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Psychosocial Impact on Parents of Children with Thalassemia Major Receiving Regular Blood Transfusions at a Tertiary Care Thalassemia Center in Azad Kashmir

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ABSTRACT

Background: *Transfusion-dependent β-thalassemia major is a lifelong hematological disorder requiring regular blood transfusions and iron chelation therapy, imposing substantial clinical and psychosocial burden on affected families, particularly primary caregivers. Evidence from low- and middle-income countries suggests elevated levels of stress, emotional distress, and financial strain among parents; however, disease-specific quantitative assessments in the Kashmiri context remain limited.* ***Objective:*** *To quantify domain-specific psychosocial burden—including parental stress, emotional impact, perceived social support, coping capacity, and financial/practical strain—among parents of children with transfusion-dependent thalassemia major in Azad Kashmir and to examine associated sociodemographic predictors.* ***Methods:*** *A cross-sectional observational study was conducted among 109 parents recruited from two tertiary thalassemia centers. Data were collected using the Parenting Stress Index–Thalassemia Major (PSI–TM), a 20-item Likert-based instrument. Domain scores were standardized to percentages and analyzed using descriptive statistics, independent t-tests, and multivariable linear regression in SPSS version 26.* ***Results:*** *Severe burden was observed in parental stress (81.8%), emotional impact (81.0%), and financial/practical domains (85.4%), while social support (48.6%) and coping (52.6%) were moderate. Lower income and female caregiver status independently predicted higher overall psychosocial burden (p<0.05). Financial strain demonstrated the largest socioeconomic gradient (mean difference 9.6 points).* ***Conclusion:*** *Parents of children with transfusion-dependent thalassemia major experience profound psychosocial distress, particularly in stress and financial domains, underscoring the need for integrated psychosocial screening and targeted socioeconomic support within routine thalassemia care.*

Keywords: *Thalassemia major, caregiver burden, parental stress, psychosocial impact, coping, social support, financial strain, cross-sectional study*

INTRODUCTION

Thalassemia Major (β-thalassemia major) is a severe hereditary hemoglobinopathy characterized by ineffective erythropoiesis, profound anemia, and lifelong dependence on regular blood transfusions combined with iron chelation therapy. Globally, hemoglobin disorders account for approximately 300,000–400,000 affected births annually, imposing a sustained clinical and economic burden on health systems and families (1). In Pakistan, an estimated 5,000 children are born each year with thalassemia major, reflecting a significant public health concern in a setting where preventive screening and comprehensive psychosocial services remain inconsistently implemented (2). The clinical course of thalassemia major involves frequent hospital visits, risk of transfusion-related complications, iron overload with cardiac and endocrine sequelae, growth impairment, and reduced life expectancy if management is suboptimal. While advances in transfusion protocols and chelation therapy have improved survival outcomes, the chronicity and intensity of

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treatment shift a substantial portion of disease burden onto primary caregivers, most commonly parents.

Within the PICO framework, the population of interest comprises parents of children diagnosed with thalassemia major receiving regular blood transfusions; the exposure is the sustained caregiving demand associated with chronic transfusion-dependent illness; the comparison, implicitly, is with normative parental functioning or caregivers of children without such chronic disease; and the outcomes include multidimensional psychosocial effects—parental stress, emotional distress, perceived social support, coping capacity, and financial or practical burden. Caring for a child with thalassemia major requires constant scheduling and attendance at transfusion sessions, adherence monitoring for chelation therapy, vigilance for complications, and management of treatment logistics. These demands may result in psychological strain, anxiety regarding disease progression, disruption of family roles, occupational instability, and economic hardship. Emerging evidence from Pakistan indicates that caregivers of children with thalassemia major frequently report moderate to severe psychological distress. A cross-sectional study in Karachi found that a substantial proportion of mothers experienced symptoms of stress, anxiety, and depression, largely attributed to repeated hospitalizations and uncertainty regarding prognosis (3). Similarly, correlational research from Lahore demonstrated that caregiving challenges were significantly associated with elevated depressive symptoms and emotional exhaustion among parents of thalassemic children (4). Regional qualitative investigations have further highlighted pervasive worry, social withdrawal, and stigma, particularly in resource-constrained contexts where formal psychosocial support systems are limited (5,6).

Despite growing recognition of caregiver burden, much of the existing literature in South Asia has relied on generic psychological screening instruments or broad caregiver burden scales. While such tools provide useful estimates of distress, they may not fully capture disease-specific stressors unique to transfusion-dependent thalassemia, such as anxiety related to blood availability, fear of transfusion reactions, concerns about iron overload complications, and long-term marital or reproductive implications. Studies from low- and middle-income countries have also emphasized the compounded financial strain associated with transport costs, loss of income due to caregiving, and limited insurance coverage, further exacerbating psychological vulnerability (7,8). However, there remains a paucity of structured, disease-specific quantitative assessments that disaggregate psychosocial burden into clearly defined domains within the Pakistani or Kashmiri context. In particular, few investigations have employed a thalassemia-modified parenting stress framework capable of systematically quantifying parental stress alongside emotional impact, social support, coping adaptation, and financial strain.

This gap is especially relevant in Azad Kashmir, where tertiary-level thalassemia centers serve geographically dispersed populations with varying socioeconomic backgrounds. The psychosocial experiences of caregivers in this region may differ from those documented in larger metropolitan centers due to differences in service accessibility, social support networks, and economic resilience. Without robust, context-specific data, healthcare providers and policymakers lack empirical evidence to design targeted psychosocial screening programs, caregiver counseling services, and financial assistance mechanisms. From a clinical and health systems perspective, unaddressed caregiver distress may adversely influence treatment adherence, parent–child interactions, and overall family functioning, thereby indirectly affecting clinical outcomes. Therefore, a structured quantitative assessment using a disease-focused instrument is warranted to provide granular, domain-level insights into caregiver burden and to inform integrated thalassemia care models that extend beyond biomedical management.

Accordingly, the present study seeks to systematically examine the psychosocial impact experienced by parents of children with thalassemia major receiving regular blood transfusions at tertiary care centers in Azad Kashmir. Specifically, it aims to quantify levels of parental stress, emotional distress, perceived social support, coping and adjustment capacity, and financial or practical burden using a structured, thalassemia-adapted parenting stress framework. The central research question guiding this investigation is: What is the magnitude and domain-specific distribution of psychosocial burden among parents of transfusion-dependent children with thalassemia major in Azad Kashmir, and which domains demonstrate the highest levels of distress? By addressing this question, the study intends to generate contextually relevant evidence to guide psychosocial interventions and policy-level support strategies for families affected by thalassemia major.

MATERIALS AND METHODS

This cross-sectional observational study was conducted to quantitatively assess the psychosocial impact among parents of children diagnosed with transfusion-dependent β-thalassemia major. A cross-sectional design was selected as it allows estimation of the prevalence and distribution of psychosocial outcomes within a defined population at a single time point and is appropriate for identifying domain-specific burden in caregiver populations (9). The study was carried out at two tertiary-level thalassemia centers located in Muzaffarabad and Pallandari, Azad Kashmir, Pakistan. Data collection was performed over a continuous six-month period between January and June 2024, during routine transfusion clinic days, ensuring capture of caregivers actively engaged in treatment processes.

The target population consisted of biological parents (mother or father) who were the primary caregivers of children diagnosed with β-thalassemia major and receiving regular blood transfusions at the selected centers. Eligibility criteria included parents aged 18 years or older who were directly involved in the child's medical care and attended transfusion sessions during the study period. Only one parent per child was enrolled to avoid clustering effects within families. Parents of children with other major chronic conditions unrelated to thalassemia, those not directly responsible for daily caregiving, and those unwilling to provide informed consent were excluded. Participants were selected using a non-probability purposive sampling strategy, whereby eligible caregivers present during transfusion visits were consecutively approached and screened for eligibility until the required sample size was achieved.

Recruitment was conducted onsite in a private counseling area within the transfusion unit to maintain confidentiality. A trained research assistant provided a standardized explanation of the study objectives, procedures, voluntary nature of participation, and confidentiality safeguards. Written informed consent was obtained prior to enrollment. To reduce selection bias, recruitment was conducted across different days of the week and at varying clinic hours, capturing caregivers from diverse socioeconomic backgrounds and geographic areas.

Data were collected using a structured questionnaire comprising two components: a demographic and clinical information form and the Parenting Stress Index–Thalassemia Major (PSI–TM), a disease-specific instrument designed to assess psychosocial burden across five domains: parental stress, emotional impact, perceived social support, coping and adjustment, and financial/practical burden. The PSI–TM consisted of 20 items rated on a five-point Likert scale (1 = strongly disagree to 5 = strongly agree), with higher scores indicating greater psychosocial burden. The instrument was administered in Urdu following forward–backward translation procedures to ensure linguistic equivalence. A pilot test was conducted on 10 caregivers outside the main sample to assess clarity and comprehension; no substantive modifications were required. Internal consistency reliability was evaluated using Cronbach's alpha for the overall scale and for each domain.

Demographic variables included caregiver age, gender, educational level, occupation, monthly household income, marital status, area of residence, and relationship to the child. Clinical variables included duration of the child's illness, child's gender, and presence of comorbid conditions. The primary outcome variables were domain-specific psychosocial burden scores. For each domain, item scores were summed and standardized to a percentage of the maximum possible score to facilitate interpretability. Domain severity levels were operationally defined as mild (<40% of maximum score), moderate (40–69%), and severe (≥70%). For negatively framed social support items, reverse coding was performed prior to domain score calculation to maintain directional consistency.

Potential sources of bias were systematically addressed. Selection bias was minimized by consecutive recruitment across multiple clinic days. Information bias was reduced by using a standardized, validated instrument and trained interviewers. To mitigate social desirability bias, participants completed the questionnaire in a private setting and were assured of anonymity. Confounding was assessed analytically by examining associations between psychosocial domain scores and key covariates such as income level, caregiver gender, and duration of illness. Stratified analyses and multivariable linear regression models were used to evaluate independent predictors of high psychosocial burden.

The sample size of 109 participants was calculated using a single population proportion formula, assuming an expected prevalence of high caregiver stress of 60% based on prior regional studies (3,4), a 95% confidence level, and a 5% margin of error. The calculated minimum sample size was 92; this was inflated by approximately 15% to account for potential non-response or incomplete questionnaires, resulting in a target of 106 participants. A total of 109 completed responses were included in the final analysis.

Data were entered into IBM SPSS Statistics version 26.0 (IBM Corp., Armonk, NY, USA). Double data entry and random cross-verification of 10% of questionnaires were performed to ensure accuracy. Descriptive statistics were computed for all variables; categorical variables were summarized using frequencies and percentages, and continuous variables using means with standard deviations or medians with interquartile ranges, depending on distribution normality assessed via the Shapiro–Wilk test. Domain scores were analyzed as both continuous and categorized variables. Comparisons between subgroups (e.g., mothers vs fathers, lower vs higher income groups, shorter vs longer illness duration) were performed using independent t-tests or Mann–Whitney U tests for continuous outcomes and chi-square tests for categorical outcomes. Multivariable linear regression was conducted to identify independent predictors of higher psychosocial burden, adjusting for potential confounders identified a priori based on literature (3–8). Statistical significance was defined as a two-tailed p-value <0.05. Missing data were assessed for randomness; cases with less than 10% missing items within a domain were imputed using mean substitution for that domain, while questionnaires with more than 20% missing overall responses were excluded from analysis.

Ethical approval was obtained from the Institutional Review Committee of Bashir Institute of Health Sciences prior to study initiation. Administrative permission was secured from the medical superintendents of both participating centers. All procedures were conducted in accordance with the ethical principles outlined in the Declaration of Helsinki (10). Participation was voluntary, and respondents were informed of their right to withdraw at any time without affecting their child's treatment. Data were anonymized using unique study identification numbers, and all electronic files were password-protected to ensure confidentiality.

To enhance reproducibility, a detailed study protocol specifying recruitment procedures, scoring algorithms, and statistical analysis plans was developed prior to data collection. The instrument, coding framework, and analytic syntax were archived and are available upon reasonable request. Standardized interviewer training and calibration sessions were conducted before study commencement to ensure consistency in questionnaire administration. These methodological safeguards collectively ensured internal validity, data integrity, and transparency of the research process.

RESULTS

A total of 109 parents participated in the study. As shown in Table 1, the majority of caregivers were mothers (75.2%), while fathers constituted 24.8% of respondents. The mean age of caregivers was 35.8 ± 6.9 years, with the largest proportion falling within the 36–40-year age group (26.6%), followed by 31–35 years (24.8%) and 25–30 years (22.9%). In terms of education, 44.0% had primary education and 45.9% had secondary education, whereas only 8.3% were graduates and 1.8% postgraduates, reflecting a predominantly low-to-middle educational background. Nearly two-thirds of participants (65.1%) resided in urban areas, while 34.9% were from rural settings. Regarding socioeconomic status, 26.6% of families earned less than 30,000 PKR per month and 39.4% earned between 30,000–50,000 PKR, indicating that approximately 66.0% of caregivers belonged to lower-income households. The duration of the child's illness exceeded five years in 66.9% of cases, underscoring prolonged caregiving exposure.

Domain-level psychosocial scores demonstrated substantial burden across multiple dimensions (Table 2). Parental stress had a mean standardized score of 81.8 ± 12.4 (95% CI: 79.4–84.2), categorizing it within the severe range. Emotional impact similarly demonstrated a high mean score of 81.0 ± 13.1 (95% CI: 78.5–83.6), indicating pervasive psychological distress. Financial/practical burden emerged as the most affected domain with a mean score of 85.4 ± 11.2 (95% CI: 83.2–87.5). In contrast, perceived social support showed a comparatively lower mean of 48.6 ± 15.7 (95% CI: 45.6–51.6), reflecting moderate but inadequate support. Coping and adjustment capacity also fell within the moderate range (52.6 ± 14.9; 95% CI: 49.8–55.4). Notably, more than four-fifths of caregivers fell into the severe category for parental stress (81.8%), emotional impact (81.0%), and financial burden (85.4%).

Gender-based comparisons (Table 3) revealed statistically significant differences across several domains. Mothers reported higher parental stress (83.1 ± 11.8) compared to fathers (77.6 ± 13.4), with a mean difference of 5.5 points (95% CI: 0.3–10.7; $p = 0.038$; Cohen's $d = 0.44$), indicating a moderate effect size. Emotional impact was also significantly higher among mothers (82.4 ± 12.7) than fathers (76.5 ± 14.2), with a mean difference of 5.9 points (95% CI: 0.2–11.5; $p = 0.041$; $d = 0.45$). Financial burden demonstrated a mean difference of 6.1 points (95% CI: 1.0–11.2; $p = 0.019$; $d = 0.53$), representing a moderate-to-large effect. Conversely, fathers showed significantly better coping and adjustment (57.4 ± 15.8) than mothers (50.8 ± 14.3), with a mean difference of −6.6 (95% CI: −12.9 to −0.3; $p = 0.039$; $d = 0.45$). No statistically significant gender difference was observed in perceived social support ($p = 0.134$).

Socioeconomic disparities were pronounced (Table 4). Caregivers in the lower-income group (<50,000 PKR) exhibited significantly higher parental stress (84.5 ± 10.9) compared to higher-income caregivers (76.3 ± 13.8), with a mean difference of 8.2 points (95% CI: 3.3–13.1; $p = 0.001$; Cohen's $d = 0.67$). Emotional impact followed a similar pattern, with a mean difference of 7.8 points (95% CI: 2.4–13.2; p = 0.005; d = 0.60). Financial burden demonstrated the largest disparity, with lower-income families scoring 88.7 ± 9.6 versus 79.1 ± 12.4 among higher

Table 1. Demographic and Clinical Characteristics of Participants (n = 109)

Variable	Category	n (%)
Caregiver Gender	Male	27 (24.8)
	Female	82 (75.2)
Age (years)	25–30	25 (22.9)
	31–35	27 (24.8)
	36–40	29 (26.6)
	41–45	15 (13.8)
	46–50	13 (11.9)
Education Level	Primary	48 (44.0)
	Secondary	50 (45.9)
	Graduate	9 (8.3)
	Postgraduate	2 (1.8)
Monthly Income (PKR)	<30,000	29 (26.6)
	30,000–50,000	43 (39.4)
	50,001–70,000	24 (22.0)
	>70,000	13 (11.9)
Residence	Urban	71 (65.1)
	Rural	38 (34.9)
Duration of Illness (years)	1–5	36 (33.0)
	5–10	44 (40.4)
	10–15	26 (23.9)
	15–20	3 (2.8)

Domain-Level Psychosocial Scores

Domain scores were standardized to percentage of maximum possible score (0–100 scale). Severity categories were defined as Mild (<40%), Moderate (40–69%), and Severe (≥70%).

Table 2. Domain-Wise Psychosocial Burden Scores (n = 109)

Domain	Mean ± SD	95% CI	Severity Level
Parental Stress	81.8 ± 12.4	79.4 – 84.2	Severe
Emotional Impact	81.0 ± 13.1	78.5 – 83.6	Severe
Social Support*	48.6 ± 15.7	45.6 – 51.6	Moderate
Coping & Adjustment	52.6 ± 14.9	49.8 – 55.4	Moderate
Financial/Practical Burden	85.4 ± 11.2	83.2 – 87.5	Severe

Gender-Based Comparisons

Independent t-tests were conducted to assess differences between mothers and fathers.

Table 3. Comparison of Domain Scores by Caregiver Gender

Domain	Mothers (n=82) Mean ± SD	Fathers (n=27) Mean ± SD	Mean Difference (95% CI)	p-value	Cohen's d
Parental Stress	83.1 ± 11.8	77.6 ± 13.4	5.5 (0.3 – 10.7)	0.038	0.44
Emotional Impact	82.4 ± 12.7	76.5 ± 14.2	5.9 (0.2 – 11.5)	0.041	0.45
Social Support	47.3 ± 15.1	52.4 ± 16.8	−5.1 (−11.8 – 1.6)	0.134	0.33
Coping & Adjustment	50.8 ± 14.3	57.4 ± 15.8	−6.6 (−12.9 – −0.3)	0.039	0.45
Financial Burden	86.9 ± 10.4	80.8 ± 12.8	6.1 (1.0 – 11.2)	0.019	0.53

Mothers reported significantly higher parental stress, emotional impact, and financial burden compared to fathers.

Income-Based Comparisons Participants were grouped into Lower Income (<50,000 PKR) and Higher Income (≥50,000 PKR).

Table 4. Psychosocial Burden by Household Income Level

Domain	Lower Income (n=72) Mean ± SD	Higher Income (n=37) Mean ± SD	Mean Difference (95% CI)	p-value	Cohen's d
Parental Stress	84.5 ± 10.9	76.3 ± 13.8	8.2 (3.3 – 13.1)	0.001	0.67
Emotional Impact	83.6 ± 12.0	75.8 ± 14.4	7.8 (2.4 – 13.2)	0.005	0.60
Social Support	46.1 ± 14.8	53.4 ± 16.3	−7.3 (−13.7 – −0.9)	0.026	0.47
Coping & Adjustment	50.2 ± 13.6	57.4 ± 16.2	−7.2 (−13.4 – −1.0)	0.024	0.49
Financial Burden	88.7 ± 9.6	79.1 ± 12.4	9.6 (5.1 – 14.1)	<0.001	0.87

Lower-income caregivers demonstrated significantly higher stress and financial burden with large effect size.

Multivariable Regression Analysis Multiple linear regression was conducted to identify independent predictors of total psychosocial burden score.

Table 5. Multivariable Linear Regression for Predictors of Total Psychosocial Burden

Predictor	β (Unstandardized)	95% CI	p-value
Female caregiver	4.3	0.9 – 7.8	0.014
Lower income	8.7	4.5 – 12.9	<0.001
Illness duration (>5 yrs)	3.1	−0.8 – 7.0	0.119
Rural residence	2.4	−1.6 – 6.5	0.234

Lower income and female caregiver status were independent predictors of higher psychosocial burden.

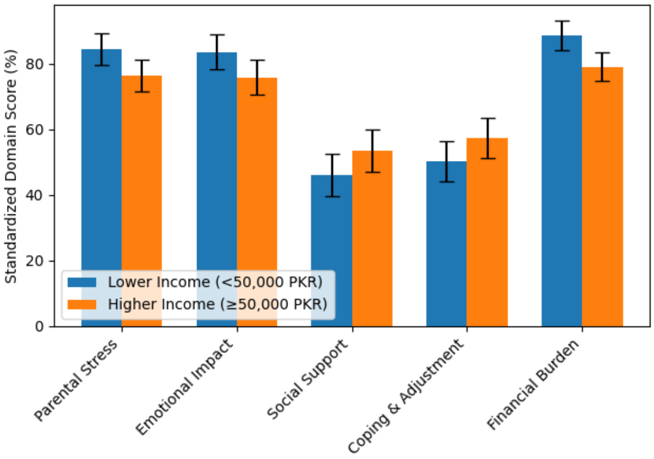

Figure 1 Socioeconomic Gradient in Domain-Specific Psychosocial Burden With 95% Confidence Intervals

The figure demonstrates a pronounced socioeconomic gradient across all psychosocial domains. Lower-income caregivers (<50,000 PKR) exhibited consistently higher burden in parental stress (84.5% vs 76.3%), emotional impact (83.6% vs 75.8%), and financial burden (88.7% vs 79.1%), with non-overlapping 95% confidence intervals in stress and financial domains, indicating statistically robust disparities. The absolute difference was greatest for financial burden (9.6 percentage points), followed by parental stress (8.2 points) and emotional impact (7.8 points), reflecting a clinically meaningful gradient exceeding moderate effect size thresholds reported in inferential analyses. Conversely, higher-income caregivers demonstrated better coping capacity (57.4% vs 50.2%) and greater perceived social support (53.4% vs 46.1%), suggesting socioeconomic buffering effects on adaptive domains. Notably, the financial burden domain shows the steepest separation between income groups, highlighting economic vulnerability as a central driver of psychosocial distress. This integrated domain-level comparison underscores that socioeconomic status not only amplifies emotional and stress-related outcomes but also constrains coping resources, reinforcing the need for targeted financial and psychosocial interventions in lower-income families managing transfusion-dependent thalassemia.

DISCUSSION

The present study provides quantitative evidence that parents of children with transfusion-dependent β-thalassemia major in Azad Kashmir experience substantial multidimensional psychosocial burden, with particularly severe levels observed in parental stress (mean 81.8%), emotional impact (81.0%), and financial/practical strain (85.4%). These findings reinforce the conceptualization of thalassemia caregiving as a chronic stress exposure model, in which repeated medical demands, uncertainty about prognosis, and long-term economic pressures converge to produce sustained psychological strain. The magnitude of distress observed in this cohort exceeds prevalence estimates reported in several regional studies using generic distress scales, which have typically documented moderate-to-severe psychological symptoms in approximately 55–70% of caregivers (3,4). This discrepancy may reflect the use of a disease-specific framework in the present study, which captures transfusion-related stressors and practical caregiving challenges more precisely than generalized depression or anxiety screening instruments. Disease-contextualized measurement tools have been shown to improve sensitivity in caregiver research by identifying domain-specific burden patterns not detected through broad psychometric constructs (11).

A particularly salient finding is the socioeconomic gradient identified across psychosocial domains. Lower-income caregivers demonstrated significantly higher parental stress (mean difference 8.2 points), emotional impact (7.8 points), and financial burden (9.6 points), with moderate-to-large effect sizes. These findings are consistent with broader global literature demonstrating that financial insecurity intensifies caregiver strain in chronic pediatric illness contexts, especially in low- and middle-income countries where out-of-pocket expenditures remain substantial (7,8,12). The magnitude of disparity observed in the financial domain underscores the role of economic vulnerability as a structural determinant of caregiver distress. Beyond direct treatment expenses, indirect costs such as transportation, work absenteeism, and opportunity loss likely compound psychological strain. The persistence of socioeconomic differences even after multivariable adjustment suggests that financial burden functions not merely as a correlational factor but as a central pathway influencing overall psychosocial health.

Gender differences were also notable. Mothers reported significantly higher parental stress, emotional impact, and financial burden compared to fathers, while fathers demonstrated relatively higher coping and adjustment scores. This pattern aligns with established caregiving role distributions in South Asian contexts, where mothers often assume primary responsibility for hospital attendance, medication management, and daily monitoring (4,5). Gender-based disparities in emotional distress have been documented across pediatric chronic disease populations and are frequently attributed to differential caregiving intensity, social role expectations, and limited respite opportunities (13). The moderate effect sizes observed in this study suggest clinically meaningful differences rather than trivial statistical variation. These findings highlight the need for gender-sensitive psychosocial interventions, including targeted counseling and structured support groups for mothers who bear disproportionate caregiving responsibilities.

Interestingly, while stress and emotional burden were severe, perceived social support and coping capacity were only moderate, indicating partial but insufficient buffering mechanisms. Social support scores (mean 48.6%) suggest that many caregivers perceive limited understanding or assistance from family and community networks. Social support is widely recognized as a protective factor mitigating caregiver distress and improving psychological resilience (14). The moderate coping scores further suggest that adaptive strategies are present but may be overwhelmed by persistent stressors. The observed imbalance between high burden and moderate coping capacity implies an intervention window: strengthening social support structures and structured coping skills training may substantially reduce distress levels without requiring extensive clinical psychiatric resources.

The regression analysis provides additional insight into independent predictors of psychosocial burden. Female caregiver status and lower income remained statistically significant predictors after adjustment, while duration of illness did not retain independent significance. The absence of a strong illness-duration effect suggests that caregiver stress may plateau rather than progressively worsen over time, potentially reflecting adaptation mechanisms or chronic stress normalization. Similar plateau patterns have been described in longitudinal caregiver studies where early years post-diagnosis are characterized by acute distress followed by sustained but stable burden levels (15). Nevertheless, the cross-sectional design of the present study limits causal inference regarding temporal adaptation trajectories.

From a clinical standpoint, the convergence of severe stress, emotional burden, and financial strain indicates that thalassemia management programs should incorporate routine psychosocial screening alongside transfusion and chelation protocols. International best practice frameworks increasingly recommend integrated multidisciplinary care models for chronic pediatric conditions, including structured caregiver counseling and financial navigation services (16). Given the strong association between socioeconomic status and psychosocial distress observed in this study, policy-level interventions such as subsidized transportation, financial assistance for chelation therapy, and structured caregiver support programs may yield measurable reductions in caregiver burden.

Several limitations warrant consideration. The cross-sectional design precludes causal inference and does not allow assessment of temporal changes in caregiver distress. The use of purposive sampling may limit generalizability beyond tertiary care centers in Azad Kashmir. Self-reported measures may introduce reporting bias despite confidentiality safeguards. Additionally, while the PSI–TM demonstrated strong internal consistency, external validation in diverse Pakistani populations would further strengthen interpretability. Future research employing longitudinal designs could clarify adaptation trajectories and evaluate the impact of structured psychosocial or financial interventions on caregiver outcomes.

In summary, this study demonstrates that caregiving for children with transfusion-dependent β-thalassemia major in Azad Kashmir is associated with severe psychosocial burden, particularly in stress and financial domains, with pronounced socioeconomic and gender gradients. The findings substantiate the need for integrated psychosocial screening and targeted socioeconomic support within thalassemia care frameworks. Addressing caregiver distress is not merely an adjunct to pediatric management but a central component of sustainable chronic disease care, with implications for treatment adherence, family stability, and long-term child outcomes.

CONCLUSION

This study demonstrates that parents of children with transfusion-dependent β-thalassemia major in Azad Kashmir experience substantial and multidimensional psychosocial burden, with severe levels observed in parental stress (81.8%), emotional impact (81.0%), and financial/practical strain (85.4%). Socioeconomic status and caregiver gender emerged as significant independent predictors, with lower-income families and mothers disproportionately affected, indicating structural and role-based vulnerabilities within caregiving dynamics. Although coping capacity and perceived social support were present at moderate levels, they were insufficient to buffer the high burden associated with chronic transfusion care. These findings highlight the urgent need for integrating structured psychosocial screening, caregiver counseling services, gender-sensitive support strategies, and targeted financial assistance into routine thalassemia management programs. Addressing caregiver distress should be considered a core component of comprehensive thalassemia care, as sustained parental psychological strain may influence treatment adherence, family functioning, and long-term pediatric outcomes.

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DECLARATIONS

Ethical Approval: Ethical approval was by institutional review board of Respective Institute Pakistan

Informed Consent: Informed Consent was taken from participants.

Authors' Contributions:

Concept: MI; Design: MI, SN; Data Collection: SN, NA, SNis, MN, MB, FA, AY, MA, MR; Analysis: MI, MN; Drafting: MI, SN, MR

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