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PHYSICAL ACTIVITY RESTRICTION AND PAIN DUE TO SEDENTARY LIFESTYLE IN THE POPULATION WITH THALASSEMIA: AN OBSERVATIONAL STUDY

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Abstract: Thalassemia is a genetic disorder in which blood production is suppressed. Lack of awareness, family history, consanguineous marriages, and limited healthcare facilities are the prime factors for the spread of disease. The descriptive study was conducted from Jan -Dec 2024 at Muhammadi Blood Bank (MBB), Karachi. The study population ranged from infancy to under 18 years. Data collection involved Brief Pain Inventory - Short Form (BPI-SF), Family Nutrition and Physical Activity (FNPA) and Wong-Baker Faces Scale (WBFS). Chi-square and ANOVA tests were assessed to understand the relationship between pain and various health and lifestyle factors. In this study, 77 children were included, with 44.2% male and 55.8% female (±11 years). Pain prevalence was high from infancy to early childhood and decreased with age, especially in the lower limbs and head, mainly impacting the quality of life. Headaches and lower limb pain were associated with walking difficulties and general activity (P=0.027). Children who avoided taking meals with family and spent more than two hours daily on screen time showed higher pain interference and reduced walking ability. Those children who assisted in physical activities showed better pain management and lower pain. These results focus on the combined effects of pain and lifestyle on children's overall well-being. Integrating physical activity into thalassemia care in Pakistan is essential for managing pain and improving patients' quality of life.

Key words: Hemoglobin, Family Nutrition and Physical Activity, Wong-Baker Faces Scale, Thalassemia

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INTRODUCTION

Thalassemia is a hereditary disorder that is characterized by impaired hemoglobin production due to genetic mutations in the globin genes, which leads to ineffective development of red blood cells. Hemoglobin serves the purpose of carrying oxygen to the red blood cells (Aksu, and Unal, 2021). The occurrence of thalassemia in more than 60 countries has been recognized by the World Health Organization (WHO) as the most widespread genetic blood disorder (Ul-Ain *et al*. 2011). Thalassemia is common in the Indian subcontinent, Southeast Asia, Mediterranean, and Middle Eastern countries and referred as the 'World Thalassemia Belt'. There are two main types of thalassemia, alpha and beta. It was reported that beta thalassemia is carried by 80-90 million people which constitutes 1.5 % of the world's population (Origa. 2017). In Pakistan, Beta-thalassemia was reported between 5.0-7.0% and high reported cases (64%) were in Sindh province. The high number of carriers and increased occurrences of consanguineous marriages, limited genetic awareness, family history, and the neglect of prenatal and postnatal screening protocols are the vital reasons for the high birth rate of children carrying thalassemia major (https://ptgd.punjab.gov.pk/whats_thalassaemia, 2010).

Thalassemia's impact extends beyond physical health as patients often experience reduced physical activity due to pain, fatigue, and musculoskeletal complications (Fung et al., 2015). Some of the major clinical and psychological aspects of thalassemia affect the quality of life (Aksu, and Unal, 2021). Thalassemia patients suffer bone deformities, short stature, heart disease, diabetes and other unseen infections which lead to a poor self-image (Origa. 2017; Telfer et al., 2005; Mikelli and Tsiantis, 2004) Physical therapy plays a pivotal role in enhancing the health-related quality of life in patients with thalassemia. It alleviates common symptoms such as fatigue, pain, depression, and anxiety.Therapeutic interventions including yoga, massage, exercise training, spirometry, TENS, and vibration therapy have been shown to improve bone mineral density, cardiopulmonary function, and biochemical markers such as serum ferritin levels

(Baraz et al., 2016; Lyrakos et al.,2012).Thalassemia is one of the most prevalent inherited blood disorders in Pakistan and poses a significant public health burden. Despite advances in the management of thalassemia, pain remains an under recognized and underreported symptom, particularly in pediatric populations. Pain may discourage participation in physical activities, leading to a more sedentary lifestyle that can further contribute to physical deconditioning, reduced functional capacity, and poorer quality of life. Additionally, lifestyle factors such as excessive screen time and reduced participation in daily physical activities may influence pain perception and overall health outcomes. In Pakistan, research focusing on the relationship between pain, physical activity restrictions, and sedentary behavior among children with thalassemia is limited. Most existing studies emphasize clinical and haematological aspects of the disease, while the impact of lifestyle factors on pain and daily functioning remains insufficiently explored. Understanding these associations is essential for developing comprehensive management strategies that extend beyond medical treatment and address modifiable behavioral factors.

This study aims to assess the physical, social, and psychological consequences of thalassemia and to assess the physical activity and sedentary behaviour of thalassemia patients and evaluate pain severity, interference, and relief.

MATERIALS AND METHODS

Study population

This cross-sectional study was conducted over one year (2025). The participants were thalassemia patients aged from infancy to less than 18 years receiving treatment at Muhammadi Blood Bank (MBB) Karachi, Pakistan. A total of 77 patients were selected using non-probability purposive sampling.

Inclusion and exclusion criteria

Inclusion criteria included a confirmed diagnosis of thalassemia through medical records, regular treatment, including transfusions and hematology evaluations, and the ability to provide informed consent or assent (with guardian consent for minors). Patients with severe comorbid conditions, recent surgeries, injuries, or cognitive impairments that hindered the reliable completion of questionnaires were excluded from the study.

Ethical approval

The study was exempted from full review by the institute's Ethics Review Committee (ERC number: PGC-ERC/2024-03/06).The committee waived the requirement for informed consent. The Ethics Review Committee approved a waiver of parental consent because the research posed no more than minimal risk to participants, the rights and welfare of participants were not adversely affected, and obtaining parental consent was impracticable. Child assent was obtained from all participants prior to participation. Regardless of the consent procedure, all eligible children were provided with age-appropriate information regarding the purpose, procedures, voluntary nature, and confidentiality of the study.

Data collection

The study was designed as a multi-part questionnaire that included demographic characteristics such as age, gender, and medical history to evaluate pain intensity and its interference with daily activities. Family Nutrition and Physical Activity Screening Tool (FNPA) and Wong-Baker FACES Pain Rating Scale (WBFS) were used to assess physical activity, lifestyle behaviors and pain intensity in pediatric patients.

Statistical analysis

Data were analyzed using SPSS version 23.0 with descriptive statistics and inferential tests (chi-square & ANOVA). Statistical significance was set at $p<0.05$.significance was set at $p<0.05$.

RESULTS

A total of 77 children were included in this study, having <18 years and mean age was 11 years. In this study, gender distribution was 44.2% male and 55.8% female, and the ratio was 1.26. The majority of participants were in the middle childhood group 6-12 years (63.6%), followed by adolescents having 13-18 years (33.8%), and infancy to early childhood 0-5 years (2.6%). Statistical analysis showed no significant differences in gender distribution across age groups ($p = 0.950$) (Table 1).

The severity of the pain was found in the age group 0-5 years (100%), while a decline was observed at the age of 13-18 years (69.2%). However, this decrease was not statistically significant ($p=0.439$), and most patients experienced mild pain, mainly localized to the lower limbs (WBF Scale) (Table 1).

Eating meals with family was significantly associated with low pain interference scores ($p < 0.001$). The current data represent that children who did not have meals with family had higher pain in general activity, walking ability, and their temper mood (Table 2). It was reported that screen time >2 hours was associated with increased pain interference ($p = 0.006$) and adverse effects on general activity ($p = 0.040$), walking ability ($p = 0.033$), and sleep quality ($p = 0.028$) (Table 2).

Physical activity during free time and participation in organized sports showed significant positive effects on mood ($p = 0.006$, $p < 0.001$) and walking ability ($p = 0.013$). Physical activity with family members was linked to lower pain ratings ($p = 0.044$). No significant impact was observed on general activity, sleep interference, or pain severity ($p > 0.05$) (Table 2).

DISCUSSION

Thalassemia is highly prevalent in low-income countries, where it imposes significant psychological, social, and financial burdens on patients and their caregivers (Yousuf, *et al.* 2022). In Pakistan, the carrier rate is between 5–8% and in India 37.90% (Khaliq, 2022; Yadav *et al*. 2022).

In our study male were 44.2% and female 55.8% , which aligns with previous studies conducted in the USA, where 61% of thalassemia patients were male and 39% were female (Fung *et al*. 2022). The findings highlight the importance of

understanding gender and age-related differences in the presentation of pain.

In current study it was found that sedentary behavior was linked to an increase in pain, while physical activity was associated with improvements in mood, mobility, and reduced pain interference. Previous studies also support these findings, suggesting that physical activity and family support can improve overall well-being and alleviate pain in children and adolescents suffering from thalassemia ((Goldberg *et al*. 2022; Leite *et al.* 2023; Shah *et al*. 2021).

Paracetamol was the most frequently used medication in our cohort, who aligns with previous studies; however, it is important to note that the metabolism of Paracetamol might vary in thalassemia patients. Moreover, vitamin D deficiency was commonly observed in these patients, contributing to musculoskeletal issues and possibly worsening pain severity (Goldberg, *et al*. 2022).

Eating meals with family was significantly associated with low pain interference scores ($p < 0.001$). The current data represent that children who did not have meals with family had higher pain in general activity, walking ability, and their temper mood (Table 2). It was reported that screen time >2 hours was associated with increased pain interference ($p = 0.006$). and adverse effects on general activity ($p = 0.040$), walking ability ($p = 0.033$), and sleep quality ($p = 0.028$) (Table 2). Physical activity during free time and participation in organized sports showed significant positive effects on mood ($p = 0.006$, $p < 0.001$) and walking ability ($p = 0.013$). Physical activity with family members was linked to lower pain ratings ($p = 0.044$). No significant impact was observed on general activity, sleep interference, or pain severity ($p > 0.05$) (Table 2).

Table 1: Age-wise distribution of participants

Variables	Infancy to Early Childhood	Middle Childhood	Adolescence	Total	X2	P-value
Age in Years	3.50 ± 0.7	9.69 ± 1.9	14.08 ± 1.0	11.01 ±2.9	76.9	**<0.001**
Gender						
Male	1(50.0)	21(42.9)	12(46.2)	34(44.2)	0.103	0.950
Female	1(50.0)	28(57.1)	14(53.8)	43(55.8)		
Pain prevalence	2(100)	39(79.6)	18(69.2)	59(76.6)	1.645	0.439
Pain interference mean	7.7143 ±1.616	4.075± 2.4122	4.2198 ±2.2301	4.2198 ±2.3012	2.317	0.106
Area of pain						
Headache	0(0.0)	6(12.2)	5(19.2)	11(14.3)		
Lower limb	1(50.0)	21(42.9)	11(42.3)	33(42.9)		
None	0(0.0)	10(20.4)	8(30.8)	18(23.4)	11.130	0.194
Other	1(50.0)	4(8.2)	0(0.0)	5(6.5)		
Upper limb	0(0.0)	8(16.3)	2(7.7)	10(13.0)		
Pain severity						
No pain	0(0.0)	2(4.1)	1(3.8)	3(3.9)		
Mild pain	2(100)	36(73.5)	19(73.1)	57(74.0)	0.726	0.948
Moderate pain	0(0.0)	11(22.4)	6(23.1)	17(22.1)		
Pain severity mean	3.500±1.412	3.413±1.718	3.471±1.657	3.435±1.671	**0.011**	0.989
WBF pain rating scale	7.00±1.414	4.08±2.613	4.00±2.884	4.13±2.702	1.172	0.315
Hemoglobin Levels	8.100 ±1.4142	7.216±1.3298	6.877±1.1462	7.125 ±1.2755	1.208	0.305
Medication	2(100)	36(73.5)	18(69.2)	56(72.7)	0.924	0.630
Treatment						
None	0(0.0)	13(26.5)	8(30.8)	21(27.3)		
Other	0(0.0)	11(22.4)	6(23.1)	17(22.1)	2.195	0.700
Paracetamol	2(100)	25(51.0)	12(46.2)	39(50.6)		

Pain commonly affects multiple body regions, leading to a decline in overall quality of life. Headaches and lower limb pain were linked with interference in general activity ($p = 0.007$, $p = 0.027$), mood ($p = 0.012$), walking ability ($p = 0.002$), and enjoyment of life ($p = 0.015$) (Figure 1).

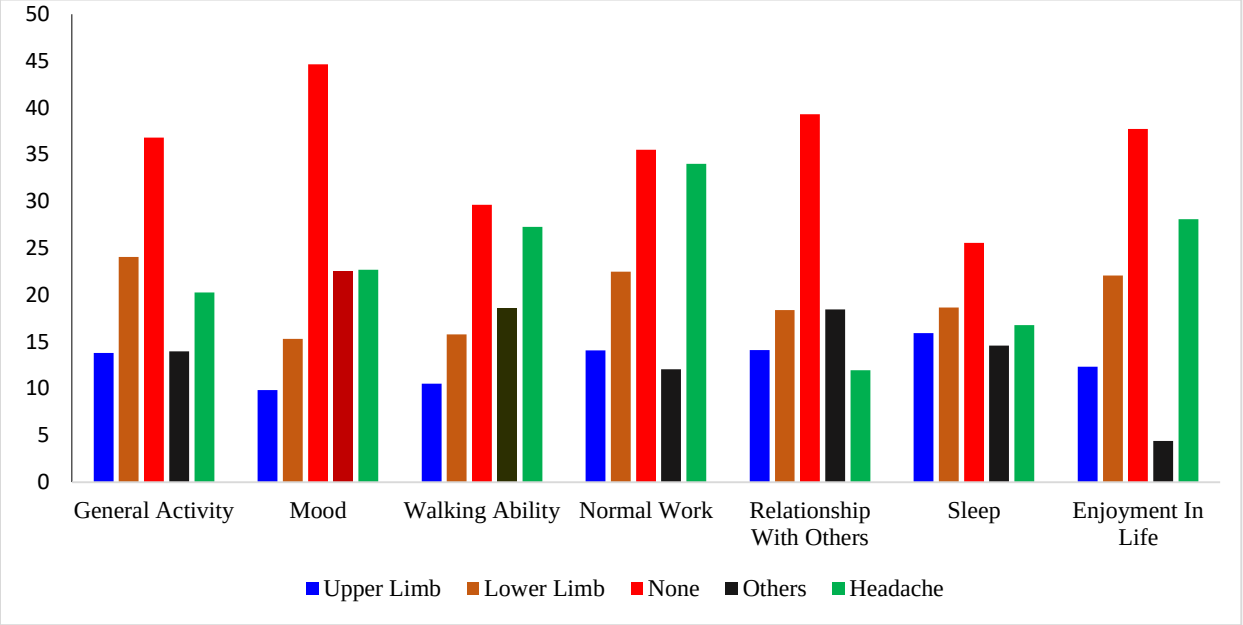

Figure 1: Co-relation between pain location and pain interference

Table 2: Association of Healthy Behaviors related to Meal, Screen Time, Sleep and Physical Activity

Variables	Meal	Screen Time	Sleep	Physical activity	Physical activity with Family	Physical activity Free Time	Physical activity with coach
Pain Severity Mean (SD)	3.435 (1.671)	3.435 (1.671)	3.435 (1.671)	3.435 (1.671)	3.435 (1.671)	3.435 (1.671)	3.435 (1.671)
Statistical Value (P-value)	1.605 (0.196)	0.732 (0.536)	2.412 (0.074)	0.922 (0.435)	0.964 (0.415)	0.003 (1.000)	0.819 (0.488)
Pain Interference Mean (SD)	4.218 (2.383)	4.218 (2.383)	4.218 (2.383)	4.218 (2.383)	4.218 (2.383)	4.218 (2.383)	4.218 (2.383)
Statistical Value (P-value)	6.434 (0.001)	4.507 (0.006)	0.951 (0.421)	2.204 (0.095)	0.653 (0.584)	0.238 (0.869)	2.569 (0.061)
Interference with General Activity Mean (SD)	4.36 (2.675)	4.36 (2.675)	4.36 (2.675)	4.36 (2.675)	4.36 (2.675)	4.36 (2.675)	4.36 (2.675)
Statistical Value (P-value)	3.076 (0.033)	2.907 (0.040)	0.082 (0.970)	1.199 (0.316)	1.657 (0.184)	1.184 (0.322)	1.549 (0.209)
Interference with Mood Mean (SD)	4.489 (3.140)	4.489 (3.140)	4.489 (3.140)	4.489 (3.140)	4.489 (3.140)	4.489 (3.140)	4.489 (3.140)
Statistical Value (P-value)	9.198 (0.001)	1.547 (0.210)	1.043 (0.379)	2.425 (0.073)	1.764 (0.162)	4.425 (0.006)	6.379 (<0.001)
Interference with Walking Ability Mean (SD)	3.94 (2.597)	3.94 (2.597)	3.94 (2.597)	3.94 (2.597)	3.94 (2.597)	3.94 (2.597)	3.94 (2.597)
Statistical Value (P-value)	8.759 (0.001)	3.072 (0.033)	4.705 (0.005)	3.821 (0.013)	0.228 (0.877)	0.414 (0.744)	2.542 (0.063)
Interference with Sleep Mean (SD)	4.65 (2.680)	4.65 (2.680)	4.65 (2.680)	4.65 (2.680)	4.65 (2.680)	4.65 (2.680)	4.65 (2.680)
Statistical Value (P-value)	2.003 (0.121)	3.219 (0.028)	0.120 (0.948)	2.270 (0.088)	1.191 (0.319)	0.929 (0.431)	1.301 (0.281)
WBF-Pain Rating Scale Mean (SD)	4.13 (2.702)	4.13 (2.702)	4.13 (2.702)	4.13 (2.702)	4.13 (2.702)	4.13 (2.702)	4.13 (2.702)
Statistical Value (P-value)	4.043 (0.010)	0.290 (0.833)	0.036 (0.991)	0.225 (0.878)	2.841 (0.044)	1.610 (0.194)	2.630 (0.056)

DISCUSSION

Thalassemia is highly prevalent in low-income countries, where it imposes significant psychological, social, and financial burdens on patients and their caregivers10. In Pakistan, the carrier rate is between 5-8% and in India 37.90% (Yadav *et al*. 2022; Fung *et al*. 2022). In our study male were 44.2% and female 55.8% , which aligns with previous studies conducted in the USA, where 61% of thalassemia patients were male and 39% were female (Fung *et al*. 2022). The findings highlight the importance of understanding gender and age-related differences in the presentation of pain. Our study found that sedentary behavior was linked to an increase in pain, while physical activity was associated with improvements in mood, mobility, and reduced pain interference. Previous studies also support these findings, suggesting that physical activity and family support can improve overall well-being and alleviate pain in children and adolescents suffering from thalassemia (Goldberg, *et al*. 2022; Leite *et al*. 2023; Shah *et al*. 2021)**.** Paracetamol was the most frequently used medication in our cohort,which aligns with previous studies; however, it is important to note that the metabolism of paracetamol might vary in thalassemia patients. Moreover, vitamin D deficiency was commonly observed in these patients, contributing to musculoskeletal issues and possibly worsening pain severity (Goldberg, *et al*. 2022). It was found that musculoskeletal pain particularly in the lower limbs is highly prevalent in children of school-going age. This finding is consistent with other studies that have reported that calves and lower back areas are common sites for pain in thalassemia patients (Fung *et al*. 2022; Lal, 2016). This pain can have a significant impact on the quality of life affecting daily activities such as walking, mood, and general activity. Regular family meals were associated with lower pain interference which could be attributed to the positive social support. Physical activities with family members were associated with lower pain ratings and better walking ability. This underscores the value of promoting both individual and family-oriented activities to manage pain and improve overall well-being in children with thalassemia.

The limitations of the study includes it is a single center study, which limits the diversity of the population with thalassemia that could be included in our study, a small sample size which could potentially affect the generalizability of the study, interventional studies could further elaborate the causative effects of mentioned variables on health outcomes.

CONCLUSIONS

The findings highlight the major impact of pain on multiple dimensions of quality of life in children with thalassemia. Behavioral factors, such as family meals, reduced screen time, and physical activity, emerged as potential moderators of pain interference. The study highlights the major benefits of adopting physical activity in handling pain and improving the quality of life for patients with thalassemia. These observations support adapting physical activity as a standard part of thalassemia care, advocating a comprehensive approach to functional improvement and pain management. The study enforces the necessity for public health initiatives and focuses on improving access to physiotherapy with exercise programs for this population.

Conflict of interest

Authors declare no conflict of interest

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