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Article:	Exploring Stress, Psychological Well-being, and Quality of Life among Caregivers of Thalassemia Children
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ABSTRACT

This cross-sectional correlational study explored the relationship of stress, psychological wellbeing, and quality of life among caregivers of children with thalassemia. The sample of one hundred and fifty participants were selected using convenient sampling from Sundas Foundation in Gujrat and Gujranwala cities. The data was collected by using three separate measures on Perceived Stress Scale (Kausar et al., 2019), Ryff Scale Psychological Wellbeing (Ryff, 1989), and Singapore Caregiver Quality of Life Scale (SCQOLS; Cheung et al. 2019). The results revealed the significant negative correlation of stress and well-being and quality of life among caregivers. Moreover, the findings showed that psychological well-being performed as a full mediator between psychological stress and the quality of life experienced by caregivers. The study overall suggested that the caregivers of thalassemia patients can benefit greatly from interventions that target specific stressors and provide adequate support networks. These measures, by minimizing the burden on caregivers, have the potential to improve patient care quality. The findings of this study may contribute to the development of such networks, ensuring that caregivers have the support they require to carry out their demanding tasks.

Key words: Stress, psychological well-being, quality of life of caregivers of thalassemia Patients.

Introduction

These days, thalassemia is a major and grave problem worldwide. It is acknowledged that this disease is inherited and is quite common (Hussain et al., 2021). According to researches, it is a major health issue which affects 72% of 229 countries worldwide. Moreover, thalassemia affects 5.2% of the world's population, 7% of expectant mothers, and 1% of couples (Tarim & Öz, 2022). According to WHO, 5% of the global population contains thalassemia (WHO, 2006). Approximately 17% of newborns born each year possess the thalassemia gene (Modell & Darlison, 2008). Around eight million people in Pakistan are carriers of thalassemia, and 5 out of every 100 individuals suffer from the disease (Moazzam & Javed, 2013). Thalassemia is a chronic illness that affects a child's normal physiological functioning and is brought on by a genetic irregularity. Every person with thalassemia faces physical, intimate, and mental problems, as well as disruptions to their own sense of fulfilment. The most severe effects of thalassemia include financial difficulty, emotional despair, and social disturbance. These barriers can have a significant influence on the lives of people with the illness and their families (Ishaq et al. 2012).

Patients with thalassemia typically require hospitalization because the condition's management necessitates consistent normal blood transfusions in addition to iron chelation therapy. The most widely recognized physiological side effects of thalassemia incorporate fair skin, postponed adolescence and development, paleness, a broadened spleen, and expanded aversion to diseases (Galanello & Origa, 2010), alongside critical mental (e.g., wretchedness and uneasiness) trouble and psychosocial challenges (e.g., low quality of life) (Tarim & Öz, 2022). Like many other chronic illnesses, thalassemia also has a significant effect on patient's lives resulting in negative mental, physical and social consequences (Öz, 2015; Öz & Öz 2020). According to Shaligram and colleagues (2007) children having thalassemia facing many emotional challenges. Children who have thalassemia may experience severe mood changes that happen suddenly. They may have feelings of pessimism, restlessness, and anxiety one day, then optimism about the future the next. While hopelessness can make people less determined to fight the illness, optimism gives them the ability to live a more normal life (Moazzam & Javed, 2013). The studies suggested that, patients with thalassemia face a significant financial burden in addition to the medical cost of receiving supportive care because their disease is chronic and requires lifetime medication in order to be managed. It is a devastating illness that has a detrimental psychosocial impact on individuals (Wahidiyat et al., 2022; Daré et al., 2019).

The empirical evidences explored the encounters of guardians of youngsters with Thalassemia Major. The subjective phenomenological strategy was utilized to decide the guardians' encounters. The sample included 14 guardians who met the consideration measures. Individual meetings, a starting data structure, a semi-organized interview structure were utilized for information assortment. The information was examined with Colaizzi's seven step strategy. In this review, the vast majority of the guardians referenced that there is nobody around who can give social support. A few guardians expressed that they got support from their mothers or companions. A parent, both of whose youngsters were determined to have thalassemia, expressed that they need social help since the treatment days are unique and they should come to the clinic from a far off district financial issues appeared to be a widespread reason for enduring of guardians with youngsters with thalassemia since the illness requires

delayed care and treatment and successive hospitalization. It was the best issue seen, particularly among guardians in the lower financial gathering (Punaglom et al., 2019).

Inamdar et al. (2015) conducted study with caregiver of thalassemia patients. It was a cross sectional study in which they conducted thirty-five interviews and the results revealed that 60.6 % caregivers were under stress and there was no statistical difference between school-educated and college-educated caregivers with psychological burden. The study also suggested that the parents of thalassemia children requires health education and counselling support to effectively manage their stress. Likewise, guardians of kids with thalassemia have announced having a stressed outlook on their kid's actual wellbeing and future, as well as encountering expanded tension and stress connected with their providing care liabilities (Anum & Dasti, 2016).

Objectives of the Research

The goals of the research were to:

- Evaluate the general quality of life of those who provide care for people with thalassemia.
- Ascertain the connection between stress, life satisfaction, and the mental health of those who provide care for patients with thalassemia.
- Analyze the average variations in stress, education, psychological health, and quality of life among care givers of patients with thalassemia.

Hypothesis:

1. The quality of life of those who care for children with thalassemia is positively correlated with their perceived stress level.
2. The quality of life for those who care for children with thalassemia is favorably correlated with psychological well-being.
3. Stress, psychological health, and carers' quality of life are negatively correlated with each other for children with thalassemia.
4. There are average disparities in fathers' stress levels, educational attainment, and quality of life.

Method:

Sample

The cross sectional, correlation study was carried out on the caregivers of patients with thalassemia from January 24-April 24. Purposive sampling technique was used to recruit 150 parents taken from different private and government hospitals of Gujrat and Gujranwala city including organizations like Sundas foundation. Before the start of data collection, participants were told study objectives and asked for their willingness to participate in the study. Only those parents were included who were given written informed consent.

Instruments

Demographic and background information

Caregiver participants reported on their demographics, including age in years, sex (male or female), area of residence (Urban, Rural), their family system (Nuclear, Joint) educational attainment levels of both fathers and mothers (Matriculation, Intermediate, Bachelors and Masters) and their socio economic status (high, middle, low).

Perceived stress scale

Perceived stress scale was a 32 item scale developed by Kausar et al. (2019). It has 7 subscales used to determine primary and secondary stressors. The response options were ranging from 5-1 (strongly agree- strongly disagree). High scores on Perceived stress scale pointed out high level of stress as for as low scores pointed out low level of stress.

The Ryff's psychological well-being scale

The scale consisted of 42 items which measured different aspects of well-being and happiness (Ryff, 1989; Ryff & Keyes, 1995). Participants responded each items on 6 point Likert scale from 1 = strongly disagree to 6 = strongly agree to express how precisely each item describes themselves. Negative items are reverse-scored. Total score was used in further analysis.

Singapore caregiver quality of life scale (SCQOLS)

The SCQOLS was used to measure quality of life of care givers of thalassemia patients. It consisted of 51 items having alpha reliability of .89-.95 (Cheung et al., 2019). Participants filled out the scale on 5 point Likert scale from 0-4 (not at all- very much). Higher scored indicated the better quality of life.

Procedure

Participants were approached in different government and private hospitals as well as Blood Collecting Organizations like Sundus Foundation where their children with thalassemia were registered for blood transfusion or doctor's appointment. Only one caregiver was taken per participant who was the most involved with the care of their child and that is why our study participants were 77% female and only 23% male (see table 1). Participants filled out all the scales on the same appointment day in a separate room in hospital or organization.

Ethical Considerations

Study was approved from the institutional board of University of Gujrat.. Researchers followed the guidelines of declaration of Helsinki for data collection. Prior to data collection, participants gave written informed consent. Privacy, anonymity and confidentiality of the participants as well as information was ensured through the research process.

Results

Table 1: Descriptive analysis of data (N=150)

Sample Characteristics	f(n)	%
Gender		
Male	34	23
Female	116	77
Family System		
Nuclear	76	51
Joint	74	49
Residential Area		
Urban	66	44
Rural	84	56
Socio-economic status		
High	3	2
Middle –class	132	10

Lower-class	15	88
Father education		
Matric	108	72
F.A	27	18
B.A	9	6
Masters	6	4
Mother education		
Matric	126	84
F.A	12	8
B.A	6	4

Table 1 described the demographic characteristics of the study participants. The sample included both male and female participants. In terms of family structure, 76 participants (50.7%) came from nuclear families, while 74 participants (49.3%) were from joint family systems.

Correlation

Table 2: Relationship among stress, psychological wellbeing and quality of life of caregivers of thalassemia patients

Variables	1	2	3
1 stress	-	-.339**	-.665**
2 wellbeing		-	-.167*
3 Quality of Life			-

Table 2 demonstrated the connections between stress, psychological wellbeing and quality of life of caregivers of thalassemia patients. The table illustrated that stress is significantly negatively correlated with well-being and quality of life which means that increased stress would result in decrease in well-being and quality of life.

Table 3: Mediation effect of Psychological wellbeing between stress and quality of life

Variable	B	95% CI	SE	β
Step 1				
Constant	16.65***	[10.369, 22.938]	3.18	
Stress	.327***	[-.267-.386]	0.03	.665***
Step 2				
Constant	7.809	[-10.725-26.343]	9.37	
Stress	.338***	[-.274-.401]	0.032	.687***
Wellbeing	0.051	[-.049-.150]	0.05	0.065

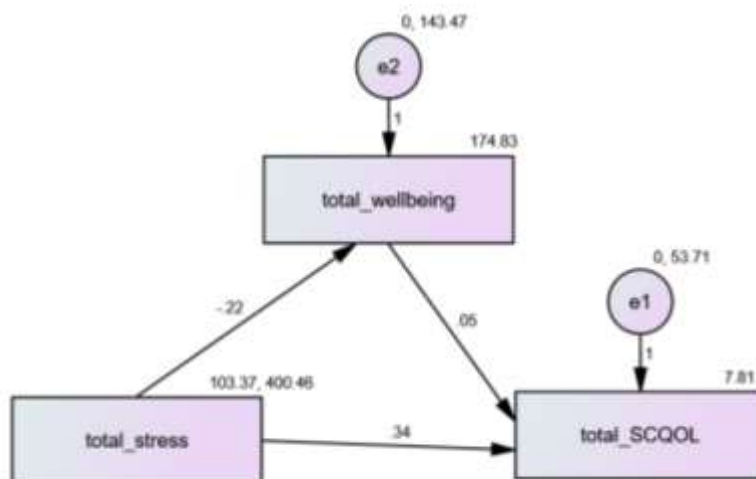


Figure 1: Model of Mediation effect of Psychological wellbeing between stress and quality of life

The results illustrated that psychological well-being acted as a full mediator between psychological stress and quality of life of care givers of patients with thalassemia. In Step 1, the R^2 value of .42 revealed that the stress explained 42% variance in the quality of life with $F(1,148) = 117.04, p \leq .001$. On the other hand, in step 2, the value of R^2 showed that both stress and well-being explained 46% variance in quality of life. The non-significant value of beta coefficient showed full mediation effect of well-being between stress and quality of life.

Table 4: Analysis of variances among father's education and stress, well-being and quality of life

Variable	matric		FA		BA		Masters		F	p
	M	SD	M	SD	M	SD	M	SD		
stress	106.85	19.15	97.62	20.03	95.44	14.05	78.33	21.25	5.93	0.001
Well-being	151.13	11.86	152.0	10.24	160.11	16.17	168.67	20.66	5.08	0.002
QOL	52.11	9.19	47.44	10.85	47.55	7.55	38.0	9.07	5.80	0.001

Table 4 presented a comparison of four groups based on father's educational level (matric, BA, and Masters) on study variables; stress, well-being, and quality of life (QOL). Table showed that all three study variables showed significant mean differences among father's education.

Table 5: Post Hoc analysis of father's education on stress, well-being and quality of life

total_stress	Matric	F.A	LL	CF	UL	95% Confidence	
						LL	UL
			9.22*	4.12	0.03	1.08	17.37
		B.A	11.41	6.64	0.09	-1.72	24.54

		Masters	28.52*	8.03	0.00	12.64	44.39
	F.A	B.A	2.19	7.37	0.77	-12.38	16.75
		Masters	19.29*	8.64	0.03	2.21	36.38
	B.A	Masters	17.11	10.09	0.09	-2.84	37.06
total_wellbeing	Matric	F.A	-0.91	2.64	0.73	-6.13	4.31
		B.A	-8.98*	4.26	0.04	-17.40	-0.56
		Masters	-17.53*	5.15	0.00	-27.72	-7.36
	F.A	B.A	-8.07	4.73	0.09	-17.42	1.27
		Masters	-16.62*	5.54	0.00	-27.58	-5.68
	B.A	Masters	-8.56	6.47	0.19	-21.35	4.24
total_SCQOL	Matric	F.A	4.67*	2.03	0.02	0.66	8.68
		B.A	4.56	3.27	0.17	-1.91	11.02
		Masters	14.11*	3.95	0.00	6.30	21.93
	F.A	B.A	-0.11	3.63	0.98	-7.28	7.06
		Masters	9.44*	4.26	0.03	1.03	17.85
	B.A	Masters	9.56	4.97	0.06	-0.27	19.38

The LSD post hoc analysis revealed that fathers having matric level education showed differences with father's having master's level education on all three variables.

Discussion

The results of this study provide important light on the connection between stress, psychological health, and quality of life for parents of thalassemia patients. The findings show that caregiver psychological health and quality of life are negatively correlated with high levels of stress. This is consistent with earlier studies that have emphasized the difficulties caregiver of patients with chronic illnesses encounter, especially when those conditions call for intensive medical care (Punaglom et al., 2019; Inamdar, 2022). Moreover, it was suggested that parents of thalassemia children were remain under stress due to the nature of this chronic illness (Inamdar et al., 2015). Stress and psychological well-being were shown to be significantly negatively correlated, indicating that psychological well-being declines with increasing stress levels. The findings are consistent with the previous research that parents of thalassemia patients have higher level of depression (Hussain et al., 2021). The concept that high levels of stress have a negative impact on caregiver mental health and cause anxiety and depression is supported by this research.

According to the literature review, a lot of caregiver mentioned feeling alone and that they didn't have enough social support (Punaglom et al., 2019). Reduced quality of life scores are correlated with higher stress levels, suggesting that stress has a substantial effect on caregiver overall life satisfaction. Researchers suggested that quality of life of family caregiver is important to consider (Cheung et al., 2019). The current study implies that stress-reduction strategies may improve the quality of life for these caregiver. It is interesting to note that there was a negative correlation between psychological well-being and quality of life, supporting the idea that raising psychological health may be essential to raising quality of life. Significant variations in stress, psychological health, and quality of life were found amongst educational

attainment groups. Higher levels of education have been linked to improved psychological health, a higher quality of life, and reduced levels of stress. This result is in line with research that indicates education could give caregiver more effective coping mechanisms and stress-reduction tools (Tarım & Öz, 2022). The caregiver socioeconomic situation is also very important; caregiver from lower socioeconomic classes reported more financial hardship, which increased their stress and had a detrimental effect on their quality of life. As the Haung et al. (2023) suggested that, individuals in need, financial barriers may also make it difficult for them to receive the proper mental health care.

Conclusion

The results of this study highlight the significant difficulties that thalassemia patient caregiver face. According to the study, caregiver endure high amounts of stress, which negatively impacts their mental health and general quality of life. The study emphasizes how important it is to provide caregiver with specialized interventions that will lessen their stress and improve their mental health. The well-being of caregivers can be significantly enhanced by addressing certain stressors and providing suitable support systems, which will ultimately improve the care given to patients with thalassemia. In order to lessen the difficulties faced by caregiver of children with chronic illnesses like thalassemia, extensive support networks must be developed, as this study provides insightful information about caregivers experiences.

References

- Anum, J., Dasti, R. Caregiver Burden, Spirituality, and Psychological Well-Being of Parents Having Children with Thalassemia. *J Relig Health* **55**, 941–955 (2016). <https://doi.org/10.1007/s10943-015-0127-1>
- Cheung, Y. B., Neo, S. H. S., Teo, I., Yang, G. M., Lee, G. L., Thumboo, J., Chia, J. W. K., Koh, A. R. X., Qu, D. L. M., Che, W. W. L., Lau, A., & Wee, H. L. (2019). Development and evaluation of a quality of life measurement scale in English and Chinese for family caregivers of patients with advanced cancers. *Health and Quality of Life Outcomes*, *17*(1), 35. <https://doi.org/10.1186/s12955-019-1108-y>
- Daré, L. O., Bruand, P. E., Gérard, D., Marin, B., Lameyre, V., Boumédiène, F., & Preux, P. M. (2019). Co-morbidities of mental disorders and chronic physical diseases in developing and emerging countries: a meta-analysis. *BMC public health*, *19*, 1-12.
- Galanello, R., & Origa, R. (2010). Epidemiology of thalassemia. *Theoretical and Clinical Pharmacology*, *3*(2), 245-261.
- Hussain, M., Ahmad, K., Lak, T. A., Alvi, A. S., & Mohsin, R. (2021). An Analysis of Experiences and Problems of Parents with Thalassemia Children. *Psychology and Education*, *58*(2), 10674-10680.
- Huang, Y., Loux, T., Huang, X., & Feng, X. (2023). The relationship between chronic diseases and mental health: A cross-sectional study. *Mental Health & Prevention*, *32*, 200307.
- Inamdar, S. (2022). Psychosocial distress among caregivers of children with thalassemia: A cross-sectional study. *Journal of Health Psychology*, *27*(5), 1024-1035. Available from: <https://njcmindia.com/index.php/file/article/view/1283>
- Ishaq, F., Abid, H., Kokab, F., Akhtar, A., & Mahmood, S. (2012). Awareness among parents of β -thalassemia major patients, regarding prenatal diagnosis and premarital screening. *Journal of the College of Physicians and Surgeons—Pakistan: JCPSP*, *22*(4), 218–221.
- Kausar, N., Akram, B., Dawood, S., Ahmad, F. (2019). Development of an Indigenous Parental Perceived Stress Scale for Children with Autism Spectrum Disorder. *Pakistan Journal of Psychological Research*, *34*(2), 433-456. <https://doi.org/10.33824/PJPR.2019.34.2.24>
- Modell, B., & Darlison, M. (2008). Global epidemiology of haemoglobin disorders and derived service indicators. *Bulletin of the World Health Organization*, *86*(6), 480–487. <https://doi.org/10.2471/blt.06.036673>
- Muazzam, A., & Javed, S. (2013). Predictors of caregiver's burden: interplay of physical and emotional health and perceived hope in children with thalassemia and hemophilia. *Pakistan Journal of Social and Clinical Psychology*, *11*(2), 36.
- Öz, F. (2015). Psychosocial nursing in cancer. *Turkiye Klinikleri J Intern Med Nurs-Special Topics*, *1*(2), 46-52.
- Oz, H. S., & Oz, F. (2020). A psychoeducation program for stress management and psychosocial problems in multiple sclerosis. *Nigerian journal of clinical practice*, *23*(11), 1598–1606. <https://doi.org/10.4103/njcp.njcp.462.19>
- Punaglom, N., Kongvattananon, P., & Somprasert, C. (2019). Experience of parents caring for their children with Thalassemia: Challenges and issues for integrative review. *The*

- Bangkok Medical Journal*, 15(1), 100-100. <https://doi.org/10.31524/bkkmedj.2019.02.018>
- Shaligram, D., Girimaji, S. C., & Chaturvedi, S. K. (2007). Quality of life issues in caregivers of youngsters with thalassemia. *The Indian Journal of Pediatrics*, 74, 275-278.
- Tarım, H. Ş., & Öz, F. (2022). Thalassemia Major and Associated Psychosocial Problems: A Narrative Review. *Iranian journal of public health*, 51(1), 12–18. <https://doi.org/10.18502/ijph.v51i1.8287>
- Wahidiyat, P. A., Sari, T. T., Rahmartani, L. D., Iskandar, S. D., Pratanata, A. M., Yapiy, I., ... & Lubis, A. M. (2022). Thalassemia in Indonesia. *Hemoglobin*, 46(1), 39-44.
- WHO (2006). Thalassemia an