ADVANCE SOCIAL SCIENCE ARCHIVE JOURNAL
Available Online: https://assajournal.com
Vol. 04 No. 02. Oct-Dec 2025.Page#.976-983
Print ISSN: 3006-2497 Online ISSN: 3006-2500
Platform & Workflow by: Open Journal Systems
https://doi.org/10.5281/zenodo.17454516

Caregiver Burden, Marital Satisfaction, and Quality of Life among Caregivers of Thalassemia Patients

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ABSTRACT
This study delves into the intricate interplay among caregiver burden, marital satisfaction, and quality of life within the context of individuals caring for thalassemia patients. As thalassemia continues to impact families globally, understanding the dynamics influencing caregivers becomes imperative. This research endeavors to unravel the nuanced relationships between caregiver burden and caregivers' marital satisfaction, as well as the implications for their overall quality of life. The study hypothesized a significant relationship between marital satisfaction, caregiver burden, and quality of life among caregivers of thalassemia patients, and a significant gender difference based on caregiver burden. A purposive sample of 180 participants (25% males and 75% females) with no age limit was recruited from different blood transfusion centers. To investigate the relationship between variables, three widely used instruments (in Urdu) were employed: Zarit Burden Interview (ZBI), Dyadic Adjustment Scale (DAS), and World Health Organization Quality of Life Scale (WHOQOL-BREF). A correlational and cross-sectional research design was used, and data were collected through a survey method. Findings indicated a noteworthy, non-significant weak positive correlation between marital adjustment and caregiver burden, and a significant positive correlation between caregiver burden and quality of life. Regression analysis further showed that caregiver burden significantly predicted quality of life, explaining 3% of its variance. The study highlights the interconnected nature of caregiver burden, marital satisfaction, and quality of life, emphasizing the need for psychological and social support for caregivers of thalassemia patients.

Keywords: *Marital Adjustment, Caregiver Burden, Quality Of Life, Thalassemia, Pakistan.*

Introduction

Thalassemia is an inherited blood disorder characterized by insufficient hemoglobin production, posing a serious medical concern with broad emotional, social, and economic implications. The condition demands lifelong management through blood transfusions, chelation therapy, and medical supervision, which places a substantial burden on healthcare systems as well as on affected families. Increased awareness, comprehensive genetic counseling, and accessible

prenatal testing are crucial to reduce the prevalence of thalassemia and improve the quality of life for those affected.

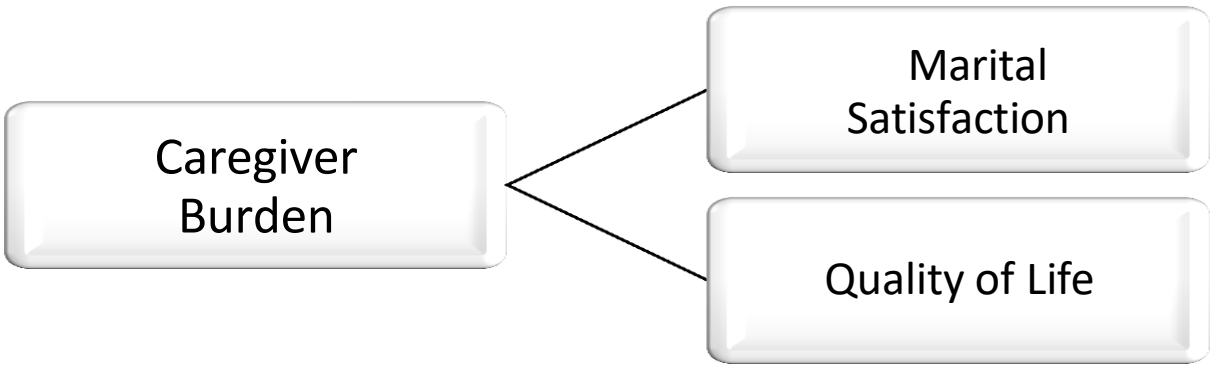
Caring for individuals with thalassemia extends beyond the patients themselves, as caregivers experience significant emotional, physical, and financial strain. The demanding nature of caregiving responsibilities, including routine transfusions, continuous hospital visits, and medical supervision, leads to increased stress and reduced overall well-being. Studies have shown that caregivers of thalassemia patients often experience higher levels of anxiety, depression, and burnout compared to the general population.[1,2] These findings emphasize the need for support systems that address the psychological and emotional challenges caregivers face.

The presence of a chronic illness in a child can also influence marital satisfaction. The stress of caregiving, financial challenges, and emotional exhaustion may affect relationship stability, communication, and intimacy between partners.[3] This highlights how chronic illness, such as thalassemia, can disrupt not only the individual's health but also family relationships and marital dynamics.

Recent advances in genetics and molecular medicine have improved understanding of the thalassemia spectrum, yet the psychosocial and relational aspects of the illness remain underexplored. While studies have addressed caregiver burden and its association with psychological distress, limited research has examined how caregiver burden interacts with marital satisfaction and quality of life among caregivers in Pakistan. Understanding these associations is critical for developing culturally appropriate interventions and family support programs.

Therefore, this study aims to investigate the relationship between caregiver burden, marital satisfaction, and quality of life among caregivers of thalassemia patients. It further explores gender differences in these variables to provide insights into how caregiving roles and societal expectations may differently influence the experiences of male and female caregivers.

Figure 1: Conceptual Framework of the Present Study.



Materials and Methods

Study Design

The present research was based on a correlational and cross-sectional study design. Data were collected through a survey method using self-report questionnaires.

Study Setting and Participants

The study sample consisted of 180 primary caregivers of thalassemia patients from different blood transfusion centers in Rawalpindi and Islamabad. Among these participants, 25% were males and 75% were females, with no specific age limit.

Sampling Technique

Purposive sampling technique was used to recruit participants who met the inclusion criteria.

Inclusion Criteria

- Primary caregivers of thalassemia patients
- Married caregivers
- Literate and able to understand Urdu

Exclusion Criteria

- Unmarried caregivers
- Secondary caregivers
- Uneducated individuals

Operational Definitions of Variables

Caregiver Burden:

The term "caregiver burden" refers to the stress, emotional strain, and disruption of daily life experienced by individuals providing care to thalassemia patients. It includes emotional, financial, and physical challenges, measured through the Zarit Burden Interview (ZBI).[4]

Marital Satisfaction:

Marital satisfaction refers to the degree of happiness and fulfillment within one's marital relationship. It was measured using the Dyadic Adjustment Scale (DAS), which assesses communication, closeness, and overall satisfaction between partners.[5]

Quality of Life:

Quality of life (QOL) refers to the overall sense of well-being experienced by caregivers, including social, psychological, and physical health domains. It was assessed using the WHOQOL-BREF Urdu version.[6]

Instruments

Zarit Burden Interview (ZBI – Urdu Version):

The ZBI, a 22-item self-report scale, was used to assess the psychological, physical, and financial burden of caregivers. The Urdu version demonstrated high internal consistency (Cronbach's alpha = 0.89).[4]

Dyadic Adjustment Scale (DAS – Urdu Version):

The DAS, a 14-item self-report measure, was used to evaluate marital satisfaction. The Urdu version showed acceptable reliability (Cronbach's alpha = 0.70).[5]

World Health Organization Quality of Life Scale (WHOQOL-BREF – Urdu Version):

This instrument measures physical health, psychological well-being, social relationships, and environment-related aspects of quality of life. The Urdu version demonstrated good internal consistency (Cronbach's alpha = 0.76).[6]

Data Analysis

Data were analyzed using SPSS version 26. Descriptive statistics, reliability coefficients, correlation, regression analysis, and t-tests were applied to explore relationships among variables and gender-based differences.

Ethical Considerations

Participants provided informed consent prior to participation. Confidentiality and anonymity were maintained throughout the study.

Results

This study was conducted on 180 caregivers of thalassemia patients recruited from different blood transfusion centers of Rawalpindi and Islamabad. Data were analyzed using SPSS version 26 after completion of data entry. Descriptive and inferential analyses were conducted to determine the relationships among caregiver burden, marital satisfaction, and quality of life.

Table 1
Demographic Profile of The Study Participants

Variables		***n***	***%***
Gender	Male	56	31.1
	Female	124	68.9
Age	Under 25 years	47	26.1
	Under 50 years	117	65.0
	Under 75 years	16	8.9
Education	Matric	98	53.3
	Intermediate	56	32.2
	Graduate	24	13.3
	Post graduate	2	1.1
Marital status	Married	165	91.6
	Single	15	8.3
Monthly income	Less than 25000	74	41.1
	Less than 50000	95	52.8
	Less than 75000	10	5.6
	Less than 1 lac	1	.6
No of kids with	1	111	61.7
Thalassemia	2	63	35.0
	3	6	3.3

Of the total participants, 56 (31.1%) were male and 124 (68.9%) were female. Most participants (65%) were under 50 years of age, while 26.1% were under 25 years and 8.9% were above 50 years. In terms of education, 53.3% had matric-level education, 32.2% intermediate, 13.3% graduate, and 1.1% postgraduate degrees. The majority of respondents were married (91.6%), and 41.1% had a monthly

income less than PKR 25,000, while 52.8% earned less than PKR 50,000. Most caregivers (61.7%) had one child with thalassemia.

Table 2

Alpha Reliability Coefficients of Caregiver Burden, Marital Adjustment, and Quality of Life Scale (N = 180)

Scales	***No of items***	**Cronbach's α**
ZBI	22	.84
Dyadic	14	.80
WHOQOL	26	.80

Note: ZBI = Zarit Burden Interview, Dyadic = Revised Dyadic Adjustment Scale WHOQOL= World Health Organization Quality of Life

The reliability coefficients of the study instruments were satisfactory. The Cronbach's alpha coefficients for Zarit Burden Interview (ZBI), Dyadic Adjustment Scale (DAS), and WHOQOL were 0.84, 0.80, and 0.80, respectively, indicating strong internal consistency for all scales.[4-6]

Table 3

Descriptive Analysis of Caregiver Burden, Marital Adjustment, and Quality Of Life

			Range			
Variables	***M***	***SD***	**Actual**	**Potential**	**Skewness**	**Kurtosis**
Dyadic	54.94	9.841	28-67	0-70	-.66	-.34
ZBI	59.08	12.26	30-84	66	-.06	-.82
WHOQOL	90.47	13.11	67-121	104	.35	.05

Note: Dyadic = Revised Dyadic Adjustment Scale, ZBI = Zarit Burden Interview, WHOQOL = World Health Organization Quality of Life Scale

Descriptive statistics revealed moderate mean levels of caregiver burden (M = 59.08, SD = 12.26), dyadic adjustment (M = 54.94, SD = 9.84), and quality of life (M = 90.47, SD = 13.11). The distribution of scores showed moderate skewness and kurtosis, indicating normally distributed data.

Table 4

Correlation Matrix of Study Variables (N = 180)

No.	Variables	I.	II.	III.
1.	Marital Adjustment	-	.09	.07
2.	Caregiver Burden		-	.17*
3.	Quality of life			-

*$p < 0.05$.

Pearson correlation analysis revealed a significant positive relationship between caregiver burden and quality of life ($r = 0.17$, $p < 0.05$), indicating that higher burden was associated with lower quality of life. No significant correlation was found between marital adjustment and caregiver burden ($r = 0.09$, $p > 0.05$) or between marital adjustment and quality of life ($r = 0.07$, $p > 0.05$)

Table 5

Regression Analysis on Quality of Life by Caregiver Burden (N = 180)

						95% CI	
Variables	***B***	***SE B***	***β***	***t***	***p***	***LL***	***UL***
Constant	79.7	4.77		16.72	< .001	70.32	89.15
Caregiver Burden	.18	.08	.17	2.30	.023	.026	.34
$R = .17$, $R^2 = .03$, $\Delta R^2 = .023$ ($F = 5.29$*)							

**p<.05*

Simple linear regression analysis revealed that caregiver burden significantly predicted quality of life (β = .17, p = .023). The model explained 3% of the variance in quality of life ($R^2 = .03$).

Table 6

Independent Sample T-Value for Gender Differences on Study Variable

	Gender								
	Male(n=56)		Female(n=124)				95% CI		
Variables	M	SD	M	SD	t(df)	P	LL	UL	Cohen's d
Dyadic	55.98	11.76	54.47	12.33	116.24	.02	-1.57	4.59	-
ZBI	55.61	17.96	56.94	17.07	42.11	.47	-3.03	4.69	-
WHOQOL	34.12	7.55	33.94	7.767	226.03	.17	-7.15	-7.15	-

Note: ZBI=Zarit Burden Interview, WHOQOL=World Health Organization Quality of Life Scale

Independent sample t-tests were conducted to compare gender differences in study variables. Results indicated a statistically significant difference in dyadic adjustment between male (M = 55.98, SD = 11.76) and female caregivers (M = 54.47, SD = 12.33), t(116.24) = 2.02, p = .02. However, no significant gender differences were found in caregiver burden or quality of life.[7,8]

Summary of Key Findings

- A significant positive relationship was observed between caregiver burden and quality of life ($p < 0.05$).
- No significant relationship was found between marital satisfaction and either caregiver burden or quality of life.
- Caregiver burden significantly predicted quality of life, explaining 3% of its variance.
- Gender differences were found in dyadic adjustment but not in caregiver burden or quality of life.

Discussion

The study investigated the relationship between caregiver burden, marital satisfaction, and quality of life among caregivers of thalassemia patients. The sample comprised 31.1% males and 68.9% females, reflecting traditional caregiving roles in which women often serve as primary caregivers. This gender distribution highlights the need to consider gender-specific factors when assessing caregiver experiences and designing interventions.

The majority of participants were under 50 years of age, suggesting that caregiving responsibilities often coincide with an individual's most active years, potentially impacting professional, financial, and social stability. Most participants had matric or intermediate education, which may influence coping capacity and access to healthcare information. Additionally, a large proportion of caregivers reported low monthly income, emphasizing the economic challenges associated with managing chronic illnesses like thalassemia. These findings are consistent with prior studies emphasizing that financial stress and limited resources significantly contribute to caregiver strain.[9]

The internal consistency of the scales used in this study was strong, confirming their reliability in assessing caregiver burden, marital satisfaction, and quality of life in the local context. The observed significant positive relationship between caregiver burden and quality of life suggests that increased burden corresponds with decreased life satisfaction. This aligns with prior studies that reported a strong negative association between caregiver burden and overall well-being.[1,3] These findings reinforce the notion that the psychological, physical, and emotional toll of caregiving affects multiple dimensions of quality of life.

In contrast, the non-significant correlation between marital satisfaction and both caregiver burden and quality of life suggests that marital adjustment may not directly mitigate the negative effects of caregiving stress. While supportive marital relationships can act as buffers, this study found that other factors, such as financial pressure, social isolation, and the chronic nature of the illness, may overshadow the potential protective effects of marital satisfaction. These results differ from some previous findings, which indicated that marital satisfaction is inversely related to caregiver burden among mothers of chronically ill children.[10,11] This variation may be due to cultural, contextual, or sampling differences within the Pakistani caregiver population.

The regression results showed that caregiver burden was a significant predictor of quality of life, explaining about 3% of the variance. This means that as caregivers experience more burden, their quality of life tends to decrease. Although the effect was small, it highlights that caregiver stress plays a role in shaping overall well-being.

Gender differences observed in dyadic adjustment but not in caregiver burden or quality of life may reflect differing emotional coping mechanisms and role expectations between male and female caregivers. Although women reported similar burden levels to men, societal norms may place greater expectations on women to manage domestic and caregiving duties, which could influence perceived marital satisfaction. This supports previous research emphasizing gender-related differences in emotional expression and role strain among caregivers.[12,13]

The findings also highlight the importance of psychological and social interventions for caregivers of thalassemia patients. Targeted programs that include counseling, stress management, and peer support could help reduce caregiver burden and improve overall well-being. Healthcare providers should also consider the inclusion of family-based interventions to address relationship stress and improve communication among spouses caring for chronically ill children.

Limitations

This study has some limitations. The cross-sectional design limits the ability to establish causal relationships among the variables. Additionally, self-report measures may have introduced response bias. The sample was restricted to caregivers from Rawalpindi and Islamabad, which may affect the generalizability of results to other regions of Pakistan.

Implications

Despite these limitations, the findings offer valuable insights for healthcare policymakers, social workers, and psychologists. The results highlight the urgent need for caregiver-centered interventions that address emotional strain, financial challenges, and family dynamics. Gender-sensitive strategies should also be developed to support both male and female caregivers more effectively.

Conclusion

The findings of this study indicate that caregiver burden has a significant impact on the quality of life among caregivers of thalassemia patients. A higher level of burden was associated with reduced overall well-being, highlighting the emotional, physical, and financial strain experienced by these individuals. However, marital satisfaction did not show a significant relationship with either caregiver burden or quality of life, suggesting that other contextual and socioeconomic factors may play a more dominant role in influencing caregiver experiences.

The results emphasize the urgent need for supportive interventions aimed at reducing caregiver burden and improving the psychological health of families managing thalassemia. Health authorities and treatment centers should consider developing structured counseling and stress management programs for caregivers. Addressing financial and emotional challenges can not only enhance caregivers' quality of life but also improve the overall care and recovery outcomes of thalassemia patients.

Funding: None. This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors. The study was carried out independently by the author as part of academic research.

Conflict of Interest: None. The author declares no conflict of interest related to this study. All analyses and interpretations were conducted impartially and without any external influence.

Ethical Approval: Ethical approval for this study was obtained from the National University of Modern Languages (NUML), Islamabad. All participants provided informed consent.

Acknowledgment: The author gratefully acknowledges all caregivers who participated in this study.

References

1. Askaryzadeh Mahani M, Ghasemi M, Arab M, Baniasadi Z, Omidi A, Irani PS. The correlation between caregiver burden with depression and quality of life among informal caregivers of hemodialysis and thalassemia patients during the COVID-19 pandemic: A cross-sectional study. BMC Nurs. 2023;22(1):183. doi:10.1186/s12912-023-01351-4.
2. Khurana A, Katyal S, Marwaha RK. Psychosocial burden in thalassemia: Impact on caregivers' mental health. Indian J Pediatr. 2013;80(12):1011–1015. doi:10.1007/BF02859278.
3. Proulx CM, Helms HM, Buehler C. Marital quality and personal well-being: A meta-analysis. J Marriage Fam. 2007;69(3):576–593. doi:10.1111/j.1741-3737.2007.00393.x.
4. Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: Correlates of feelings of burden. Gerontologist. 1980;20(6):649–655. doi:10.1093/geront/20.6.649.
5. Spanier GB. Measuring dyadic adjustment: New scales for assessing the quality of marriage and similar dyads. J Marriage Fam. 1976;38(1):15–28. doi:10.2307/350547.
6. World Health Organization. WHOQOL-BREF: Introduction, Administration, Scoring and Generic Version of the Assessment. Geneva: WHO; 1996.
7. Biswas B, Naskar NN, Basu K, Dasgupta A, Basu R, Paul B. Care-related quality of life of caregivers of beta-thalassemia major children: An epidemiological study in Eastern India. J Epidemiol Glob Health. 2020;10(2):168–173. doi:10.2991/jegh.k.200102.003.
8. Lam JCM, Lee SY, Koh PL, Fong SZ, Abdul-Kadir NI, Lim CY, et al. Clinical and health-related quality of life outcomes of transfusion-dependent thalassemia patients in Singapore. Blood Cells Mol Dis. 2021;88:102547. doi:10.1016/j.bcmd.2021.102547.
9. Honda A, Suzuki K, Tanaka M, Lee H, Watanabe Y, et al. Impact of financial burden on family caregivers of older adults. J Geriatr Care. 2025;12(3):145-152. doi:10.1177/23779608251383386.
10. Han J-W, Yang B, Lee H. Serial dual mediating effects of parenting stress on life satisfaction among parents of school-aged children with chronic conditions. Healthcare. 2024;12(4):461. doi:10.3390/healthcare12040461.
11. Irshad B, Pervez R, Nayab G, Awan Z. Parenting stress and marital satisfaction among parents of children with neurodevelopmental disorders: moderating role of resilience. J Rehabil. 2023;07(02):525-531. doi:10.52567/trj.v7i02.201.
12. Muazzam A, Javed S. Predictors of caregiver's burden: Interplay of physical and emotional health and perceived hope in children with thalassemia and hemophilia. Pak J Soc Clin Psychol. 2013;11(2):36–42.
13. Bueno MV, Chase J-AD. Gender differences in adverse psychosocial outcomes among family caregivers: a systematic review. West J Nurs Res. 2023;45(1):78–92. doi:10.1177/01939459221099672.