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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.

SUBJECTS AND METHODS

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 (≤ 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 a chronic, lifelong, transfusion-dependent hereditary blood disorder commonly seen in South Asia, the Middle East, and parts of Africa.[1] In Pakistan, approximately 5–7% of the population carries the β-thalassemia trait, and nearly 5,000 children are diagnosed each year.[2-4] The burden of this chronic blood disorder extends beyond the affected child to deeply affect the family, especially the caregivers. Mekran, the southwestern region located in the province of Balochistan, Pakistan, is a resource-limited area where economic hardship is widespread and awareness about genetic disorders is low. Poverty is high, and healthcare access is minimal in the Mekran region. These conditions

create an environment where caregiving responsibilities can become overwhelming, and psychological distress is profound [5,6]

Parents and other family members take responsibility for the medical management of the children with BTM. Primarily, the mothers are entrusted to take responsibility for frequent hospital visits and blood transfusions, while invariably, the fathers take on the challenge of the financial 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 counselling and therapeutic intervention.[9] As a result, anxiety and depression can affect their quality of life and their ability to provide continuous care to their children with BTM. Given the socioeconomic and healthcare disparities, assessing the psychological impact on caregivers is necessitated.[11]

This study aims to assess the frequency of anxiety and depression among caregivers of children with BTM, thereby highlighting the need for integrated mental health interventions within the care of Thalassemia.

SUBJECTS AND METHODS

Participants

This descriptive cross-sectional study was conducted at 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. The sample size was calculated using Open Epi, assuming a 95% confidence interval level, 10% margin of error, and an expected depression prevalence of 35% reported by a previous peer-reviewed study.[12] A 10% margin of error was used due to the study's exploratory nature and limited access to the geographically dispersed population in Mekran. This yielded a total sample size of 88 participants who visited the teaching hospital's thalassemia center, Turbat, to manage their patients with BTM were enrolled through a consecutive sample technique. The inclusion criteria were caregivers between 18 to 65 years of age, from both genders, who had been providing care for patients with BTM for at least six months. 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 applying the structured clinical interview for disorders (SCID) of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5).[13] The Urdu version of the hospital anxiety and depression scale (HADS), a cross-culturally validated rating scale, 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 of both subscales containing 7 items, scored on a 4-point Likert scale (0-3), 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

Ethical approval was obtained from the ethical research board/institutional research board, No: 1/1-R/Estt 5283 on 11th June 2024. Written informed consent was obtained from all participants following a detailed explanation of the study objectives. Caregivers were interviewed to complete the questionnaires.

Data entry and analysis were conducted using IBM SPSS version 20. 0. Descriptive statistics, including mean and standard deviation (SD), were computed for continuous variables such as age and duration of BTM diagnosis in children. Frequencies and percentages were calculated for categorical variables such as gender, marital status, level of education, monthly income, and relationship with patients. Binary logistic regression was performed to explore the important predictors of anxiety and depression, adjusting for potential confounders.

RESULTS

88 caregivers of BTM were included in the study, the mean age was 36.1 ± 11.8 years. There were 47 (53.4%) male and 41 (46.6%) female caregivers. The children with beta-thalassemia major had a mean age of 7.17 years (SD ± 4.37), and the average duration since diagnosis was 1.68 years (SD ± 2.52), ranging from one month to 11 years. When anxiety levels were grouped as normal (HADS-A < 8) versus abnormal (HADS-A ≥ 8), it was found that 50% of caregivers reported abnormal levels of anxiety. Similarly, 38.6% of caregivers scored in the abnormal range for depression (HADS-D ≥ 8). Depression was moderate in 27 (30.7%) caregivers, mild in 24 (27.3%), normal in 31 (35.2%), and severe in 6 (6.8%).

Table 1

Logistic Regression Analysis of Factors Associated with Moderate to Severe 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

Variable	OR* (95% CI)**	p-value	aOR*** (95% CI)	p-value
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 (yrs)	1.12 (0.88 – 1.42)	0.350	1.10 (0.86 – 1.40)	0.430

Univariate and Multivariate tests applied, OR*= Odd ratio, CI**= Confidence Interval, aOR***= adjusted Odd ratio.

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 ≤50,000 PKR were found to have significantly greater odds of moderate to severe 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 summarized in Table 1.

DISCUSSION

In the current study, nearly one-third of the caregivers of children with beta-thalassemia major were found to have moderate to severe depression. Half of them reported moderate anxiety. These findings reflect a significant emotional distress among caregivers, especially in resource-limited settings such as Mekran. Similar trends were reported in studies from Bangladesh, India, and Iran, where a high proportion of caregivers experienced anxiety and depression while caring for their children with beta thalassemia major [9,16,17]. In previous studies female caregivers were more likely to experience higher levels of anxiety and depression than their male counterparts specially in previous local studies conducted in Islamabad, Rawalpindi, and Karachi [11,18], where women, particularly mothers, reported psychological burden due to the dual responsibility of caregiving and household management.

Educational status and income level were significantly associated with depression in this study. Caregivers who lacked formal education, without any writing and reading skills, or had lower monthly incomes were more likely to suffer from moderate to severe depressive symptoms. These findings are consistent with previous local studies from Karachi and Peshawar, which highlighted that illiteracy and financial constraints contribute significantly to psychological distress among caregivers of patients with chronic illnesses.[18,19]

This study adds important insights into the mental health of caregivers in the underserved areas of Mekran. The findings emphasize the need for psychological screening and support services within thalassemia care programs.

The study has several limitations. Being a single-center study with a relatively small sample size, the generalizability of the results is limited. However, this research highlights an often-overlooked caregiver population and underlines the urgent need for mental health interventions in low-resource settings. Future studies with larger, multicenter samples and mixed-method designs are recommended.

These findings highlight the need to integrate basic mental health services into thalassemia care units for the management of anxiety and depression. Routine screening and counseling for caregivers could reduce emotional strain and improve caregiving outcomes.

CONCLUSION

This study shows a significant number of caregivers suffer from psychological distress, including high levels of anxiety and depression. Limited mental health education, low monthly household income, and illiteracy were the main factors associated with depression. These findings draw attention to an often-overlooked aspect of caregiving in resource-limited regions like Mekran. Addressing psychological stress is necessary for the continuity of care provided by the caregivers to their children with beta thalassemia major. There is a clear need to integrate the basic psychological support into thalassemia care programs.

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