

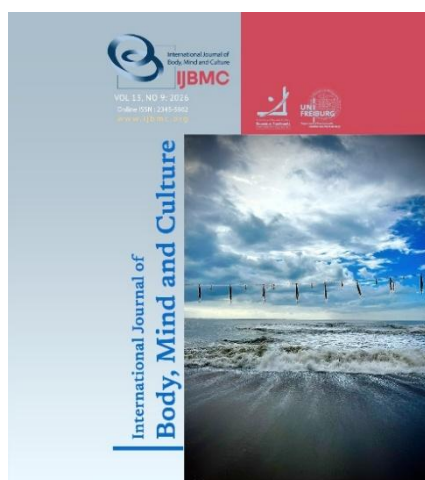
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1 Babylon Health Directorate, Babylon, Iraq.
2 Pediatric Health Nursing, College of Nursing,
University of Babylon, Babylon, Iraq.

Corresponding author email address:
nur.mohammad.talib@uobabylon.edu.iq

Association of Family Management Styles with Health-Related Quality of Life among Children with Thalassemia

Dunya Fahem. Shakir¹ , Mohammed Talib. Abed^{2*} 



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ABSTRACT

Objective: To examine the association between family management and HRQoL among children with thalassemia and to identify sociodemographic and clinical factors associated with both outcomes.

Methods and Materials: A descriptive correlational study was conducted at the Hereditary Blood Diseases Center in Babylon Governorate, Iraq. A purposive sample of 205 families of children aged 6-18 years completed an Arabic version of the Family Management Measure and the PedsQL 4.0 Parent Proxy-Report. Descriptive statistics, bivariate tests, Spearman correlation, and multiple linear regression were performed in SPSS 27.

Findings: Most families had a moderate family-management level (94.1%; mean total score = 158.03, SD = 17.94), whereas 56.1% of children were classified in the low HRQoL category (mean raw score = 28.61/92, SD = 12.06). Overall family management was positively associated with HRQoL ($\rho = .489$, $p < .001$). In adjusted analysis, family management remained the strongest correlate of HRQoL ($\beta = .443$, $p < .001$); maternal education and family type were positively associated with HRQoL, whereas illness duration was negatively associated.

Conclusion: More effective family management was associated with better parent-reported HRQoL among children with thalassemia. Family-centered nursing support, caregiver education, and attention to long-term disease burden may be important components of comprehensive thalassemia care, while the cross-sectional design precludes causal inference.

Keywords: Family Management, Thalassemia, Children, Health-Related Quality of Life, Family-Centered Care.

Introduction

Thalassemia is an inherited hemoglobin disorder caused by reduced or absent synthesis of alpha- or beta-globin chains. Clinical expression ranges from asymptomatic carrier states to severe transfusion-dependent anemia requiring lifelong monitoring and treatment (Baird et al., 2022; Khare et al., 2024). The disease remains concentrated in the Mediterranean, Middle East, South Asia, and Southeast Asia, and its chronic treatment burden extends well beyond hematologic management to school participation, emotional well-being, family routines, and healthcare utilization (Arioua & Shaw, 2025; Hockenberry et al., 2022). Iraqi patients also face the cumulative demands of repeated transfusions and long-term follow-up, making family participation especially important (Alshihmani et al., 2025).

Health-related quality of life (HRQoL) is a multidimensional outcome that reflects physical, emotional, social, and school functioning from the perspective of the child or a proxy respondent. Studies across several countries have consistently documented reduced HRQoL in children and adolescents with thalassemia, although the magnitude of impairment varies with clinical status, transfusion dependence, age, socioeconomic conditions, and access to support (Mikael & Al-Allawi, 2018; Shafie et al., 2020; Ababneh et al., 2025). Recent Iraqi evidence has similarly shown substantial physical and psychological burden in school-age children with major thalassemia (Abood & Hasan, 2025).

Family management provides a useful framework for understanding how families define a child's chronic condition, organize daily care, coordinate treatment, and integrate disease-related demands into ordinary family life. The Family Management Measure (FaMM) captures six dimensions: Child's Daily Life, Condition Management Ability, Condition Management Effort, Family Life Difficulty, Parental Mutuality, and View of Condition Impact (Knafl et al., 2011). These dimensions reflect both family strengths and perceived management burden. Across pediatric chronic conditions, family-management patterns have been associated with child and family functioning (Knafl et al., 2013; Im et al., 2019; Xia et al., 2025).

In thalassemia specifically, repeated transfusions, chelation, hospital visits, school absence, financial demands, and

uncertainty may place sustained pressure on family routines. Prior studies have linked stronger family management and family well-being with better child outcomes and HRQoL (Chusri et al., 2016; Chusri et al., 2019; Thiagarajan et al., 2019; Adly et al., 2023). Family support is also salient in Iraq, where recent evidence indicates that parental psychological support varies with education and residence among families of children with thalassemia (Sahib & Mohammed, 2025).

Despite this evidence, data from central Iraq remain limited, and family management may operate differently across cultural, socioeconomic, and healthcare contexts. The present study therefore examined family management and parent-reported HRQoL among children with thalassemia attending a specialized center in Babylon Governorate. The study addressed four questions: (1) what level of family management is reported by participating families; (2) what level of HRQoL is reported for affected children; (3) how are family management and HRQoL associated; and (4) which selected sociodemographic and clinical characteristics are associated with these outcomes?

Methods and Materials

Study Design and Setting

A descriptive correlational, cross-sectional design was used. The study was conducted at the Hereditary Blood Diseases Center in Babylon Governorate, Iraq. The overall study period extended from September 1, 2025, to May 1, 2026, and primary data collection was conducted from December 8, 2025, to February 8, 2026. The target population comprised families of children aged 6-18 years with a confirmed diagnosis of thalassemia who attended the center.

Sample Size and Sampling

The required sample size was estimated from an accessible population of approximately 540 eligible children using the finite-population sample-size formula with $z = 1.96$, $p = .50$, and $e = .05$ (Daniel, 1999). The resulting estimate was 224.47, rounded to 225. Twenty participants were used in the pilot phase and excluded from the main analysis, leaving 205 families in the final study sample. Participants were recruited by purposive sampling. Eligibility required a child aged 6-18 years with a confirmed thalassemia diagnosis and a parent or primary caregiver directly involved in the child's daily care.

Measures

Sociodemographic and clinical questionnaire. Parent variables included age, primary-caregiver status, residence, educational attainment, occupational status, monthly family income, household size, and family type. Child variables included age, sex, illness duration, birth order, transfusion frequency, and the number of children with thalassemia in the family.

Family Management Measure (FaMM). The FaMM is a 53-item measure developed to assess how families incorporate management of a child's chronic condition into everyday family life (Knafl et al., 2011). It contains six dimensions. Higher scores indicate more favorable management on Child's Daily Life, Condition Management Ability, and Parental Mutuality, whereas higher scores indicate greater management burden on Condition Management Effort, Family Life Difficulty, and View of Condition Impact. Eighteen reverse-worded items were reverse-scored within their respective domains. For the study-specific overall composite, the three negatively oriented domains were additionally direction-aligned so that higher composite values consistently represented more effective family management. Because the FaMM was originally developed as a multidimensional instrument, domain-specific results were also retained and interpreted separately.

PedsQL 4.0 Parent Proxy-Report. HRQoL was assessed using the 23-item Pediatric Quality of Life Inventory 4.0 Generic Core Scales parent proxy-report, covering physical, emotional, social, and school functioning (Varni et al., 2001). Responses were coded so that higher values represented fewer problems and better HRQoL: Always = 0, Often = 1, Sometimes = 2, Rarely = 3, and Never = 4. A raw summed score from 0 to 92 was used in the study; this raw score is linearly equivalent to a 0-100 transformed score when multiplied by 100/92. For descriptive classification, the raw total was divided into equal intervals: low (0-30), moderate (31-61), and high (62-92). No missing questionnaire data were identified in the final analytic sample.

Translation, Content Validity, and Reliability

Both instruments were translated into Arabic using forward and backward translation by bilingual experts. Content validity was reviewed by a panel of 16 experts from Iraqi universities with at least 14 years of relevant experience, and wording was refined in response to their feedback. A pilot study was

conducted to assess clarity and feasibility. In the main study, internal consistency was acceptable for the family-management composite (Cronbach's alpha = .794) and excellent for the HRQoL scale (alpha = .920).

Data Collection and Ethical Considerations

Data were collected through structured face-to-face interviews lasting approximately 25-35 minutes. Parents serving as the child's primary caregiver completed the study instruments, and the PedsQL was administered only in the parent proxy-report format. Ethical approval was obtained from the Scientific Research Ethics Committee at the College of Nursing, University of Babylon, followed by administrative permission from the Babylon Health Directorate and the participating center. Verbal informed consent was obtained from participating parents after explanation of the study purpose, confidentiality protections, voluntary participation, and the right to withdraw without consequences.

Statistical Analysis

Data were analyzed in SPSS version 27. Descriptive statistics included frequencies, percentages, means, standard deviations, and observed ranges. Distributional assumptions were examined with the Kolmogorov-Smirnov test. Because family-management scores were non-normally distributed, Spearman correlation, Mann-Whitney U tests, and Kruskal-Wallis tests were used as appropriate. HRQoL scores were approximately normally distributed; Pearson correlation, independent-samples t tests, and one-way analysis of variance were therefore used for HRQoL subgroup analyses. The primary association between family management and HRQoL was evaluated with Spearman's rho because one of the two variables was non-normal. Multiple linear regression was then used to examine whether family management remained associated with HRQoL after adjustment for sociodemographic and clinical covariates. Statistical significance was set at two-sided $p < .05$. The numerous subgroup comparisons were considered exploratory and were interpreted cautiously because no formal multiplicity correction was applied.

Findings and Results

Family Management and HRQoL Levels

Among the 205 participating families, 193 (94.1%) were classified in the moderate family-management category, while 8 (3.9%) were in the low category and 4 (2.0%) were in the high category. The observed family-management total ranged from 110 to 203, with a mean of 158.03 (SD = 17.94). These results are summarized in [Table 1](#).

Table 1

Distribution of family-management levels among families of children with thalassemia

Level	Study-defined range	n (%)	Observed Min-Max	Mean $\pm$ SD
Low	53-123	8 (3.9%)		
Moderate	124-194	193 (94.1%)		
High	195-265	4 (2.0%)		
Total	53-265	205 (100%)	110-203	158.03 $\pm$ 17.94

Note. The overall composite was direction-aligned so that higher scores represented more effective family management. The low/moderate/high categories were study-defined equal intervals of the theoretical total-score range.

For HRQoL, 115 children (56.1%) were classified in the low category, 89 (43.4%) in the moderate category, and 1 (0.5%) in the high category. The mean raw summed HRQoL score was 28.61 (SD = 12.06) on the 0-92 study scale, equivalent to approximately 31.1 on a 0-100 linear transformation. The distribution is presented in [Table 2](#).

Table 2

Distribution of parent-reported health-related quality-of-life levels

Level	Study-defined range	n (%)	Observed Min-Max	Mean $\pm$ SD
Low HRQoL	0-30	115 (56.1%)		
Moderate HRQoL	31-61	89 (43.4%)		
High HRQoL	62-92	1 (0.5%)		
Total	0-92	205 (100%)	5-62	28.61 $\pm$ 12.06

Note. The study used a raw 0-92 sum of 23 items coded 0-4 in the positive direction. The three descriptive categories were based on equal intervals of that raw range.

The contrasting distributions of family-management and HRQoL categories are illustrated in [Figure 1](#). The figure is descriptive and does not imply that the categorical thresholds are clinically validated cut points.

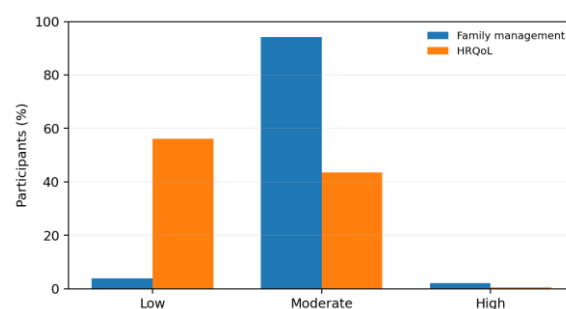


Figure 1. Distribution of family-management and HRQoL categories in the study sample.

Association between Family Management and HRQoL

Overall family management was moderately and positively associated with HRQoL ($\rho = .489$, $p < .001$). The domain-level pattern was theoretically coherent: Child's Daily Life, Condition Management Ability, and Parental Mutuality were positively associated with HRQoL, whereas Condition Management Effort, Family Life Difficulty, and View of Condition Impact were negatively associated. Family Life Difficulty showed the largest absolute domain-level correlation ($\rho = -.463$, $p < .001$). The complete set of correlations is shown in [Table 3](#).

Table 3

Correlations between family-management domains and health-related quality of life

Family-management domain	Spearman rho	p
Child's Daily Life (+)	.379	<.001
Condition Management Ability (+)	.214	.002
Condition Management Effort (-)	-.258	<.001
Family Life Difficulty (-)	-.463	<.001
Parental Mutuality (+)	.200	.004
View of Condition Impact (-)	-.347	<.001
Overall direction-aligned composite (+)	.489	<.001

Note. Positive-domain scores increase with more favorable management; negative-domain scores increase with greater perceived management burden. The overall composite was direction-aligned before summation.

Sociodemographic and Clinical Associations

Exploratory subgroup analyses identified several associations with the family-management mean item score. Better family management was observed among families in urban settings, those with higher parental education and higher income, employed mothers, and families in which the mother was the primary caregiver. Family size was inversely related to family-management score, and family management also differed by child sex and transfusion frequency. The detailed results are reported in [Table 4](#).

Table 4*Associations of family-management mean item scores with sociodemographic and clinical characteristics*

Characteristic	Subgroup	Mean item score	Test statistic	p
Father age group	< 30 years	3.11	$\rho = .024$	.732
Father age group	30-40 years	2.96		
Father age group	41-50 years	2.97		
Father age group	> 50 years	3.00		
Mother age group	< 30 years	3.07	$\rho = .034$	.627
Mother age group	30-40 years	2.93		
Mother age group	41-50 years	2.96		
Mother age group	> 50 years	3.15		
Primary caregiver	Mother	2.99	$Z = -2.176$	.030
Primary caregiver	Father	2.79		
Place of Residence	Urban	3.02	$Z = -2.390$	.017
Place of Residence	Rural	2.93		
Father education	Illiterate	2.82	$H = 29.217$	<.001
Father education	Literate	2.87		
Father education	Primary	2.96		
Father education	Intermediate	3.09		
Father education	Preparatory	3.13		
Father education	Diploma	3.07		
Father education	College and above	3.23	$H = 20.817$	.002
Mother education	Illiterate	2.93		
Mother education	Literate	2.83		
Mother education	Primary	2.95		
Mother education	Intermediate	3.11		
Mother education	Preparatory	3.19		
Mother education	Diploma	3.22	$Z = -1.942$	.052
Mother education	College and above	3.09		
Father occupation	Employed	3.02		
Father occupation	Unemployed	2.94	$Z = -2.413$	.016
Mother occupation	Employed	3.18		
Mother occupation	Unemployed	2.96	$H = 27.259$	<.001
Family monthly income	$\leq 500,000$ ID	2.89		
Family monthly income	501,000 - 1,000,000 ID	2.98		
Family monthly income	1,001,000-1,500,000 ID	3.14		
Family monthly income	> 1,500,000 ID	3.28	$\rho = -.182$	.009
Family size	Two - Three	3.11		
Family size	Four -Five	3.01		
Family size	More Than Five	2.95	$Z = -.731$	.465
Family type	Nuclear	2.96		
Family type	Extended	2.99	$\rho = .076$	.278
Child age	6 -12 School-Age	2.96		
Child age	13 - 18 Adolescent	2.99	$Z = -2.052$	.040
Child sex	Male	2.93		
Child sex	Female	3.01	$\rho = -.043$	.540
Birth order	First	2.97		
Birth order	Second - Third	3.00		
Birth order	Fourth - Fifth	2.92	$\rho = .020$	.775
Birth order	Bigger than fifth	2.97		
Duration of illness	< 5 years	2.97		
Duration of illness	5 - 10 years	2.99		
Duration of illness	11 - 15 years	2.93	$H = 27.505$	<.001
Duration of illness	> 15 years	2.99		
Frequency of blood transfusion	Once a month	3.01		
Frequency of blood transfusion	Twice a month	3.08		
Frequency of blood transfusion	More than twice	2.72	$\rho = -.085$	.227
Frequency of blood transfusion	As needed (irregular)	2.85		
Children with thalassemia in family	One	3.00		
Children with thalassemia in family	Two	2.99		
Children with thalassemia in family	Three or more	2.87		

Note. Mean values are mean item scores on the 1-5 family-management response metric, not low/moderate/high category codes. Spearman rho was used for ordered variables, Mann-Whitney U for two-group comparisons (reported as Z), and Kruskal-Wallis H for comparisons with more than two groups. These analyses were exploratory and were not adjusted for multiple comparisons.

For HRQoL, higher parental education and higher family income were associated with better mean item scores. HRQoL also differed by family type and transfusion frequency, while child age and duration of illness were

inversely correlated with HRQoL. Other examined characteristics were not statistically significant. Detailed subgroup results are provided in Table 5.

Table 5*Associations of HRQoL mean item scores with sociodemographic and clinical characteristics*

Characteristic	Subgroup	Mean item score	Test statistic	p
Father age group	< 30 years	1.08	r = -.070	.321
Father age group	30-40 years	1.33		
Father age group	41-50 years	1.16		
Father age group	> 50 years	1.29		
Mother age group	< 30 years	1.40	r = -.091	.197
Mother age group	30-40 years	1.24		
Mother age group	41-50 years	1.21		
Mother age group	> 50 years	1.20		
Primary caregiver	Mother	1.25	t = .641	.522
Primary caregiver	Father	1.16		
Place of Residence	Urban	1.28	t = .938	.349
Place of Residence	Rural	1.21		
Father education	Illiterate	1.27	F = 3.167	.005
Father education	Literate	1.02		
Father education	Primary	1.19		
Father education	Intermediate	1.29		
Father education	Preparatory	1.67		
Father education	Diploma	1.40	F = 5.804	<.001
Father education	College and above	1.51		
Mother education	Illiterate	1.21		
Mother education	Literate	.94		
Mother education	Primary	1.20		
Mother education	Intermediate	1.56	t = .601	.549
Mother education	Preparatory	1.73		
Mother education	Diploma	1.36		
Mother education	College and above	1.47		
Father occupation	Employed	1.27		
Father occupation	Unemployed	1.23	t = .979	.329
Mother occupation	Employed	1.39		
Mother occupation	Unemployed	1.23	F = 2.813	.040
Family monthly income	≤ 500,000 ID	1.17		
Family monthly income	501,000 - 1,000,000 ID	1.29		
Family monthly income	1,001,000-1,500,000 ID	1.32		
Family monthly income	> 1,500,000 ID	1.64	r = -.017	.807
Family size	Two - Three	1.34		
Family size	Four -Five	1.18		
Family size	More Than Five	1.26	t = -3.271	.001
Family type	Nuclear	1.17		
Family type	Extended	1.43	r = -.179	.010
Child age	6 -12 School-Age	1.33		
Child age	13 - 18 Adolescent	1.16	t = -.551	.582
Child sex	Male	1.26		
Child sex	Female	1.24	r = .075	.284
Birth order	First	1.20		
Birth order	Second - Third	1.28		
Birth order	Fourth - Fifth	1.18		
Birth order	Bigger than fifth	1.41	r = -.260	<.001
Duration of illness	< 5 years	1.71		
Duration of illness	5 - 10 years	1.33		
Duration of illness	11 - 15 years	1.23		
Duration of illness	> 15 years	1.07	F = 2.919	.035
Frequency of blood transfusion	Once a month	1.30		
Frequency of blood transfusion	Twice a month	1.24		
Frequency of blood transfusion	More than twice	1.02		
Frequency of blood transfusion	As needed (irregular)	1.39	r = -.089	.206
Children with thalassemia in family	One	1.27		
Children with thalassemia in family	Two	1.27		
Children with thalassemia in family	Three or more	1.11		

Note. Mean values are mean item scores on the 0-4 positively oriented HRQoL coding metric; multiplying by 25 yields the corresponding 0-100 linear score. Pearson r was used for continuous/ordered variables as specified in the source analysis, independent-samples t tests for two-group comparisons, and one-way ANOVA for variables with more than two groups. These subgroup tests were exploratory and unadjusted for multiplicity.

Adjusted Association with HRQoL

The multiple linear regression model explained 42.5% of the variance in HRQoL ($R = .652$, $R^2 = .425$; adjusted $R^2 = .370$). Family management was the strongest independent correlate of HRQoL ($\beta = .443$, $p < .001$). Maternal education ($\beta = .257$, $p = .001$) and family type ($\beta = .209$, $p = .002$) were positively associated with HRQoL, whereas

longer illness duration was negatively associated (beta = -.396, $p = .012$). The remaining covariates were not statistically

significant in the adjusted model. Regression estimates are shown in Table 6.

Table 6

Multiple linear regression of health-related quality of life

Predictor	B	beta	t	p	95% CI for B
Family management	.677	.443	6.508	<.001	[.472, .882]
Father age	.001	.008	.080	.936	[-.012, .013]
Mother age	-.005	-.068	-.664	.508	[-.019, .009]
Primary caregiver	-.041	-.021	-.359	.720	[-.267, .185]
Residence	-.001	-.001	-.011	.991	[-.127, .126]
Father education	-.002	-.006	-.082	.934	[-.050, .046]
Mother education	.095	.257	3.345	.001	[.039, .151]
Father occupation	-.039	-.036	-.442	.659	[-.210, .133]
Mother occupation	.171	.077	1.088	.278	[-.139, .481]
Family monthly income	.031	.054	.619	.536	[-.068, .131]
Family size	.013	.043	.540	.590	[-.035, .061]
Family type	.243	.209	3.116	.002	[.089, .396]
Child age	.023	.179	1.096	.274	[-.018, .064]
Child sex	.021	.020	.341	.734	[-.102, .145]
Birth order	.039	.123	1.368	.173	[-.017, .095]
Duration of illness	-.047	-.396	-2.538	.012	[-.084, -.011]
Transfusion frequency	.041	.075	1.150	.252	[-.030, .112]
Children with thalassemia in family	-.014	-.019	-.306	.760	[-.106, .077]

Note. Model statistics: $R = .652$, $R^2 = .425$, adjusted $R^2 = .370$. B = unstandardized coefficient; beta = standardized coefficient; CI = confidence interval. Coefficients reflect the coding scheme used in the study dataset.

Discussion and Conclusion

This study examined how families manage childhood thalassemia and how family management is associated with parent-reported HRQoL in a specialized Iraqi care setting. Three findings are especially important. First, almost all families fell within the moderate family-management category. Second, more than half of the children were classified as having low HRQoL. Third, family management showed a moderate positive association with HRQoL and remained the strongest correlate in the adjusted model, although the cross-sectional design does not establish temporal or causal direction.

The predominance of moderate family management is broadly consistent with reports from families caring for children with thalassemia in other settings (Chusri et al., 2016; Sumadon et al., 2020). A moderate profile may reflect the dual reality of chronic illness management: families can develop routines and competence over time while still experiencing substantial effort, disruption, and uncertainty. Evidence from broader pediatric chronic-disease research similarly suggests that family management is not a simple dichotomy between effective and ineffective care, but a multidimensional pattern that incorporates perceived normalcy, management confidence, effort, family-life disruption, and shared caregiving (Knafl et al., 2013; Sutthisompohn & Kusol, 2021).

The low HRQoL observed in a large proportion of children is also consistent with prior thalassemia literature. Studies from

Iraqi Kurdistan and Basrah have documented clinically important quality-of-life limitations in children and adolescents with thalassemia (Mikael & Al-Allawi, 2018; Hameed et al., 2024). Similar impairment has been reported in other countries (Abdel Hakeem et al., 2018; Shafie et al., 2020; Nargis et al., 2025), while recent Iraqi work has highlighted both physical and psychological disadvantages among school-age children with major thalassemia (Abood & Hasan, 2025). Such findings are plausible given the cumulative burden of chronic anemia, transfusion schedules, school disruption, treatment fatigue, and psychosocial stress.

The positive association between the direction-aligned family-management composite and HRQoL is compatible with earlier thalassemia studies in which stronger family-management capacity or family well-being was associated with better child quality of life (Chusri et al., 2019; Thiagarajan et al., 2019; Adly et al., 2023). The domain-level findings strengthen this interpretation: Child's Daily Life, Condition Management Ability, and Parental Mutuality were positively related to HRQoL, whereas greater Condition Management Effort, Family Life Difficulty, and perceived Condition Impact were inversely related. This pattern is consistent with the conceptual structure of the FaMM rather than being driven solely by the constructed overall score.

The adjusted regression provides an additional perspective because family management remained associated with HRQoL after simultaneous consideration of demographic and clinical

covariates. This is consistent with research showing that family-management processes can contribute to child outcomes even in the presence of disease-related stressors (Im et al., 2019; Liu et al., 2020). However, the regression coefficients should not be interpreted as evidence that changing family management would necessarily produce a corresponding improvement in HRQoL. Reverse or reciprocal pathways are plausible: children with more severe or burdensome illness may simultaneously experience lower HRQoL and impose greater management demands on their families.

Several socioeconomic and family-context variables were associated with outcomes. Higher parental education and higher family income were linked with more favorable scores in bivariate analyses, and maternal education remained significant in the adjusted model. This pattern is consistent with evidence that caregiver knowledge, resource access, and healthcare navigation can shape the experience of chronic pediatric illness (Celik et al., 2024; Spurr et al., 2023). Family type was also independently associated with HRQoL. In an Iraqi context, extended-family networks may provide additional practical and emotional support, although this interpretation requires direct measurement of social support rather than inference from household structure alone. Recent Iraqi data likewise underscore the relevance of family support to the psychological needs of children with thalassemia (Sahib & Mohammed, 2025).

Longer illness duration was negatively associated with HRQoL in the adjusted model, and more frequent transfusion was associated with less favorable outcomes in exploratory analyses. These findings are clinically plausible because cumulative treatment exposure may increase school absence, procedural burden, fatigue, and disruption of ordinary activities. Similar associations between treatment burden and quality-of-life outcomes have been reported across transfusion-dependent populations (Purnamasari et al., 2025; Tsagkou et al., 2024). Family support may also influence adherence to transfusion schedules, reinforcing the need for family-centered rather than child-only care (Nurmansyah et al., 2024).

Clinical and Nursing Implications

The findings support a family-centered approach to thalassemia care. Nurses and multidisciplinary teams can assess not only treatment adherence but also how families perceive the child's daily life, confidence in managing the condition,

caregiving effort, family-life disruption, and parental mutuality. Structured education may be particularly useful for families with lower educational attainment or limited resources, while psychosocial support should address the cumulative burden of long-term treatment. Interventions that improve communication, problem solving, shared caregiving, and access to reliable health information may strengthen family capacity, although their effectiveness should be tested prospectively rather than assumed from the present associations (Gibson-Young et al., 2014; Punaglom & Mangkarakeree, 2020).

Quality-of-life assessment should also be incorporated into routine follow-up. Parent proxy-report is valuable, especially in younger or clinically burdened children, but it captures the caregiver's perception and may differ from the child's own experience (Rajmil & Herdman, 2019). When feasible, combining parent proxy-report with age-appropriate child self-report would provide a more complete clinical picture. Support for caregivers themselves is also relevant because the chronic illness may affect parental quality of life and social support needs (Chandra et al., 2022; Ibrahim et al., 2021).

Limitations

Several limitations should be considered. The purposive sample was recruited from a single specialized center, which may underrepresent families with limited access to specialist services and restrict generalizability beyond Babylon Governorate. The cross-sectional design establishes association only and cannot determine whether family management precedes HRQoL, whether child health shapes family management, or whether the relationship is reciprocal. All major variables were based on parent report, creating potential common-method and social-desirability bias, and the study did not include child self-report of HRQoL.

Measurement choices also warrant caution. The FaMM is fundamentally a multidimensional measure; the direction-aligned overall composite used in this study was a study-specific summary and should not replace interpretation of the six validated domains. Similarly, the PedsQL was analyzed as a 0-92 raw sum rather than the conventional 0-100 transformed scale, although the two are linearly equivalent under the coding used. The low/moderate/high categories for both instruments were study-defined equal intervals rather than externally validated clinical thresholds. Finally, multiple exploratory subgroup

comparisons were conducted without formal multiplicity correction, increasing the possibility of type I error. Future studies should use larger multisite probability samples, standard scoring conventions, child and parent reports, and longitudinal or intervention designs.

Among families of children with thalassemia attending a specialized center in Babylon, family management was generally moderate and parent-reported HRQoL was frequently low. More effective family management was moderately associated with better HRQoL, and the association remained statistically significant after adjustment for a broad set of sociodemographic and clinical factors. Maternal education and family type were positively associated with HRQoL, whereas longer illness duration was negatively associated. These findings support the relevance of family-centered assessment and caregiver support in thalassemia services, while emphasizing that prospective research is needed before causal conclusions or intervention effects can be inferred.

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Declaration of Interest

The authors declared no conflict of interest.

Ethical Considerations

Ethical approval was obtained from the Scientific Research Ethics Committee at the College of Nursing, University of Babylon, with subsequent administrative permission from the Babylon Health Directorate and the participating thalassemia center. Verbal informed consent was obtained from participating parents before data collection. Confidentiality and voluntary participation were maintained throughout the study.

Transparency of Data

De-identified study data may be made available by the corresponding author upon reasonable request, subject to institutional and ethical requirements.

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Authors' Contributions

Dunya Fahem Shakir contributed to data collection, data management, and preparation of the initial manuscript. Mohammed Talib Abed contributed to study supervision, methodology, interpretation of findings, and critical revision of the manuscript. Both authors approved the final manuscript.

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