Vol. 29, No. 2, 2025, Pages 1-15

Thi-Qar Medical Journal (TQMJ)

Thi-Qar Medical Journal was established in 2006 and is published by the College of Medicine, University of Thi-Qar, Iraq

ISSN (PRINT): 1992-9218 | ISSN (ONLINE): 3006-4791

www.jmed.utq.edu.iq utjmed@utq.edu.iq

Caregivers' burdens of Thalassemic Patients in Ranya city: A Cross-Sectional Study

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Received:2.5.2025
Revised:1.7.2025
Accepted:4.7.*2025*
DOI:

DOI: 10.32792/jmed.2025.29.18

Keywords:
Keywords1: Thalassemia
Keywords2: caregivers' burdens
Keywords3: physical burdens
Keywords4: psychosocial burdens

How to cite

Harem Hama Najm [1], Blend B. Ameen [2]. Caregivers' burdens of Thalassemia Patients in Ranya city: A Cross-Sectional Study. *Thi-Qar Medical Journal (TQMJ)*. **2025**;Volume (**29**) no.2: 1-15.

Thalassemia, a prevalent autosomal recessive disorder in Iraq with an incidence of 35.7 per 100,000. Affected individuals rely heavily on family caregivers for medical management and psychosocial support, which often results in significant caregiver emotional, mental, physical, and economic burden. This study aimed to identify the types of family caregivers' burdens of thalassemia patients and to find out the association between types of burden and among caregivers' and some sociodemographic characteristics. A cross-sectional study was conducted in thalassemia and hemophilia center in Rania City. from September 22, 2024 to the end of April, 2025. This study employed a census approach, including all thalassemia clients' caregivers who were directly involved in patient care, which was 65 caregivers who have been providing care for thalassemia patient. The data were collected using a constructed questionnaire based on a review of relevant literature and standardized psychological assessment tools. A total of 65 caregivers, all of them were patients mainly (67.7%) were mothers. The overall caregiver burden for physical and financial problems was high and moderate burdens for psychosocial health problems. The study also showed an association between caregivers' socioeconomic factors (lower education, lower income, and specific marital statuses) and physical and financial burdens. Caregivers of thalassemia patients experience significant physical and financial hardships, as well as moderately impacted psychological and social aspects. The Kurdistan Regional Government (KRG) should subsidize thalassemia treatments and partner with NGOs to ease the financial burden. The Ranya Center needs integrated mental health services and peer support groups.

Introduction:

Thalassemia is one of the most common hereditary blood conditions in the world, it is common in Southeast Asia, the Middle East, and the Mediterranean. Severe anemia may result from this genetic disorder, which is characterized by decreased hemoglobin synthesis (1). Many thalassemia patients are being put at risk of severe organ damage because the life-saving blood transfusions they get aren't properly balanced with accessible iron chelation therapy. Inadequate management of beta-thalassemia treatment transforms it into a significant burden for healthcare systems, particularly straining the limited resources of low- and middle-income nations (2). Geographically, β-thalassemia is more common in some areas than others; the Mediterranean region (Italy, Greece, and Cyprus), the Middle East (Iran, Iraq, and Saudi Arabia), and parts of Asia (India, Pakistan, and Bangladesh) have elevated β-thalassemia prevalences. (3). In Iraq, thalassemia is a prevalent autosomal recessive condition that affects 35.7 out of every 100,000 people. Beta thalassemia major is a potentially fatal illness with numerous consequences that, if left untreated, could result in early death (4). The last estimated total number of registered cases of thalassemia in Iraq is 13390, giving a prevalence of 3.4/10000 (5). A study in Iraq showed that about 66.0% of the patients were under 15 years of age, 78.8% of whom reported a related parent (consanguineous marriage). Thalassemia represented 75% of all hemoglobinopathies in Iraq (6).

Patients with thalassemia rely heavily on their family members. Family caregivers are truly essential in the lives of thalassemia patients. They provide a lifeline of emotional, physical, and financial support, making a huge difference in their loved one's ability to cope with this challenging condition. Often, these dedicated caregivers are parents, spouses, or other close family members who make incredible sacrifices, pouring their time and resources into meeting the constant needs of their loved one with thalassemia. While providing care is frequently viewed as kindness and compassion, it carries significant burdens. Caregivers often face immense emotional, mental, physical, and financial strain. This constant pressure can significantly impact their quality of life, leading to exhaustion, anxiety, depression, and even health issues (7).

Define caregiver burdens as pressures faced by caregivers of thalassemic patients that involve the physical and mental health of these caregivers. Caregivers play a variety of roles in meeting the needs of thalassemia patients, including scheduling and attending medical and hospital appointments, giving medication, taking care of the patient's psychological and emotional health, in addition to handling the financial pressure and struggle to pay continuing medical bills. It is usually expected of caregivers to maintain these obligations with their social, professional, and personal life, this balancing act can add even more stress and pressure to an already challenging situation. Caregivers frequently endure severe psychological discomfort, which includes feelings of guilt, anxiety, and powerlessness. Additionally, insufficient support systems and limited access to mental health resources for both the patient and the caregiver sometimes make the burden even worse. These challenges may cause the caregiver's personal health and well-being to decline, which might affect their capacity to provide patient care (8). Therefore, the goal of the current study is to identify the types of family caregivers' burdens of thalassemic patients and the association between caregivers' burden types and some sociodemographic characteristics.

Material and Methods:

Study design and ethical approval

Quantitative design a cross-sectional study design was conducted in thalassemia and hemophilia center in Ranya teaching hospital to assess the Caregivers' burdens of thalassemia patients in Rania City, Sulaimani, Iraq, from September 22, 2024 to the end of April, 2025. Ethical approval for the study was obtained from the University of Raparin/College of Nursing and the Ranya General Directorate of Health. Additionally, oral consent was obtained from all participants. Participants were assured that their data would remain anonymous and be used solely for research purposes.

Study population and data collection method

This study employed a census approach, including all thalassemic clients' caregivers who were directly involved in patient care, (N=65). The sample was chosen based on the inclusion criteria such as Caregivers who provided their consent to participate in this study, Caregivers who have been providing care for at least 6 months. The data were collected using a developed questionnaire form based on a literature review of similar studies and from standardized psychological assessment tools, including the Depression, Anxiety, and Stress Scale - 21 items (DASS-21) (9), and the Hopkins Symptom Checklist-25 (HSCL-25) (10), to assess the variables of the current study. The questionnaire consists of two parts. The first part focused on the demographic and work characteristics of the caregivers and the patient. The second part was the assessment portion, which included four sections. The first section assessed General physical health problems through 9 questions. The second section assessed caregivers' psychological problems by assessing depression and anxiety symptoms of caregivers through 34 question (Depression 17, and Anxiety 14). The third section is about assessing social burden via 14 questions. And section four about caregivers' financial problem via 7 questions. Data collection was carried out using a structured interview technique to gather quantitative data from participants. The researcher conducted face-to-face interviews with each participant to ensure accurate and reliable responses.

Scoring and Coding of the Data Collection Tool

To measure the information items accurately and statistically. the researcher used the following Likert scale and scores to find out the caregivers' burdens [Physical, Psychological (Depression and Anxiety), Social, and Financial] as the following: Always (2), Sometimes (1), and Never (0). For the burdens, scores were assigned as follows: "always" received 2 points for high burden, "sometimes" received 1 point, and "never" received 0 point. For reverse question, the scored have been reversed according to the grading process. After scoring, the cut-off point was used to categorized burdens as follows: high burden scores between 1.34 - 2. Moderate burdens 0.67-1.33. And low burdens 1- 0.66.

Validation and Reliability of the instrument and Data analysis

The questionnaire was validated by 19 experts, and a reliability test was performed through a pilot study conducted on 10% of the total study sample size. The pilot study aimed to identify and address any obstacles and ensure the feasibility of the research process. The Cronbach's alpha test indicated an acceptable consistency level as the following: Physical Activity Section = 0.805, Depression Section= 0.954, Anxiety Section = 0.975, Social Section = 0.816, Financial Section = 0.816, Overall Cronbach alpha Reliability for total 63 questions were = 0.970. The collected data were analyzed using SPSS software version 25. Descriptive measures, including frequency and percentage, were generated to describe the data. The Chi-square test was used to determine significant differences between categorical variables. For data sets with fewer than 10 cases, Fisher's exact test was used instead of the Chi-square test. A significance level of 0.05 was considered as the threshold for statistical significance.

Results:

Table 1. Socio-demographic characteristics of patients and his disease status N=65

No	Socio-demographic characteristics	Variables	Frequency	Percentage
1	Sex	Male	27	41.5
		Female	38	58.5
2	Age	1-5 years old	3	4.6
		6-10 years old	4	6.2
		11-15 years old	18	27.7
		16+ years old	40	61.5
3	Level of Education	Unable to Read and Write	4	6.2
		Primary School Graduate	9	13.8
		Secondary School Graduate	20	30.8
		Preparatory School Graduate	18	27.7
		Institute Graduate	11	16.9
		College Graduate	3	4.6
4	Occupational status	Self-Employed	19	29.2
		Student	38	58.5
		Unable to work	5	7.7
		Child	3	4.6
5	Duration of illness	1-10 years	7	10.8
		11-20 years	34	52.3
		21-30 years	21	32.3
		31-41 years	3	4.6
6	Type of thalassemia	Beta major	57	87.69
		Beta intermedia	8	12.31
7	Removed spleen	Yes	35	53.85
		No	30	46.15
8	Comorbidity	Diabetes mellitus	5	7.7

		Thyroidectomy	3	4.6
		Osteoporosis	2	3.1
		epilepsy	1	1.5
		None	54	83.1
9	Blood transfusion therapy	Every 14 days	7	10.8
		Every 21 days	37	56.9
		Every 28 days	15	23.1
		Every 30 days	1	1.5
		Every 60 days	5	7.7
10	How many months did iron chelation therapy last?	Every month	1	1.5
		Every 2 months	1	1.5
		Every3 months	63	96.9

Table1. shows A total of 65 thalassemic patients 58.5 were female and the most of them were aged 16 years or older (61.5%). (30.8 %) Of the thalassemic patients were secondary school graduates, followed by 27.7% who were graduates of preparatory school. Most of the respondents (58.5%) were students. More than half of the (52.3%) had thalassemia for 11 to 20 years. The majority (87.69%) were diagnosed with beta thalassemia major, and the rest had beta thalassemia intermedia. Additionally, over fifty percent of the individuals (53.85%) had undergone splenectomy. Among participants, the majority (83.1%) had no other morbidities associated with their condition. The results also showed that (56.9%) of the thalassemic patients required blood transfusions at intervals of 21 days, while a predominant (96.9%) received iron chelation treatment every three months, with only a negligible number receiving it at shorter intervals.

Table 2. Socio-demographic characteristics of caregivers with spouse relativeness, number of siblings, and number of thalassemia patients in the family N=65

No	Socio-demographic characteristics	Variable	Frequency	Percentage
1	Parent caregiver	Fathor	21	32.3
		Mother	44	67.7
2	Caregivers Age	30-35	8	12.3
		36-41	20	30.8
		42-47	16	24.6
		≥ 48	21	32.3
3	Caregivers Educational Level	Unable to Read and Write	22	33.8
		Able to Read and Write	17	26.2
		Primary School Graduate	10	15.4
		Secondary School Graduate	8	12.3
		Preparatory School Graduate	5	7.7
		Institute Graduate	3	4.6
4	Caregivers’ Occupational Status	Governmental Employee	6	9.2
		Self-Employee	6	9.2
		Retired	3	4.6
		Available Daily worker	6	9.2
		House wife	44	67.7
5	Residential Area	Urban	33	50.77
		Rural	25	38.46
		Suburban	7	10.77
6	Parent marital status	Still married	57	87.6
		Widow	7	10.7
		Widower	1	1.5
7	Spouse relativeness	Relative	27	41.5
		No relative	38	58.5
8	Number of siblings	None	5	7.7

		1-2 siblings	31	47.7
		3-4 siblings	18	27.7
		5-6 siblings	11	16.9
9	Number of thalassemia patients in the family	None	39	60
		One sibling	24	36.9
		Two siblings	2	3.1

Table 2. Reveals that the shows that the majority of caregivers (68%) were mothers, and (32%) were fathers. Predominant age group for caregivers is more than 48 years old, 21 (32.3%), and a significant percentage of caregivers, 22 (33.8%), were unable to read and write. The majority of caregivers were housewives, 44 (67.7%). In addition, slightly more than half of families 33 (50.7%) lived in urban areas. 57 (86.7%) of parents still married. and more than 40% of parents were relatives. Concerning the other thalassaemic patients in the family, the majority 39 (60.0%) reported no other one in family have thalassemia. 24 (36.9%) indicated they have another family member with thalassemia, while 3.1% reported two siblings of the patient have thalassemia**.**

Caregivers' burdens.

Table 3. Physical burdens among caregivers with three Likert scale: always, sometimes, and never, N=65

No	Items of physical burdens	Always (%)	Sometimes (%)	Never (%)	M.S	Burden Severity
1	My physical health has worsened since becoming a caregiver	60 (92.3)	3 (4.6)	2 (3.1)	1.89	**H.B**
2	limiting my physical activities due to caregiving responsibilities	45 (69.2)	18 (27.7)	2 (3.1)	1.66	**H. B**
3	lost work or other commitments due to caregiving responsibilities	43 (66.2)	21 (32.3)	1 (1.5)	1.64	**H. B**
4	Caregiving affected my daily routine and schedule	44 (67.7)	19 (29.2)	2 (3.1)	1.64	**H. B**
5	Experience difficulty in performing daily activities	30 (46.2)	33 (50.8)	2 (3.1)	1.43	**H. B**
6	I had to make any significant changes to my lifestyle or living arrangements	35 (53.8)	29 (44.6)	1 (1.5)	1.52	**H. B**
7	Follow up with a healthcare provider for your health concerns	24 (36.9)	39 (60.0)	2 (3.1)	1.34	**H. B**
8	I delay seeking medical attention due to caregiving responsibilities.	2 (3.1)	16 (24.6)	47 (72.3)	0.31	**L.B**
Total		283 (435.40)	178 (273.80)	59 (90.80)	1.43	**H. B**

H. B High Burdens L.B Low Burdens

Table 3. Shows that the mean scores are high on items (1, 2, 3, 4, 5, 6, 7) and low on item (8). The overall mean score for physical health problems was 1.43, which falls within the high severity range. This indicated that thalassemic parents had high physical burdens.

Psychological burdens (Depression and Anxiety)

Table 4. Psychological burdens (Depression symptoms) among caregivers with three Likert scale: always, sometimes, and never, N=65

NO	Items of depression	Always F (%)	Sometimes F (%)	Never F (%)	M.S	Burden Severity
1	Experienced prolonged periods of sadness or lack of interest in activities you usually enjoyed	55 (84.6)	10 (15.4)	0 (0.0)	1.85	**H.S. D**
2	The feeling of being trapped or caught	51 (78.5)	11 (16.9)	3 (4.6)	1.74	**H.S. D**
3	Lost the pleasure of anything in my life	23 (35.4)	38 (58.5)	4 (6.2)	1.29	**M.S. D**
4	I have a feeling of disappointment about myself	14 (21.5)	24 (36.9)	27 (41.5)	0.80	**M.S. D**
5	I blame myself because I feel it was my mistake	4 (6.2)	9 (13.8)	52 (80.0)	0.26	**L.S. D**
6	How often do you feel pessimistic about the future?	11 (16.9)	41 (63.1)	13 (20.0)	0.97	**M.S. D**
7	I cry more than usual these days.	45 (69.2)	17 (26.2)	3 (4.6)	1.65	**H.S. D**
8	I feel that I am missing my concern for others.	14 (21.5)	47 (72.3)	4 (6.2)	1.15	**M.S. D**
9	lost pleasure in my life	14 (21.5)	47 (72.3)	4 (6.2)	1.15	**M.S. D**
10	Unable to work efficiently as usual	46 (70.8)	11 (16.9)	8 (12.3)	1.58	**H.S. D**
11	I am unable to sleep as well as usual	40 (61.5)	20 (30.8)	5 (7.7)	1.54	**H.S. D**
12	I feel tired more than usual.	53 (81.5)	11 (16.9)	1 (1.5)	1.80	**H.S. D**
13	diminution of appetite	11 (16.9)	35 (53.8)	19 (29.2)	0.88	**M.S. D**
14	I am disturbed by my health issues.	13 (20.0)	46 (70.8)	6 (9.2)	1.11	**M.S. D**
15	I have a guilty feeling	4 (6.2)	8 (12.3)	53 (81.5)	0.25	**L.S. D**
16	I have a thought about harming myself	4 (6.2)	26 (40.4)	35 (53.8)	0.52	**L.S. D**
17	I feel shy and embarrassed, which makes me socially isolated.	9 (13.8)	31 (47.7)	25 (38.5)	0.75	**M.S. D**
Total					**1.02**	**L.S. D**

H.S. D=High Severity Depression M.S. D=Moderate Severity Depression L.S.D=Low Severity Depression
M. S= Mean of Score %= Percentage

The table above shows that the mean scores are high on items (1, 2, 7, 10, 11, 12) and moderate on items (3, 4, 6, 8, 9, 13, 14, 17), while low on items (5, 15, 16). The item 1. About caregivers' Experienced prolonged periods of sadness or lack of interest in activities you usually enjoy had heist mean of score 1.85. The average mean score for depression was 1.02, which falls within the moderate severity range.

Table 5. Psychological burdens (Anxiety) among caregivers with three Likert scale: always, sometimes, and never, N=65

No	Items of Anxiety	Always F (%)	Sometime F (%)	Never F (%)	M.S F (%)	Burden Severity
1	Feeling nervous, restless	44 (67.7)	14 (21.5)	7 (10.8)	1.57	**H.S. A**
2	Become so easily irritated as usual	38 (58.5)	18 (27.7)	9 (13.8)	1.45	**H.S. A**
3	I feel disturbed for a reason.	14 (21.5)	44 (67.7)	7 (10.8)	1.11	**M.S. A**
4	I feel like falling down	10 (15.4)	47 (72.3)	8 (12.3)	1.03	**M.S. A**
5	I have concerns about my patient.	34 (52.3)	26 (40.0)	5 (7.7)	1.45	**H.S. A**
6	I worry about not controlling my family life	12 (10.8)	38 (58.5)	15 (23.1)	0.95	**M.S. A**
7	I feel that my limbs are shaking	11 (16.9)	49 (75.4)	5 (7.7)	1.09	**M.S. A**
8	I feel that I am under tension	40 (61.5)	20 (30.8)	5 (7.7)	1.54	**H.S. A**
9	Less concerned about sexual affairs	7 (10.8)	38 (58.5)	20 (30.8)	0.80	**M.S. A**
10	Fear of the unknown	17 (26.2)	40 (61.5)	8 (12.3)	1.14	**M.S. A**
11	Difficulty going to sleep	35 (53.8)	21 (32.3)	9 (13.8)	1.40	**H.S. A**
12	I have nightmares that I cannot afford after sleeping	18 (27.69)	30 (46.15)	17 (26.15)	1.02	**M.S. A**
13	I have a feeling of a rapid heartbeat	10 (15.4)	44 (67.7)	11 (16.9)	0.98	**M.S. A**
14	I have dry mouth and sweating	9 (13.8)	46 (70.8)	10 (15.4)	0.98	**M.S. A**
15	Trembling or shaking	12 (18.5)	44 (67.7)	9 (13.8)	1.05	**M.S. A**
16	Having a sense of impending doom or danger	17 (26.2)	39 (60.0)	9 (13.8)	1.12	**M.S. A**
17	I am concerned about the future of my other kids	9 (13.8)	45 (69.2)	11 (16.9)	0.97	**M.S. A**
Total					1.16	M.S. A

H.S. D=High Severity Anxiety M.S. D=Moderate Severity Anxiety L.S. D=Low Severity Anxiety M.S= Mean of Score %= Percentage

This table shows that the mean scores are high on items (1, 2, 5, 8, 11), moderate on items (3, 4, 6, 7, 10, 12, 13, 14, 15, 16, 17), and there are no low-severity items. The mean score for anxiety problems was 1.15, which falls within the Moderate Severity.

Table 6. Social burdens among caregivers with three Likert scales: always, sometimes, and never, N=65

No	Items of the caregiver's social burden	Always %	Sometime %	Never %	M.S	Severity
1	How has Caregiving affected your relationships with your family members?	32 (49.2)	28 (43.1)	5 (7.7)	0.58	**L.B**
2	Friends and relatives offered help	4 (6.2)	18 (27.7)	43 (66.2)	1.60	**H. B**
3	Communicate regularly with other families dealing with thalassemia.	8 (12.3)	56 (86.2)	1 (1.5)	0.89	**M.B**
4	How has caregiving impacted your ability to maintain friendships?	4 (6.2)	54 (83.1)	7 (10.8)	1.05	**M.B**
5	I think that others do not respect me when I engage in social occasions	4 (6.2)	43 (66.2)	18 (27.7)	0.78	**M.B**
6	I feel I lost my social activities (e.g., outings with friends) since childbirth.	35 (53.8)	23 (35.4)	7 (10.8)	1.43	**H. B**
7	I cannot spend a long time with people	29 (44.6)	27 (41.5)	9 (13.8)	1.31	**M.B**
8	I have difficulty talking to new individuals	2 (3.1)	58 (89.2)	5 (7.7)	0.95	**M.B**
9	I think that others are unable to value my achievement, and they are not	3 (4.6)	53 (81.5)	9 (13.8)	0.91	**M.B**
10	I think others don't want to build social relationships with me	2 (3.1)	47 (72.3)	16 (24.6)	0.78	**M.B**
11	Brothers and sisters are anxious about their social future.	5 (7.7)	51 (78.5)	9 (13.8)	0.94	**M.B**
12	Marital problems after diagnosis of thalassemia	0 (0.0)	2 (3.1)	63 (96.9)	0.03	**L.B**
13	Inconsistent schedules and numerous commitments make it difficult for parents to spend time together	10 (15.4)	51 (78.5)	4 (6.2)	1.09	**M.B**
14	It can be challenging to find center care for patients, which also makes it hard for parents to go out as a couple	59 (90.8)	4 (6.2)	2 (3.1)	1.88	**H. B**
Total					1.02	**M.B**

H.S. D=High Severity M.S.D=Moderate Severity L.S.D=Low Severity M.S= Mean of Score %= Percentage

This table shows that the mean scores are low on items (1, 12), moderate on items (3, 4, 5, 7, 8, 9, 10, 11, 13), and high on items (2, 6, 14). The item 14. About caregivers' challenging to find centre care for patients, which also makes it hard for parents to go out as a couple had highest mean of score 1.88. And the lowest mean of score was on item 1. About caregiving affected the relationships with your family members was 0.31. The mean score for family social burden was 1.02, which falls within the Moderate Severity range.

Table 7. Financial burdens among caregivers with three Likert scale: always, sometimes, and never, N=65

No	Items of Family Financial Problems	Always %	Sometime %	Never %	M.S	Severity
1	The patient's condition causes the consumption of an incredible rate of the family's income	53 (81.5)	8 (12.3)	4 (6.2)	1.75	**H. B**
2	Monitoring a patient's condition can be costly.	65 (100.0)	0 (0.0)	0 (0.0)	2.00	**H. B**
3	Visits to the rehabilitation center are costly	64 (98.5)	1 (1.5)	0 (0.0)	1.98	**H. B**
4	Had to change your employment status due to caregiving responsibilities	34 (52.3)	14 (21.5)	17 (26.2)	1.26	**H. B**
5	We have to perform additional jobs to meet the needs of the child and family	49 (75.4)	9 (13.8)	7 (10.8)	1.64	**H. B**
6	had to take loans or debts because of the patient's condition	40 (61.5)	15 (23.1)	10 (15.4)	1.46	**H. B**
7	Have you faced difficulty paying for medication or treatment	36 (55.4)	17 (26.2)	12 (18.5)	1.37	**H. B**
Total					1.63	**H. B**

H.S=High Severity M.S=Moderate Severity L.S=Low Severity M.S= Mean of Score
%= Percentage

Table 7. Shows that the mean scores are high on all items (1, 2, 3, 4, 5, 6, 7). The overall mean score for family financial problems is 1.63, which falls within the high severity range. Which indicated that all caregivers' complaint from financial strain that faced them.

Table 8. Association between morbidity patterns and some sociodemographic characteristics of the study sample, such as age, sex, level of education (n=65).

1. Socio-demographic variable	**2. Physical Health Challenges**		**3. Psychological Health Challenges**				**4. Family Social Burden**		**5. Family Financial Problems 8.**	
			6. Depression		**7. Anxiety**					
9. 1-Caregiving	**10. P-value**	**11. 0.467**	**12. P-value**	**13. 0.867**	**14. P-value**	**15. 0.251**	**16. P-value**	**17. 0.793**	**18. P-value**	**19. 0.092**
	20. Chi-square	**21. 1.524**	**22. Chi-square**	**23. 0.285**	**24. Chi-square**	**25. 2.764**	**26. Chi-square**	**27. 0.465**	**28. Chi-square**	**29. 4.766**
30. 2-Caregiver age	**31. P-value**	**32. 0.227**	**33. P-value**	**34. 0.194**	**35. P-value**	**36. 0.051**	**37. P-value**	**38. 0.079**	**39. P-value**	**40. 0.011**
	41. Chi-square	**42. 8.148**	**43. Chi-square**	**44. 8.652**	**45. Chi-square**	**46. 12.556**	**47. Chi-square**	**48. 11.323**	**49. Chi-square**	**50. 16.528**
51. 3-Caregiver education level	**52. P-value**	**53. 0.002**	**54. P-value**	**55. 0.226**	**56. P-value**	**57. 0.301**	**58. P-value**	**59. 0.005**	**60. P-value**	**61. 0.018**
	62. Chi-square	**63. 27.918**	**64. Chi-square**	**65. 12.953**	**66. Chi-square**	**67. 11.773**	**68. Chi-square**	**69. 24.997**	**70. Chi-square**	**71. 21.517**
72. 4-caregiver occupation	**73. P-value**	**74. 0.745**	**75. P-value**	**76. 0.962**	**77. P-value**	**78. 0.132**	**79. P-value**	**80. 0.575**	**81. P-value**	**82. 0.069**
	83. Chi-square	**84. 5.116**	**85. Chi-square**	**86. 2.496**	**87. Chi-square**	**88. 12.466**	**89. Chi-square**	**90. 6.644**	**91. Chi-square**	**92. 14.550**

93. 5-Income level	94. P-value	95. 0.003	96. P-value	97. 0.288	98. P-value	99. 0.120	100. P-value	101. 0.282	102. P-value	103. < 0.001
	104. Chi-square	105. 15.729	106. Chi-square	107. 4.989	108. Chi-square	109. 7.309	110. Chi-square	111. 5.047	112. Chi-square	113. 45.753
114. 6-Parents marital status	115. P-value	116. 0.138	117. P-value	118. 0.668	119. P-value	120. 0.444	121. P-value	122. 0.894	123. P-value	124. 0.001
	125. Chi-square	126. 6.967	127. Chi-square	128. 2.372	129. Chi-square	130. 3.727	131. Chi-square	132. 1.101	133. Chi-square	134. 18.056
135. 7-Family resident area	136. P-value	137. 0.167	138. P-value	139. 0.129	140. P-value	141. 0.262	142. P-value	143. 0.214	144. P-value	145. 0.175
	146. Chi-square	147. 6.468	148. Chi-square	149. 7.141	150. Chi-square	151. 5.255	152. Chi-square	153. 5.804	154. Chi-square	155. 6.343
156. 8-Spouses relativeness	157. P-value	158. 0.200	159. P-value	160. 0.079	161. P-value	162. 0.050	163. P-value	164. 0.346	165. P-value	166. 0.857
	167. Chi-square	168. 3.222	169. Chi-square	170. 5.084	171. Chi-square	172. 5.986	173. Chi-square	174. 2.123	175. Chi-square	176. 0.308
177. 9-Number of siblings	178. P-value	179. 0.690	180. P-value	181. 0.498	182. P-value	183. 0.722	184. P-value	185. 0.489	186. P-value	187. 0.078
	188. Chi-square	189. 3.901	190. Chi-square	191. 5.365	192. Chi-square	193. 3.667	194. Chi-square	195. 5.437	196. Chi-square	197. 11.348
198. 10-Number of other thalassemia patients in the family	199. P-value	200. 0.001	201. P-value	202. 0.179	203. P-value	204. 0.307	205. P-value	206. 0.655	207. P-value	208. 0.281
	209. Chi-square	210. 17.988	211. Chi-square	212. 6.279	213. Chi-square	214. 4.812	215. Chi-square	216. 2.445	217. Chi-square	218. 5.066

The table above shows that caregiving status (father or mother) had no significant association with physical health challenges (p = 0.467), psychological health challenges, depression (p = 0.867), anxiety (p = 0.251), family social burden (p = 0.793), or family financial problems (p = 0.092). as well for caregiver age the result showed no significant association with physical health challenges (p = 0.227), depression (p = 0.194), anxiety (p = 0.051), or family social burden (p = 0.079), but a significant association was found with family financial problems (p = 0.011), this indicate that caregiver age may impact financial strain. Caregiver education level demonstrated a significant association with physical health challenges (p = 0.002), family social burden (p = 0.005), and family financial problems (p = 0.018), while no significant association was observed with depression (p = 0.226) or anxiety (p = 0.301), indicating that lower education levels might relate to worse physical and financial outcomes. Caregiver occupation showed no significant association with physical health challenges (p = 0.745), depression (p = 0.962), anxiety (p = 0.132), family social burden (p = 0.575), or family financial problems (p = 0.069). Income level had a significant association with physical health challenges (p = 0.003) and family financial problems (p < 0.001), suggesting that lower income may contribute to poorer physical health and financial difficulties, but no significant association was found with depression (p = 0.288), anxiety (p = 0.120), or family social burden (p = 0.282). Parents' marital status showed no significant association with physical health challenges (p = 0.138), depression (p = 0.668), anxiety (p = 0.444), or family social burden (p = 0.894), but a significant association was found with family financial problems (p = 0.001), indicating that marital status may affect financial outcomes. Family resident area showed no significant association with any of the outcomes, including physical health challenges (p = 0.167), depression (p = 0.129), anxiety (p = 0.262), family social burden (p = 0.214), and financial problems (p = 0.175). Spouse’s relativeness had no significant association with physical health challenges (p = 0.200), depression (p = 0.079), family social burden (p = 0.050), anxiety (p = 0.346), or family financial problems (p = 0.857). The number of siblings showed no significant association with physical health challenges (p = 0.690), depression (p = 0.498), anxiety (p = 0.722), family social burden (p = 0.489), or family financial problems (p = 0.078). Finally, the number of other thalassemia patients in the family showed a significant association with physical health challenges (p = 0.001), suggesting that the presence of more thalassemia patients may worsen physical health outcomes; however, no significant association was observed with depression (p = 0.179), anxiety (p = 0.307), family social burden (p = 0.655), or family financial problems (p = 0.281).

Discussion:

The socio-demographic profile of the 65 caregivers and patients provides a critical lens for understanding the caregiving context in Ranya city. Patients were predominantly female (58.5%) and aged 16 years or older (61.5%), with most being students (58.5%) or self-employed (29.2%). (6) reported that 66% of thalassemia patients in Iraq are under 15, suggesting that improved medical interventions, such as regular blood transfusions and iron chelation therapy, may have extended the life expectancy of patients (11). The higher proportion of female patients may reflect genetic predispositions or cultural practices like consanguineous marriages, which increase thalassemia prevalence (12, 13). Notably, the finding that 87.69% of patients had beta-thalassemia major. This aligns with Mutar et al. (2019), who noted its dominance in Iraq, underscoring the intensive care needs driving caregiver burdens (4).

All caregivers were parents, with mothers comprising 68% and fathers 32%, reflecting the gendered division of caregiving roles in Kurdish culture, where mothers are often expected to prioritize family care and father has to work to secure their daily lives. The age distribution, with 32.3% of caregivers over 48 years, and the educational disparity, 43.2% of mothers were illiterate compared to 47.6% of fathers who could read and write, highlight how socio-cultural norms and limited access to education shape caregiving dynamics. (14), Health literacy represents an important public health concern. Unpaid caregivers of older adults with limited health literacy may struggle to provide care, which can adversely affect the caregiving process. The occupational profile, with all mothers being housewives (100%) and fathers engaged in diverse roles (e.g., 28.6% government employees, self-employed, or daily workers), underscores economic dependency on male earners, amplifying financial strain when caregiving disrupts work (15).

The finding of Figure 2 illustrates that 67.7% of caregivers reported insufficient income, with 50.7% residing in urban areas, which points to economic and geographic barriers to healthcare access. Urban caregivers may benefit from proximity to the Rayna Thalassemia and Hemophiliac Centre, but rural caregivers (38.5%) face additional travel burdens. A challenge often noted in rural healthcare access in the region by (16), in their study about Treatment Status of Patients with B-Thalassemia Major in Northern Iran. The prevalence of nuclear families (100%) and consanguineous marriages (over 40%) aligns with (5,17), emphasizing how genetic and social factors perpetuate thalassemia in Iraq. These socio-demographic characteristics not only frame the caregiving experience but also exacerbate the physical, psychological, social, and financial burdens.

Regarding physical Burdens, caregivers experienced high physical burdens, with a mean score of 1.43 (high severity range (1.34–2). All caregivers (100%) reported back pain and muscle aches, with 92.3% experiencing fatigue, 81.5% sleep disturbances, and 93.8% digestive problems. Physical strain from repetitive tasks like assisting with mobility, preparing for hospital visits, and administering medications. The intensive care demands of thalassemia, including blood transfusions every 21 days for 56.9% of patients and iron chelation therapy every three months for 96.9%, may also contribute to chronic fatigue and musculoskeletal issues. The high prevalence of splenectomy (53.85%) among patients is noted in Table 4.5. Further complicates care, requiring additional monitoring for infections, which adds to physical strain.

The study also indicated a significant association between physical burdens and caregivers’ education level, income, and the number of other thalassemia patients in the family ($P \leq 0.05$). Lower education likely limits understanding of self-care strategies, as supported by (18), in their study about caregiver burden and related factors in parents of children with Thalassemia. while insufficient income restricts access to hired help or ergonomic aids (19). The presence of multiple thalassemia patients in a family requires double the efforts by the family for caring for them. The study illustrated that 36.9% of caregivers reported having another family member with thalassemia, and 3.1% had two members. The study also indicated no association between physical burdens and caregivers' age, occupational status, residential area, or spouse relationship. Physical burdens are universal, driven by the relentless nature of thalassemia care. The level of hardship described by both patients and caregivers dealing with transfusion-dependent β-thalassemia is substantial, shaped by the time needed for ongoing disease management as well as frequent exhaustion, discomfort, and reduced quality of life. (20). This universality contrasts with high-income settings, where professional caregiving services mitigate physical strain (21), highlighting the resource constraints in Rayna city. Unexpectedly, the high prevalence of digestive problems (93.8%) among caregivers suggests a psychosomatic component, potentially linked to stress (22). This warrants further investigation, as it may reflect an interplay between physical and psychological burdens (23).

Concerning psychological burdens were moderate, depression (mean score: 1.02) and anxiety (mean score: 1.15) fell within the moderate severity range (0.67–1.33). High-severity depression symptoms included prolonged sadness, pessimism, and fatigue, while anxiety was marked by nervousness, restlessness, and panic concerning the patient. These findings resonate with Islam, et al. (2025),

The study found that many mothers caring for children with thalassemia reported experiencing stress (around 62%), anxiety (about 58%), and depression (approximately 63%). Furthermore, how often blood transfusions were needed and the monthly costs of treatment had a meaningful effect on the levels of anxiety and depression these mothers felt

(24). The moderate severity in Ranya may reflect cultural resilience, as caregivers draw on familial duty and community ties and adaptive coping mechanisms like religious faith. The moderate severity of anxiety items suggests persistent worry about patients' health, future complications, and financial instability Other reasons back to lack of mental health resources in Ranya city, a challenge seen in other low-resource settings as noted by Son et al. (2012) in their study in South Korea (25), Thalassemia affects not only the persons with the disorder but also their caregivers in several aspects, including their psychosocial well-being (26).

exacerbates the burdens of caregivers to inability to access mental health counselling or support groups, unlike in high-income settings which thy have access to different mental health services

Notably, the study found no significant associations between depression and socio-demographic variables such as caregiving status (p = 0.867), age (p = 0.194), education level (p = 0.226), occupation (p = 0.962), income (p = 0.288), marital status (p = 0.668), residential area (p = 0.129), spouse relativeness (p = 0.079), number of siblings (p = 0.498), or number of other thalassemia patients in the family (p = 0.179). Similarly, anxiety showed no significant associations with most variables, including caregiving status (p = 0.251), education level (p = 0.301), occupation (p = 0.132), income (p = 0.120), marital status (p = 0.444), residential area (p = 0.262), number of siblings (p = 0.722), or number of other thalassemia patients (p = 0.307), though borderline significance was observed with age (p = 0.051) and spouse relativeness (p = 0.050), this may back to small sample size number in this study and suggesting potential areas for further exploration. An intriguing finding is the moderate psychological burdens despite high financial and physical burdens, which might be expected to drive more severe psychological distress (7). This could reflect underreporting due to cultural stigma around mental health in Kurdish communities or a normalization of stress among caregivers, warranting qualitative follow-up to explore coping mechanisms.

About social burdens were moderate, with a mean score of 1.02, reflecting significant challenges in maintaining relationships and social engagement. High-severity items included loss of social activities and marital strain, while low-severity items involved external help from friends or relatives. This aligns with Inamdar et al. (2015), who noted social isolation among thalassemia caregivers due to time constraints and societal stigma, particularly in communities where chronic illness carries shame. The cultural expectation in Kurdistan for mothers prioritizes caregiving over personal relationships, with 100% of nuclear families relying heavily on immediate family support (27).

The moderate social burden suggests some caregivers maintain limited social connections, possibly through informal family networks. Mirzaei (2015) observed in similar settings (14). However, the high prevalence of marital strain (a high-severity item) is notable, as the demands of thalassemia care—frequent hospital visits, financial stress, and emotional exhaustion—can erode spousal relationships (28). The low severity of external help (e.g., from friends) may reflect community solidarity in Ranya, but the lack of formal support services, as noted by Hockenbery et al. (2011), limits caregivers' ability to engage socially (29). The findings show that caregivers with less education often feel more alone and carry heavier burdens, while things like age or income do not seem to have a big impact. One possible reason is that education helps people find resources, connect with others, and develop coping skills—giving them tools to handle the challenges of caregiving. Studies support this idea; for example, Schnitzer et al. (2017) found that caregivers with higher education reported feeling less physical and mental strain, likely because they have more ways to care for their own well-being and reach out for support when needed. Unfortunately, those with lower educational backgrounds may not always have access to helpful networks, which can leave them feeling isolated and make caregiving even harder. These results highlight how critical it is to provide extra support and opportunities for connection to caregivers who have had fewer educational opportunities, so they do not face these struggles alone (30).

Regarding the financial burdens, the study observed that the financial burdens were the most severe among caregivers, with a mean score of 1.63, which is located in the high severity range. All items, including medical expenses, visits to the rehabilitation center, changing employment, performing additional jobs, and taking on debt, scored high, reflecting the profound economic toll of thalassemia care. This corroborates Cappellini et al. (2020), who highlighted direct costs (e.g., transfusions, chelation therapy) and indirect costs (e.g., lost income) as major burdens in low-resource settings. The universal use of medications like deferasirox, calcium, and folic acid is used by every thalassemia patient (11). Frequent hospital visits exacerbate costs, particularly for caregivers with insufficient income (31). The finding that 96.9% of patients received iron chelation therapy every three months underscores the ongoing financial commitment. The study also showed a significant association between financial burdens and income level. Financial constraints limit caregivers' ability to mitigate physical strain through hiring help or accessing medical resources that can alleviate their health burdens.

Further analysis revealed significant associations between financial burdens and caregiver age (p = 0.011), education level (p = 0.018), income level (p < 0.001), and parents' marital status (p = 0.001), indicating that older caregivers, those with lower education, lower income, and possibly those in specific marital situations face greater financial challenges; caregiver occupation approached significance (p = 0.069), while no associations were found with residential area (p = 0.175), spouse relativeness (p = 0.857), number of siblings (p = 0.078). families affected by thalassemia often face severe financial stress as the costs of treatment and care can be overwhelming compared to their incomes. This reality makes it crucial for researchers to understand and measure just how much of a financial strain thalassemia puts on households, so that support systems and resources can be better tailored to meet their needs. This result also supported by Barua et al. (2022), they concluded that many families, keeping up with the ongoing costs of thalassemia treatment can feel overwhelming, placing a heavy strain on their finances and everyday life, so better support systems can be designed to truly help these families manage their expenses and feel less overwhelmed (32).

Conclusion

In conclusion, the study predominantly involved female thalassemia patients (58.5%). Most patients had been living with thalassemia for 11-20 years, with Beta Thalassemia major being the most common diagnosis among them. Regular blood transfusions every 21 days for more than half of them are needed in addition to iron chelation therapy, 96.9%, mostly every three months. Caregivers of thalassemia patients experience significant physical and financial hardships, as well as moderately impacted psychological and social aspects. Socioeconomic factors like education and income, along with specific family circumstances like the number of affected children, play a significant role in the severity of these burdens.

Recommendations

The Kurdistan Regional Government should prioritize subsidies for thalassemia treatments, including blood transfusions, iron chelation therapy (e.g., deferasirox), and essential medications like folic acid and calcium, to alleviate financial burdens. In addition to partnerships with international NGOs, it could supplement funding, ensuring consistent access to medications. Integrate mental health services into the Ranya Thalassemia and Hemophiliac Centre, offering free or low-cost counselling. For Rural Caregivers, the government should address geographic disparities by establishing mobile clinics or transportation subsidies for rural caregivers to reduce the physical and financial burden. Furthermore, establish peer support groups at the Ranya Centre, facilitated by nurses or social workers, to enable caregivers to share experiences and coping strategies, reducing social isolation. Lastly, conduct longitudinal studies to track changes in caregiver burdens over time and evaluate intervention effectiveness.

Acknowledgments:

We would like to express our thanks to all participating caregivers and patients for their valuable time and responses. Our gratitude goes to the Thalassemia and Hemophiliac Centre in Ranya Teaching Hospital for their generosity in allowing this research to be carried out and cooperation during the period of study.

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