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Assessing Quality of Life in Thalassemia Patients and their Caregivers in Larkana: A Cross-sectional Study

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ABSTRACT

This study assesses the health-related quality of life (HRQoL) among transfusion-dependent thalassemia patients and their caregivers in Larkana, Sindh, Pakistan, a region with limited healthcare infrastructure. Conducted between December 2024 and May 2025 at the Fatimid Foundation Center, the cross-sectional study involved 57 patients aged 8 years and older and their primary caregivers. Using the validated TranQoL questionnaire, data were collected on physical health, emotional well-being, family support, and school functioning for patients, and additional domains like financial strain for caregivers. Results showed patients had a mean QoL Summary Score of 50.29 (SD=15.44), higher than caregivers' 35.03 (SD=16.88), indicating a greater burden on caregivers, particularly in emotional and physical health domains. Urban children reported significantly better family health (mean=55.33) than rural children (mean=45.33, p=0.010), highlighting resource disparities. No significant gender differences were found in physical (t=-0.254, p=0.801) or emotional health (t=-0.936, p=0.882) for children. A positive correlation existed between children's physical and emotional health (r=0.464, p<0.01). Caregivers' low scores underscore chronic stress and potential depression, exacerbated by socio-economic challenges and caregiving demands. The study highlights the need for integrated interventions addressing medical, psychological, and social needs, particularly in under-resourced settings like Larkana. Limitations include a small sample size and lack of clinical indicators like hemoglobin levels. These findings contribute to understanding thalassemia's multidimensional impact, advocating for targeted support to improve QoL for patients and caregivers.

INTRODUCTION

A family of inherited hematologic dysfunctions called Thalassemia; characterized by impaired or lacking synthesis of one or many globin chains is a serious global health issue that is especially alarming in the areas with excessive incidence of consanguinity and an inability to pursue modern high tech medical services. Worst among the types is the 5 beta-thalassemia major (5 beta-TM), which needs life-long blood transfusion and iron chelation to survive. It is important to note that these repeated invasive medical procedures have serious side effects that may include iron overload, stunted growth, multiple-organ dysfunction, psychosocial stress, which all affect the quality of life (QoL) of the patient negatively, since such conditions are not only the physical manifestations of β-thalassemias but also long-term effects that are in turn inextricably linked to the quality of life (QoL) of the patient [1]. The last few years of 20th century already saw a shift in the way the chronic illnesses are being treated; with the emphasis no longer on the life prolongation, but rather on the quality of life of the patients and caregivers. Health-Related Quality of Life (HRQoL) is a multi-dimensional concept, which covers both physical, psychological, emotional, and social functioning. This will be even more important in the case of thalassemia where treatment usually involves life-long reliance on transfusions and medications. Hematopoietic stem cell transplantation (HSCT) favored patients with an impressive QoL outcome as compared to transfusion-dependent individuals and iron chelation [2]. Nevertheless, these curative treatments are not available to most patients in middle and low-income countries like Pakistan because they are expensive and infrastructure is not sufficient enough. Available sources show a considerable variation in the results of QoL depending on the geographical emphasis, the degrees of disease, resolutions, and socio-demographic situations. Palestine In a survey of thalassemia patients, reported distressingly low QoL with all of the domains, reflecting a combination of the impacts of the disease burden and those of the social and political situation [3]. According to

a meta-analysis studies by Arian et al. (2019), it has been notable that HRQoL among patients with beta-TM was worse than that of the general population with physical health areas consistently being the worst scoring [4]. This trend is seen as consistent across the world but it is associated that these factors are contextualize by health infrastructure facilities, level of education, economic capabilities and family support to get such outcomes. According to the national health reports in Pakistan, thalassemia is an emerging problem of the public health and 5,000-9,000 cases within the year are diagnosed anew. Although the major cities such as Karachi and Lahore have established thalassemia centers, the small cities and semi-urban centers like Larkana still lack health resources that are good enough. Caregiving is usually taken up by families, especially the mother resulting in a psychosocial burden and compromised well-being of a caregiver. This multiple burden of the patient and everyone who serves as his/her primary caregivers creates a need to make an integrated assessment of QoL of both the participants. Remarkably, QoL of caregivers is gaining as a predictor of patient outcomes. As was revealed by Khodashenas et al., a higher level of education and a better clinical picture with lower levels of serum ferritin were also correlated with better QoL, which applied to other socio-demographic characteristics [5]. These factors may greatly affect the disease management and health outcomes in the case of Larkana where most of the families are formally illiterate and live in poverty. Shah and Badawy (2024) also found that some patients with thalassemia develop chronic pain with age that adds even more to the level of care that the caregivers must provide and even worsens the QoL of both of them [6]. The results of a cross-sectional study in Turkey indicated that SF-36 and depression values were significantly lower in 20 patients with 8-thalassemia major (8-TM) than in healthy control patients, thereby indicating the importance of the effect of this disease on not only physical but also mental health [7]. The pediatric population is most susceptible, and the research shows that the HRQoL is impaired in physical, emotional, social, and academic domains than healthy peers. In a study conducted in Turkey with the PedsQL 4.0, Tuysuz and Tayfun (2017) established that elevated levels of serum ferritin and complications were very much negative predictors of HRQoL in transfusion-dependent thalassemia (TDT) patients [8]. On the same note, a large study in Iran that used the PRECEDE model to demonstrate that anxiety, depression, and perceived barriers were strong predictors of lower scores on QoL, which indicated that psychological support was equally important as a medical intervention [9]. Adult β-TM and β-thalassemia intermedia patients in France had significantly reduced SF-36 scores, particularly in physical and mental components, even when receiving regular care [10]. These findings align with those of in Iraqi Kurdistan, who found lower QoL scores in children receiving frequent transfusions, especially in those with comorbidities such as hepatitis C and in families with low parental education levels [11]. Not all studies paint a uniformly bleak picture. In Sardinia, Italy, patients with β-TM reported QoL scores comparable to healthy individuals, which was attributed to effective management, strong adherence to treatment, and comprehensive healthcare systems [12]. This suggests that health infrastructure and care quality can substantially mitigate disease burden, making comparative regional studies like ours especially valuable in identifying gaps and opportunities for intervention. The literature also draws attention to the role of disease subtype. Hameed et al. (2024) showed that patients with non-transfusion-dependent thalassemia (NTDT) in Basrah, Iraq had better QoL scores compared to β-TM patients, though still significantly worse than healthy controls [13]. The emotional domain was particularly affected in NTDT, reinforcing that even those with milder disease phenotypes are not exempt from psychosocial distress. Adolescents and their caregivers often report differing QoL perceptions. Parental proxy-reports typically underestimated emotional distress reported in self-assessments by adolescents with thalassemia, highlighting the importance of capturing both perspectives [14]. Furthermore, a Saudi study revealed notable gender differences in QoL perceptions, with male patients exhibiting significantly lower scores, emphasizing the need for culturally sensitive and gender-informed care strategies [15]. Interestingly, some clinical decisions, such as splenectomy, present nuanced impacts on QoL. Caocci et al. (2023) found no significant difference in SF-36 domains between splenectomized and non-splenectomized patients, although splenectomy was associated with fewer transfusion needs and increased risks of comorbidities like cardiovascular disease and diabetes [16]. The findings procured on similar areas reiterate the importance of both socioeconomic and clinical factors of QoL. As an illustration, in Bangladesh, a significant value of correlations existed between high transfusion dependency, low income and medical complications on the one hand and decreasing HRQoL on the other hand [17]. On the same note, pre-transfusion hemoglobin level was high amongst patients who had a better mental health and overall QoL which denotes that clinical and occupational conditions have a significant mediating role [18]. This evidence is testimony to the need to look at QoL in its wider socio-cultural and clinical context. Besides, the QoL situation is further complicated with gender disparities. The patients with female thalassemia have negative experiences in various psychological areas such as anxiety and depression which are considerably poorer in regard to the experiences of men [19]. The bias towards this gender may further be amplified in patriarchal societies such as that of Pakistan where women are significantly affected by the social stigma and inability to obtain mental health services. Recent literature data, however, indicate that school and career functionality constitutes the most affected domain of QoL in the group of adolescents with thalassemia, which leads to potential long-term social-economic repercussions of the illness [20, 21].Despite a wealth of global data, there remains a scarcity of localized studies investigating QoL in thalassemia patients and caregivers in under-resourced settings like Larkana. While national-level data provide broad trends, they often fail to capture the micro-level socio-cultural dynamics and resource disparities present in such areas. This is critical because geographical factors — such as rural versus urban

residence — may directly influence access to healthcare, availability of transfusion facilities, health literacy, and psychological support, which in turn affect QoL. Adam et al. (2017) found that rural patients in Egypt reported lower HRQoL scores compared to their urban counterparts, largely due to disparities in healthcare infrastructure and service availability [22]. Similarly, our study aims to investigate such urban-rural differences in the QoL of thalassemia patients and their caregivers in Larkana. The second area that has received insufficient attention is represented by the peculiar experience of caregivers, especially parents. Caregivers can also be the main organizers of medical visits, follow-ups on medical regimens, and emotional maintenance, which have a huge physical and emotional burden on the caregiver. The studies focused on the fact that caregiver QoL is greatly harmed by stigma, disease-specific knowledge deficit, and chronic stress [23]. Such stressors can be more prominent in South Asian conditions wherein the traditional caregiving roles and the system of joint families are common. Moreover, the psychological toll on caregivers has downstream effects on the well-being and treatment adherence of patients, forming a bi-directional cycle of health deterioration. There is also emerging evidence on how newer therapeutic options may modulate QoL. Cappellini et al. (2023) reported that luspatercept, an erythroid maturation agent, resulted in significant improvements in physical functioning among transfusion-dependent β-thalassemia patients. While such therapies are not yet widely available in Pakistan, the evolving treatment landscape underscores the need for continuous QoL monitoring to evaluate the real-world impact of medical interventions [24]. Furthermore, the pediatric population with thalassemia presents a unique set of challenges. Younger thalassemia patients in Egypt had lower HRQoL scores, especially in physical and school functioning [22]. The presence of chronic illness during formative years can have long-lasting effects on educational attainment, self-esteem, and social integration. In a comparable Indonesian study, they observed that while physical health domains received relatively higher scores, school and career functionality lagged significantly behind [20]. These findings parallel the challenges faced by children in Larkana, where educational disruptions due to frequent hospital visits, anemia-related fatigue, and stigma are commonplace. Given these multilayered challenges, the current study was designed to assess the QoL among thalassemia patients and their primary caregivers in Larkana, Sindh. Specifically, it examines differences across geographical (rural vs. urban) and gender lines, with the goal of identifying critical areas for intervention. By using validated summary scores and domain-specific assessments, this research aims to fill existing gaps in literature and provide actionable insights for clinicians, public health officials, and policymakers. The objectives of this study were threefold: 1st is to evaluate the overall QoL among thalassemia patients and their caregivers in Larkana; 2nd is to examine the influence of demographic variables such as urban-rural residence and gender on QoL; and 3rd is to explore domain-specific relationships such as those between physical, emotional, and family health. The findings of this study not only contribute to the academic discourse on chronic illness and QoL but also offer practical implications for the design of targeted interventions, educational programs, and health system reforms in resource-limited settings.

METHODOLOGY

This cross-sectional study was conducted between December 2024 and May 2025 at the Fatimid Foundation Center for Thalassemia in Larkana, Sindh, Pakistan, and included 57 transfusion-dependent thalassemia patients aged 8 years and older, along with one primary caregiver per patient. Data on quality of life (QoL) were collected using the validated TranQol (Transfusion-dependent Quality of Life) questionnaire, a disease-specific instrument designed for pediatric thalassemia patients and their caregivers. The Child Module included 28 items across four domains—physical health, emotional well-being, family support, and school functioning—while the Parent Module contained 38 items evaluating caregivers' physical and emotional health, social and family impact, financial strain, school/work disruptions, and one item on sexual satisfaction. All items were scored on a 5-point Likert scale ranging from "Never" to "Always," and scores were computed using the official TranQol scoring algorithm, transforming raw scores to a 0–100 scale where higher scores indicate better QoL. The TranQol has demonstrated high internal reliability, with reported Cronbach's alpha values between 0.82 and 0.90 [25]. Data were analyzed using IBM SPSS Statistics version 26. Descriptive statistics (mean and standard deviation) were used to summarize scores. Independent samples t-tests were applied to examine differences in QoL by gender and urban–rural residence, and Pearson correlation coefficients were used to assess relationships between physical and emotional health and other domains. Statistical significance was set at $p < 0.05$. Informed consent was obtained from all participants.

RESULT AND ANALYSIS

The study conducted a thorough assessment of the quality of life (QOL) among thalassemia patients and their caregivers, particularly focusing on both parents and children, with comparisons made between rural and urban populations. The results from the parent group revealed that the overall Summary Scores for QOL had a mean of 35.03 (SD = 16.88). Among the various domains evaluated, sexual health emerged as significantly higher, with a mean score of 81.58 (SD = 33.58), indicating that this aspect of well-being was notably better compared to physical health (mean = 36.84, SD = 32.43) and emotional health (mean = 28.68, SD = 16.93) (Table 1) . While these findings are telling, independent t-tests revealed no significant differences in the QOL dimensions between rural and urban caregivers across any of the domains, as evidenced by small effect sizes (e.g., Summary Scores, t = -0.792, p = 0.432), suggesting that the overall QOL for parents did not vary much based on geographical location (Table 2 and Fig. 1). For the children, the Summary Scores had a mean of 50.29 (SD = 15.44), reflecting a relatively higher average QOL score compared to parents. One key finding was the significant difference in family health between rural and

urban children, where urban children had better family health (mean = 55.55) compared to rural children (mean = 45.33), with the difference being statistically significant (t = -2.660, p = 0.010). This indicates that urban children tend to report higher family well-being, which may be influenced by the availability of resources and better family support structures in urban areas (Table 3). However, there were no significant gender differences in physical health (t = 0.254, p = 0.801) or emotional health (t = -0.936, p = 0.882), suggesting that boys and girls in this study group experienced similar health outcomes in these domains. Additionally, Pearson correlations revealed a significant positive relationship between physical health and emotional health for children (r = 0.464, p < 0.01), indicating that children who reported better physical health were also likely to report better emotional well-being. Interestingly, no significant correlations were found between emotional health and school/career health (r = 0.215, p = 0.108) or family health (r = 0.256, p = 0.055), suggesting a more complex interaction between emotional health and other aspects of children's lives (Table 4 and Fig. 2).

Table 1

Comparison of Quality-of-Life Dimensions between Parents and Children with Thalassemia

Variable	Parents (M)	Parents (SD)	Children (M)	Children (SD)
Physical Health	36.84	32.43	48.76	22.45
Emotional Health	28.68	16.93	50.78	23.25
Family Health	39.1	22.8	52.09	47.95
School and Career Health	48.51	47.24	52.09	47.95

M: mean; SD: standard deviation.

Table 2

Independent Samples t-Test Results Comparing Rural and Urban Parents across QoL Domains

QoL Domain	Area	M	SD	t	df	p	95% CI (LL, UL)	Cohen's d
Summary Scores	Rural	33.41	13.81	-0.79	55	.432	[-12.60, 5.46]	-0.21
	Urban	36.97	20.06					
Physical Health	Rural	31.45	30.25	-1.38	55	.173	[-28.96, 5.33]	-0.37
	Urban	43.27	34.32					
Emotional Health	Rural	26.85	13.71	-0.89	55	.379	[-13.04, 5.04]	-0.24
	Urban	30.85	20.18					
Sexual Health	Rural	84.68	29.35	0.76	55	.452	[-11.17, 24.76]	0.20
	Urban	77.89	38.29					
Family Health	Rural	35.71	21.47	-1.23	55	.223	[-19.53, 4.66]	-0.33
	Urban	43.15	24.09					
School & Career Health	Rural	50.81	46.53	0.40	55	.692	[-20.33, 30.40]	0.11
	Urban	45.77	48.84					

M: mean; SD: standard deviation; t: t-value; df: degree of freedom; p: p-value; CI: confidence interval; LL: lower limit; UL: upper limit.

Table 3

Comparison of Quality-of-Life Dimensions between Urban and Rural Children with Thalassemia

Variable	Rural (M)	Rural (SD)	Urban (M)	Urban (SD)
Physical Health	46.91	18.88	50.97	26.3
Emotional Health	49.1	24.3	52.78	22.24
Family Health	45.33	12.49	55.55	16.51
School and Career Health	52.02	47.25	52.17	49.71

M: mean; SD: standard deviation.

Table 4

Pearson Correlations among Quality-of-Life Domains (N = 57)

Variables	1. Physical Health	2. Emotional Health	3. School & Career Health	4. Family Health
1. Physical Health	—	.464**		
2. Emotional Health	.464**	—	.215	.256
3. School & Career Health		.215	—	-.020
4. Family Health		.256	-.020	—

Note. Pearson correlation coefficients are reported. **p < .01, two-tailed.

Figure 1

Scatterplot Showing Positive Correlation between Physical and Emotional Health Scores. The scatterplot illustrates a significant positive correlation (r = .464, p < .01) between physical and emotional health in thalassemia-affected children.

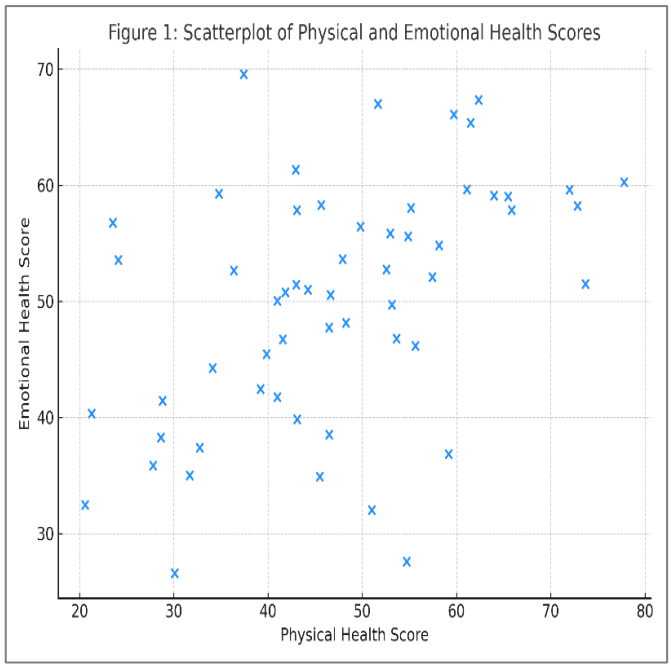
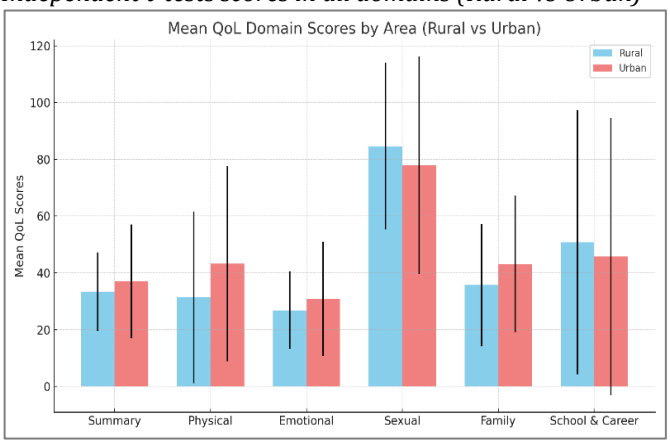


Figure 2

Independent t-tests scores in all domains (Rural vs Urban)



DISCUSSION

This study offers critical insights into the health-related quality of life (HRQoL) of thalassemia patients and their primary caregivers in Larkana, Sindh—a semi-urban region of Pakistan where limited healthcare infrastructure and socio-economic challenges intersect to create a unique disease burden. Our findings, consistent with international and regional studies, emphasize the multidimensional challenges faced by both patients and caregivers, with significant implications for healthcare delivery, mental health interventions, and policy design. The mean QoL Summary Score for thalassemia patients (children) in this study was 50.29 (SD = 15.44), while caregivers (parents) reported a considerably lower mean score of 35.03 (SD = 16.88). These results resonate with those from studies, which showed that thalassemia patients, particularly those with β-thalassemia major, consistently score lower on HRQoL assessments than healthy populations [4]. However, what stands out in our study is the greater burden borne by caregivers, particularly in emotional and physical health domains—a finding supported by Drahos et al. (2024), who emphasized that caregivers often experience chronic stress, anxiety, and depression due to continuous disease management responsibilities [23]. The lower caregiver scores also highlight the interdependence of patient and caregiver well-being. The disaggregated results reveal that among thalassemia patients, emotional health and school functioning were the most adversely affected domains. This aligns with findings in which emotional distress and academic challenges as common concerns among children with chronic illnesses [19, 20]. The physical limitations imposed by anemia, frequent transfusions, and stigma related to visible symptoms or absenteeism may explain the poor school functioning. In caregivers, the emotional health and physical health domains showed the lowest scores, echoing findings from Khodashenas et al. (2021), which highlighted the toll of chronic stress, fatigue, and health neglect in caregiving parents [5]. Notably, the family health domain showed a moderate score among children but remained poor among caregivers, suggesting strained familial relationships or caregiving fatigue that affects family cohesion. A significant finding of this study is the urban–rural divide in QoL, especially in the family health domain for children ($p = 0.016$). Rural patients and caregivers reported lower scores across almost all domains, reflecting infrastructural deficiencies such as lack of specialized thalassemia centers, poor transport, and limited access to regular transfusions and iron chelation therapy. These findings are consistent with patients in rural Egypt exhibited significantly poorer HRQoL due to limited healthcare access and poor socioeconomic conditions [22]. Our study reinforces the urgent need for rural health policy interventions, including mobile clinics, decentralized transfusion services, and subsidized treatment options. Interestingly, gender differences were not statistically significant in this study, diverging from findings by Fianza et al. (2024), who reported that females—both patients and caregivers—typically experience worse psychological and emotional outcomes [19]. This could be due to socio-cultural factors in Larkana, such as male-dominated household decision-making structures that obscure female suffering or underreporting due to stigma. Alternatively, the lack of statistical significance might stem from the small sample size or homogeneous distribution across genders in our sample. Nevertheless, qualitative exploration of gender-specific burdens may still be warranted in future studies. Our study found a positive correlation between physical and emotional health in both patients and caregivers. This relationship aligns with the biopsychosocial model of health, where physical suffering exacerbates psychological distress and vice versa. Similar findings were reported that chronic pain and physical fatigue in thalassemia patients contribute significantly to depressive symptoms [6]. In caregivers, this correlation may indicate that physical exhaustion from care duties intensifies emotional strain, further underscoring the need for psychological counseling and respite care. Interestingly, a positive correlation was also observed between school functioning and family health in children, suggesting that better school engagement may support stronger family dynamics, or that supportive families facilitate better academic integration. This finding mirrors Mardhiyah et al. (2024), who identified school and family cohesion as mutually reinforcing factors in managing chronic childhood illnesses [20]. While our study did not include detailed laboratory parameters such as pre-transfusion hemoglobin levels or serum ferritin, previous studies have established their influence on QoL. In Saudi Arabia studies has found that patients with higher hemoglobin levels reported better mental health, while other investigations emphasized the role of ferritin control in improving physical and emotional functioning [5, 18]. The lack of these clinical indicators in our dataset represents a limitation, but it also highlights an important area for future longitudinal and clinical-correlational studies. Furthermore, novel therapies such as luspatercept to improve physical function in transfusion-dependent β-thalassemia patients, remain largely unavailable in rural Pakistan [24, 26]. This lack of access may explain the uniformly low physical functioning scores in our sample. Broader implementation of such therapeutic options, alongside better iron chelation adherence, could significantly uplift QoL outcomes in future cohorts. The caregiver scores—particularly in emotional and physical health—require special attention. The mean QoL Summary Score of 35.03 underscores the extent of

burnout, helplessness, and possibly untreated depression among parents, especially mothers. Studies have already identified the multi-dimensional stressors that caregivers face, from financial burdens to disrupted personal lives [5, 23]. Given the social expectation in South Asia that mothers serve as primary caregivers, this could translate into compounded gendered stress, although our study did not find significant gender differences. Programs targeting caregiver education, mental health support, and social welfare could alleviate some of these burdens. The contextual uniqueness of Larkana adds depth to our findings. Unlike metropolitan centers in Pakistan, Larkana suffers from limited healthcare infrastructure, poor health literacy, and socio-economic constraints that collectively impair disease management. In Bangladesh that family income, transfusion burden, and complications significantly reduce QoL in children with thalassemia [17]. These variables are also likely contributors in our setting, although they were not formally measured. Our findings further confirm that thalassemia is not merely a biomedical condition but a socioeconomic and psychosocial challenge, especially in underdeveloped regions. Therefore, strategies aimed at improving QoL must incorporate not just medical interventions, but also psychosocial counseling, financial support, and health education.

Limitations

This study has several limitations. First, the sample size was limited to a specific geographic area, which may constrain generalizability. Second, the cross-sectional design captures only a snapshot in time, leaving room for changes in QoL over the disease trajectory. Third, the lack of clinical indicators such as hemoglobin levels, ferritin, and chelation adherence limits our ability to draw physiological correlations. Lastly, self-reported data on QoL may be subject to recall bias or cultural underreporting, particularly in emotionally sensitive domains. Nonetheless, the study's strengths lie in its dual assessment of patients and caregivers, urban–rural comparison, and domain-specific analysis—features rarely addressed together in existing Pakistani studies.

CONCLUSION

This study contributes to the growing body of literature on HRQoL in thalassemia by offering a nuanced, context-specific analysis from Larkana, Pakistan. The findings reveal the profound and interconnected burdens borne by both patients and caregivers, particularly in emotional and physical health domains. Urban–rural disparities further compound these challenges, reflecting broader systemic inequities. By identifying key correlates and domains of concern, our study underscores the urgent need for integrated medical, psychological, and social interventions tailored to the realities of under-resourced regions. Addressing QoL holistically, and not merely through a clinical lens, is essential for improving the lived experiences of thalassemia-affected families.

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