ORIGINAL ARTICLE

Challenges experienced by the parents of children with thalassemia at Liaquat University hospital, Hyderabad

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Abstract

Background: Thalassemia an inherited genetic blood disorder that requires ongoing transfusion therapy and creates major psychological, social, economic, informational, and healthcare access challenges for caregivers. This study aimed to assess the challenges experienced by parents of children with thalassemia attending a tertiary care hospital in Hyderabad.

Material and methods: A descriptive cross-sectional study took place in the thalassemia ward of Liaquat University Hospital, Hyderabad, from Feb to July 2025. Convenience sampling was used to recruit 112 parents/guardians. Data were gathered using a structured questionnaire, and SPSS version 26 was used for data analysis. Chi-square tests with $p < 0.05$ were utilized, along with descriptive statistics (frequencies, percentages, means, and standard deviations).

Results: The study comprised 112 participants with almost equal males (50.9%) and females (49.1%). The highest age group was 31–40 years (33.9%); Psychological distress was common, including fatigue and restlessness (63.4%); uncertainty about the future (61.6%); and hopelessness (58.9%). 65.2% of respondents reported financial burden, 57.1% reported informational difficulties, 53.6% reported limited social support, and 56.3% reported healthcare access issues. There were significant associations between caregiver challenges and gender, education, residence, family type, and income ($p < 0.05$), but not with age.

Conclusion: Parents of children with thalassemia experience significant multidimensional burdens, with significant socioeconomic contributions. There is a need for specific interventions such as caregiver education, community or workplace psychosocial support, and better availability of health services to minimize caregiver burden.

Keywords: Caregiver Burden, Health Services Accessibility, Thalassemia

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INTRODUCTION

Thalassemia is a hereditary blood disorder that leads to a deterioration in the production of hemoglobin (Hb). This leads to lifelong anemia and to blood transfusion needs over the life span.[1] Beyond clinical characteristics, thalassemia places an ongoing burden on the family, mainly on the parents, whose primary role is in adherence to the treatment, hospital visits, and everyday management. [2] Evidence indicates that the care of children with thalassemia is linked to psychological burden, financial difficulties, disruptions in family relationships, and diminished life quality. These burdens are strongly influenced by socioeconomic factors such as income level, education, family structure, and access to healthcare services.[3] However, the severity of caregiver burden varies across regions due to differences in healthcare infrastructure and social protection systems.[4] In South Asia, including Pakistan, the burden of thalassemia remains high due to genetic, cultural, and socioeconomic factors, including high rates of consanguineous marriages and limited preventive screening programs.[5] Approximately 5-8% of the population are thalassemia carriers, resulting in 5,000 to

9,000 new cases of thalassemia major annually. [6] In Sindh, a higher prevalence has been reported among Balochi and Sindhi communities, with most cases associated with consanguineous marriages. [7] Parents of children with thalassemia experience major challenges beyond clinical management, including psychological distress, financial problems, limited access to specialized medical services, and social stigma. These challenges make it hard for people to do things, and they also affect their quality of life. Some studies from Bangladesh and Pakistan have shown that parents who take care of children with thalassemia often feel stressed, tired, and anxious because they have to go to the hospital a lot and take care of their children all the time. [9, 10] The cost of treatment is also a problem for families because people with thalassemia need to get blood transfusions for their whole life, they need iron chelation therapy, and they have to travel to big hospitals a lot, which costs a lot of money.[11] In addition, it is also hard for caregivers to get the help they need to feel better, and many people do not know much about health, which makes things even harder for the people who take care of those with thalassemia, especially when they do not have resources. [12, 13] Despite existing evidence, research from Pakistan remains fragmented and limited to single domains such as psychological or financial burden. Few studies have assessed caregiver burden using a multidimensional framework or examined its relationship with socioeconomic factors in tertiary care settings. This highlights a clear evidence gap in understanding the full scope of caregiver experiences despite the high disease burden. A multidimensional approach is needed to identify vulnerable groups and guide comprehensive interventions. Therefore, this study aims to assess the challenges experienced by parents of children with thalassemia at Liaquat University Hospital, Hyderabad, using an integrated approach.

MATERIAL AND METHODS

A descriptive cross-sectional study was carried out at the thalassemia ward of Liaquat University Hospital, Hyderabad, between February and July 2025. The sample size was calculated using OpenEpi Version 3.0 based on a previously reported prevalence of 7% [6], with a 95% confidence interval and a 5% margin of error, which yielded a minimum sample size of 102. A 10% non-response was assumed, which led to a final sample of 112 participants. Parents/guardians of children with a clinical diagnosis of thalassemia and who signed informed consent were included. Participants were excluded if they refused to participate or if their child had any other chronic disease. Data were collected by a structured questionnaire adapted from the previous study. [14] The tool included socio-demographic characteristics and questions related to the psychological, informational, social, economic, and health access challenges faced by caregivers. All responses were made using a four-point Likert scale (1 = Strongly Disagree, 4 = Strongly Agree), with higher scores indicating more difficulties. An item analysis as well as a domain analysis was completed. To perform item-wise analysis, the responses of “Agree” and “Strongly Agree” were taken as having a challenge, whereas “Disagree” and “Strongly Disagree” were taken as no challenge. A unique identification code was given to each participant to maintain confidentiality. The data was entered and analyzed in IBM SPSS Statistics version 26. Descriptive statistics (mean, standard deviation, frequencies, and percentages) were used in analyzing the data. The association of the caregiver challenges with demographic variables was analyzed using chi-square test with p value < 0.05. The study received Ethical approval from the Research Ethics Committee, Liaquat University of Medical and Health Sciences, Jamshoro (LUMHS/REC/-618). All participants gave written informed consent before the data was collected. The study was carried out in a confidential, anonymous, and safe way and participants had the right to withdraw at any time.

RESULTS

The study included a total of 112 parents/guardians of children with thalassemia. There was approximately an equal number of males (50.9%) as females (49.1%). The age 31–40 years group has the higher number of respondents (33.9%). In terms of education, 32.1% had secondary-level schooling, and 17.9% were uneducated. The majority of the participants were from urban areas (64.3%) and belonged to nuclear

families (53.6%). As for occupation, 35.7% were unemployed, 26.8% were employed, 24.1% reported as labourers, followed by business owners with (7.1%) and others (6.3%) (Table-I). Psychological challenges among caregivers included fatigue/restlessness (63.4%), uncertainty for the future (61.6%), and hopelessness (58.9%). Also, nearly half (49.1%) of the respondents felt guilty and worthless. Mean Likert values also confirmed the results, with fatigue/restlessness (3.48 ± 0.76) and uncertainty about the future (3.46±0.78) being the most severe psychological problems among the caregivers (Table-II). In the domains of informational, social, economic, and healthcare access challenges, more than half of participants reported multiple difficulties. 53.6% reported limited social support, and 57.1% reported a lack of knowledge regarding thalassemia and its management. The most common challenge was financial burden (65.2%), indicating significant economic stress. Further, 56.3% experienced long distances to access healthcare services, and 58.9% faced transport challenges, which were significant impediments to accessing healthcare services (Table-III). Results from chi-square analysis indicated that Monthly income ($p = 0.043$) and gender ($p = 0.032$) were significantly associated with psychological challenges, suggesting that emotional distress is not the same across socio-demographic groups. Lower education level ($p = 0.021$) and rural residence ($p = 0.033$) were strongly associated with informational problems, indicating that lower education and rural residence are related with less disease-related awareness. Social supports problems were significantly correlated with family type ($p = 0.029$) and living in rural areas ($p = 0.041$), suggesting lower social supports in nuclear and rural families. Monthly income was associated with economic burden and statistically significant ($p < 0.001$), thus reflecting greater economic burden among lower-income households. Healthcare access challenges were significantly associated with gender ($p = 0.021$), education level ($p = 0.011$), family type ($p = 0.041$), residence ($p < 0.001$), and monthly income ($p < 0.001$), indicating that socio-demographic factors play an important role in determining access to healthcare services (Table-IV).

Table-I: Socio-demographic Characteristics of Study Participants (n = 112)

Variable	Category	Frequency (n)	Percentage (%)
Gender	Male	57	50.9
	Female	55	49.1
Age (years)	≤30	28	25.0
	31–40	38	33.9
	41–50	30	26.8
	>50	16	14.3
Education	Illiterate	20	17.9
	Primary	30	26.8
	Secondary	36	32.1
	Above	26	23.2
Occupation	Unemployed	40	35.7
	Employed	30	26.8
	Business	8	7.1
	Labor	27	24.1
	Others	7	6.3
Monthly Income (PKR)	≤20,000	69	61.6
	20,001–40,000	28	25.0
	>40,000	15	13.4
Residence	Urban	72	64.3
	Rural	40	35.7
Family Type	Nuclear	60	53.6
	Joint	52	46.4

Table-II. Psychological and Emotional Challenges Among Parents (n = 112)

Category	SA n (%)	A n (%)	DA n (%)	SD n (%)	Mean ± SD
Loss of interest	58 (51.8)	33 (29.5)	12 (10.7)	9 (8.0)	3.25 ± 0.89
Hopelessness	66 (58.9)	29 (25.9)	9 (8.0)	8 (7.1)	3.37 ± 0.85
Uncertainty about the future	69 (61.6)	30 (26.8)	8 (7.1)	5 (4.5)	3.46 ± 0.78
Fatigue and restlessness	71 (63.4)	28 (25.0)	8 (7.1)	5 (4.5)	3.48 ± 0.76
Guilt and worthlessness	55 (49.1)	32 (28.6)	16 (14.3)	9 (8.0)	3.19 ± 0.90

Table-III: Informational, Social, and Financial Challenges Faced by Parents (n = 112)

Category	SA n (%)	A n (%)	DA n (%)	SD n (%)	Mean ± SD
Lack of disease information	64 (57.1)	31 (27.7)	10 (8.9)	7 (6.3)	3.36 ± 0.82
Limited family/social support	60 (53.6)	29 (25.9)	14 (12.5)	9 (8.0)	3.25 ± 0.86
Financial burden of treatment	73 (65.2)	24 (21.4)	9 (8.0)	6 (5.4)	3.46 ± 0.81
Long travel to the treatment center	63 (56.3)	32 (28.6)	10 (8.9)	7 (6.3)	3.35 ± 0.86
Transportation difficulties	66 (58.9)	31 (27.7)	9 (8.0)	6 (5.4)	3.40 ± 0.83

Table-IV: Association between Demographic Variables and Major Challenges (n = 112)

Demographic Variable	Psychological Challenges	Informational Challenges	Social Support Challenges	Economic Challenges	Healthcare Access Challenges
Gender	0.032	0.148	0.087	0.061	0.021
Age Group	0.091	0.112	0.072	0.083	0.134
Education Level	0.064	0.021	0.138	0.052	0.011
Residence	0.071	0.033	0.041	0.059	<0.001
Family Type	0.058	0.076	0.029	0.094	0.041
Monthly Income	0.043	0.064	0.054	<0.001	<0.001

DISCUSSION

This study highlights the multidimensional caregiver burden among parents of children with thalassemia, revealing significant psychological, informational, social, economic, and healthcare access challenges influenced by socioeconomic determinants. In this study, psychological distress was highly prevalent, with fatigue and restlessness (63.4%), uncertainty about the future (61.6%), and hopelessness (58.9%) being the most commonly reported symptoms. Nearly half of caregivers reported guilt and worthlessness (49.1%). Statistically significant associations were observed with gender (p = 0.032) and monthly income (p = 0.043), indicating that female caregivers and low-income families are more psychologically vulnerable. These findings are consistent with studies from Pakistan, Bangladesh, and Nepal[15-19], where caregiver psychological distress is strongly linked to chronic treatment demands and financial instability. The higher level of distress observed in the present study may be explained by limited access to structured psychosocial counseling and mental health support services in the study setting. Informational challenges were reported by 57.1% of participants and were significantly associated with education level (p = 0.021) and residence (p = 0.033). This suggests that low educational attainment and rural residence are key determinants of poor disease-related knowledge. Similar findings have been reported in international studies from Egypt, where caregivers of children with thalassemia demonstrated significant knowledge gaps, particularly in disease management, transfusion complications, and iron chelation, with lower education levels strongly associated with reduced health literacy and poor understanding of long-term care requirements.[20] However, other research in urban China shows higher levels of caregiver awareness because of the more organized health education systems and hospital-based counseling services, which help to account for regional differences in awareness. [21] Lack of social support was reported by 53.6% of the participants and was significantly related to family type (p = 0.029) and place of residence (p = 0.041). The family support networks were much weaker for

nuclear families and rural families than for joint and urban families. Similar trends have been observed in Pakistan and China [22, 23], where informal caregiving networks are diminished, and geographic isolation leads to increased burden on caregivers. This statistical significance underscores the importance of the role of joint family systems in South Asian cultures, where extended families offer emotional and financial support. The most prominent challenge was the economic burden reported by 65.2% of the participants, which was highly correlated with monthly income ($p < 0.001$). Financial stress associated with transfusions, medications, and transportation was much higher among low-income households. The same results have been reported in Pakistan, India, and Malaysia [24, 25], where out-of-pocket expenditure is still a significant obstacle to chronic disease care. This highly significant p-value ($p < 0.001$) highlights that income is an overwhelming factor in determining economic stress in caregivers. The disproportionate burden in this study may be due to the lack of full insurance coverage and less robust financial protection mechanisms in the health system. Over half of participants experienced difficulties accessing care, largely due to transportation (58.9%) and distance to care (56.3%). Strong structural inequities in access to care were observed with strong associations with gender ($p = 0.021$), education level ($p = 0.011$), family type ($p = 0.041$), residence ($p < 0.001$), and monthly income ($p < 0.001$). These are similar to the findings from India and Pakistan [26, 27], where geographic distance and transportation costs significantly reduce access to specialized healthcare services. The very strong significance of residence and income (both $p < 0.001$) highlights major rural-urban and socioeconomic disparities in healthcare accessibility. There was no significant relationship between age group and each of the study domains, indicating that the burden on the caregiver is not related to age, but to socioeconomic factors. This is in line with the reports from Nepal and China, where financial and educational status proved to be more predictive of the caregiver burden than demographic age. [28, 29] Parents of children with thalassemia, particularly mothers, in low-income families, rural communities, and with lower levels of education, face a significant psychological burden, as well as an information, social, economic, and healthcare burden. These interventions must involve caregiver education, psychosocial supports, access to financial resources, and better access to health services to help minimize these issues and improve the outcomes for parents and children.

CONCLUSION

According to the study, there are significant multidimensional burdens associated with caring for children with thalassemia, which are greatly impacted by sociodemographic factors such as family structure, income, education, and place of residence. These results highlight the necessity of focused, integrated interventions to lessen caregiver burden and enhance family well-being, such as caregiver education, psychosocial support, financial aid, and better access to specialized healthcare services.

RECOMMENDATIONS

Implement structured educational programs to inform parents, especially those in rural and less-educated communities, about thalassemia. Caregiver stress, especially among mothers, requires psychosocial support, especially counselling and peer support. Financial and transportation assistance should be considered to reduce the economic burden of care. Incorporating increased family participation and community-based support services could further increase caregiver capacity and well-being.

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