These findings are shown in Table 3.

Table 3
Logistic Regression Analysis of Depression among Caregivers (n = 88).

Variable	OR* (95% CI)**	p-value	aOR*** (95% CI)	p-value
Sex				
Female	1.33 (0.52 – 3.39)	0.545	1.41 (0.54 – 3.69)	0.481
Male	1	—	1	—
Marital Status				
Widowed	4.43 (0.71 – 27.60)	0.111	4.98 (0.76 – 32.56)	0.095
Married	1	—	1	—
Education				
No formal education	3.60 (1.08 – 11.98)	0.037	3.28 (1.01 – 10.67)	0.049
Primary	2.50 (0.62 – 9.95)	0.196	2.41 (0.57 – 10.10)	0.230
Graduate	1	—	1	—
Income (PKR)				
≤50,000	5.43 (1.50 – 19.61)	0.010	4.65 (1.29 – 16.76)	0.019
50,000–100,000	2.67 (0.65 – 10.92)	0.170	2.51 (0.60 – 10.42)	0.204
>100,000	1	—	1	—
Duration since diagnosis (years)	1.12 (0.88 – 1.42)	0.350	1.10 (0.86 – 1.40)	0.430

OR*= Odds ratio, CI**= Confidence Interval, aOR***= adjusted Odds ratio.

Discussion

The study observed substantial psychological distress among caregivers of children with beta thalassemia major. Nearly half of the participants experienced anxiety, and nearly two-thirds had abnormal HADS-D scores. These outcomes were consistent with studies conducted in neighboring countries such as Bangladesh, India, and Iran, where caregivers of beta thalassemia experienced significant psychological distress.^{9,16,17} Compared with males, female caregivers reported higher levels of anxiety and depression in this study. However, the difference was not statistically significant. Caregivers with a lack of formal education and low income were vulnerable to experiencing symptoms of depression in the present study. Our findings were consistent with studies conducted in Peshawar and Karachi. Financial hardship and no formal education have been identified as important factors associated with psychological distress of chronic illnesses in studies conducted in Peshawar and Karachi.^{18,19} Widowed caregivers showed higher levels of depression in comparison to married caregivers. After adjustment, this was no longer statistically significant; however, it suggests that a lack of spousal support may increase psychological vulnerability among caregivers. Previous studies have reported that a longer duration of caregiving is associated with greater psychological distress. However, this study did not observe a statistically significant relationship. Previous studies also reported that emotional burden can build slowly, making it harder to detect through statistical analysis alone.^{20–22}

Limitations

The study was limited by its single-institution setting and small sample size, given the dispersed population.

Conclusion

A considerable proportion of caregivers of children with beta-thalassemia major experience anxiety and depression. Low income and lack of formal education were independently associated with depression. These findings show the need to integrate mental health services into thalassemia care programs, particularly in resource-constrained settings.

Recommendation

Integration of psychosocial support and routine screening for anxiety and depression is recommended.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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AUTHOR(S) CONTRIBUTION / UNDERTAKING STATEMENT

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Sr. No.	Author(s) Name	Affiliation	Contribution
1	Shoaib Ahmed Kashani	Department of Psychiatry, Mekran Medical College (MMC), Turbat, Pakistan.	Conceptualisation and study design, supervision of research activities, patient and caregiver recruitment, statistical analysis and interpretation, drafting the manuscript, and final approval for the published version.
2	Muhammad Ayub	Department of Psychiatry, Mekran Medical College (MMC), Turbat, Pakistan.	Selection of assessment instruments, clinical evaluation and diagnostic input, data analysis and interpretation, and critical revision of the manuscript.
3	Zafar Abdul Nabi	Department of Medicine, Mekran Medical College (MMC), Turbat, Pakistan.	Conceptualisation and study design, statistical analysis, data interpretation, critical revision of the manuscript, and final approval for the published version.
4	Chakar Tajwidi	Eye Department, Mekran Medical College (MMC), Turbat, Pakistan.	Conceptualisation and design of the study, data collection, statistical analysis, drafting of the manuscript
5	Imam Bakhsh	Department of Surgery, Mekran Medical College (MMC), Turbat, Pakistan.	Data acquisition and data collection, interpretation of study findings, critical revision of the manuscript, and final approval for the published version.
6	Wahid Bakhsh	Orthopedic Department, Mekran Medical College (MMC), Turbat, Pakistan.	Data collection and administration of assessment tools, data entry and statistical analysis using SPSS, interpretation of results, critical revision of the manuscript.