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Caregiving Burden and Quality of Life among Caregivers of Thalassemia Patients at the Thalassemia and Congenital Blood Disorders Center, Sulaimaniyah, Iraq

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Abstract— **Background:** Thalassemia is a chronic, inherited blood disease that causes severe and transfusion-dependent anaemia. The disease burden affects patients' quality of life (QoL) and their families. **Objective:** To assess the caregivers' burdens and their QoL. **Patients and Methods:** This quantitative–descriptive study was conducted from February 2022 to April 2023 in Sulaimani Thalassemia and Blood Disorder Center, Sulaimaniyah, Iraq, on 304 thalassemia patients' caregivers. A validated questionnaire collected participants' data, including sociodemographic characteristics, caregiving-related factors, QoL, and caregivers' burden points. **Results:** Participants mean age was 42.43 ± 8.12 years. Most of them (67.1%)were middle-aged (36-49 years), females (59.2%),housewives (56.6%), had no formal education (48.7%), their income was less than their expenditure (57.9%), and were mothers (61.8%). On the other hand, 23.7% had a chronic disease, did not perform the premarital test (81.6%),were ready to perform the antenatal test (63.2%), and 60.5% were prepared to abort the fetus if diagnosed as thalassemia. Regarding QoL domains, 68.4% had a poor physical domain, 67.1% of each environment domain, and overall QoL was poor; 59.2% had a poor psychological domain. In comparison, the proportion of poor social relations domain was 53.9%. Most (39.5%) had moderate to severe caregiving burdens, and 34.2% had severe caregiving burdens. A negative correlation was found between QoL and caregiving burdens (r: -0.52; $p \leq 0.001$). **Conclusions:**Caregiving for thalassemia patients causes moderate and severe burdens and deteriorates overall QoL and its dimensions; therefore, elevating caregiving burdens leads to worsening QoL among family caregivers.

Keywords: Caregiver, burden, quality of life, thalassemia patients

Introduction

Thalassemia is a hemoglobinopathy and genetic chronic illness demanding lifetime blood transfusions, drugs, and investigations, causing a financial burden and emotional on the family [1]. Thalassemia is a common disease in Iraq, with an incidence of 35.7 per 100,000. Beta thalassemia major is a life-threatening disorder with many complications and could cause death early if the complications are not controlled [2].

Thalassemia comes from the lack or impaired production of either alpha or beta globin chain, a hereditary hemoglobinopathy. Based on clinical severity, Beta thalassemia is further categorized as beta-thalassemia major, intermedia, and minor [3]. Thalassemia in children is vital to continue to receive care throughout their childhood from their caretakers. The child's quality of life (QoL) depends substantially on the matching caregivers' QoL[4]. Caregivers of thalassemia children undergo tremendous difficulties and strain to provide their children with the best possible medical care. The care-related QoL is likely to be low and dependent on the QoL of their ward and other features (i.e., sociodemographic, clinical-therapeutic, perception-related, and financial) [5].

Numerous techniques to prevent thalassemia, including parental awareness, population screening, genetic counselling, and prenatal diagnosis, are the best strategies to lessen the burden of thalassemia [3].A person caring for someone with a chronic disease like thalassemia may encounter stressors such as financial pressure, physical strain, mental health, relationship with the care receiver, and social support. The cost of treatment of the disease and its complications impose a significant load on the clients of thalassemia. It also exerts a considerable cost on their careers and society at large [5]. The assessment of the QoL and caregiving may provide evidence to develop nursing management accordingly. Thus, this study was designed to assess the QoL.

Patients and Methods

The current study is a quantitative-descriptive research conducted at the Thalassemia and Congenital Blood Disorders Center in Sulaimaniyah, Iraq. The study centred on those caring for individuals with thalassemia from February 2022 to April 2023. The study utilized a non-probability, convenience sampling method to recruit 304 caregivers for participation.

Data collection

A formal written agreement was obtained before conducting the interviews with the caregivers. Subsequently, the researcher provided a concise introduction and elucidated the goal of the research to the caregivers. The primary data-gathering sources consisted of the carriers themselves. The data were obtained by administering a questionnaire through structured interviews with carriers. The study employed researcher-administered questionnaires. The interview took place in the facility's dedicated and comfortable conference room during the morning hours.

Study instruments

The questionnaire comprises two sections. The first section pertains to patients' sociodemographic data, caregiving-related aspects, and clinical features. The subsequent section has two standardized scales employed to assess caregivers' burdens and QoL.

Zarit Burden Interview (ZBI)

The ZBI was formulated by Zarit et al., 1980 and utilized to assess the level of challenge caregivers encounter in assisting those requiring care[6]. The scale consists of 22 items and can be completed by either the respondent or the researcher. It is designed to assess the effects of caregiving on the caregiver's life. The Likert-type scale utilized in this study consists of five response options for each item. The potential range of the total score would span from 0 to 88, with a positive correlation between the score and the magnitude of the burden. The levels of burden are classified into four categories: no burden (0–20), mild burden (21–40), moderate burden (41–60), and severe burden (61–88). The ZBI is extensively utilized in research, and data collected from multiple studies consistently indicate internal solid consistency, as evidenced by Cronbach's alpha coefficients exceeding 0.80. The test-retest reliability and face validity of the ZBI has been previously proven [7].

WHOQOL-BREF

WHOQOL-BREF is a 26-item instrument that consists of four domains: physical health (7 items), psychological health (6 items), social relationships (3 items), and environmental health (8 items). It also contains QOL and general health items. Each WHOQOL-BREF item is scored from 1 to 5 on the response scale, which is a five-point ordinal scale. The scores are then transformed linearly to a scale of 0-100 [8]. Physical health includes mobility, daily activities, functional capacity, energy, pain, and sleep. Psychological domain measures include self-image, negative thoughts, attitudes, self-esteem, mentality, learning ability, memory concentration, religion, and mental status. The social relationships

domain contains questions on personal relationships, social support, and sex life. The environmental health domain covers financial resources, safety, health, social services, living physical environment, opportunities to acquire new skills and knowledge, recreation, general environment (noise, air pollution, etc.), and transportation [9]. A score of <60 was considered poor for overall QoL and its domains.

Ethical approval

The research was approved by the College of Medicine ethics committee at the University of Sulaimani, Sulaimaniyah, Iraq (No. 177 on 19 Sep 2021). The data utilized in this study was obtained via interviews, with explicit formal agreement obtained from each participant.

Inclusion criteria

Parents of thalassemiapatients.

Exclusion criteria

Family caregivers who had declined to participate in the study. Also, caregivers with severe physical or mental disorders and non-parent family caregivers were excluded.

Statistical analysis

Data was analyzed using the Statistical Package for Social Science (SPSS, version 26). Descriptive statistics were used to summarise the data, including frequency, percentage, and mean. Inferential statistics were utilized to make inferences about the population based on the sample. Furthermore, the correlation coefficient was used to determine the correlation among dependent variables, with a significance level of $p<0.05$.

Results

Table 1 provides a detailed sociodemographic characteristic of thalassemia caregivers and reveals that most caregivers (67.1%) were middle-aged (36-49 years), with a mean age of 42.43 ± 8.12years. Most caregivers (17.1%) were aged ≥50, indicating that caregiving responsibilities persist into later life. Most caregivers were females (59.2%), highlighting the need for gender-sensitive interventions. Also, most caregivers were housewives (56.6%), and 35.55% lost their jobs because of their caregiving responsibilities. The majority had no formal education (48.7%) and, were mothers (61.8%), were from urban areas (78.9%) and had more than five children (52.6%). Regarding thefinancial status of caregivers, 57.9% reported incomes less than their expenditures.

Table 1. Sociodemographic characteristics of thalassemia caregivers.

Thalassemia caregivers' sociodemographic characteristic		Frequency	Percentage
Age Groups (Years)	20 - 35	48	15.8
	36 - 49	204	67.1
	≥ 50	52	17.1
Gender	Female	180	59.2
	Male	124	40.8
Occupation	Housewives	172	56.6
	Paid employed	56	18.4
	Self-employed	72	23.7

	Retired/jobless	4	1.3
Loss of the job because of caregiving	No	196	64.5
	Yes	108	35.5
Education	No formal education	148	48.7
	Primary	84	27.6
	Secondary	48	15.8
	Institute/University	24	7.9
Financial status	Income more than expenditure	24	7.9
	Income equal expenditure	104	34.2
	Income less than expenditure	176	57.9
Relation	Mother	188	61.8
	Father	116	38.2
Residency	Urban	240	78.9
	Rural	64	21.1
Number of children in the family	1 to 2	76	25.0
	3 to 4	160	52.6
	5 & more	68	22.4
Total	**304**	**304**	**100**

Table 2 presents data on caregiving-related characteristics among thalassemia patients. It reveals that a significant proportion (23.7%) of caregivers have chronic diseases, which may impact their well-being, and 81.6% had undergone premarital testing, but 18.4% had not. Reasons for not performing premarital testing include "Not Available" (52.6%) and "Marriage Outside the Court" (28.9%). A majority (63.2%) of caregivers underwent antenatal testing during pregnancy. Approximately 60.5% of caregivers believed in religious fatwas, and 59.2% agreed with abortion when necessary.

Table 2. Distribution of some caregiving-related characteristics.

Caregivers' characteristics		**Frequency**	**Percentage**
Chronic Disease	No	232	76.3
	Yes	72	23.7
Premarital Test	No	248	81.6
	Yes	56	18.4
Reason for not performing Premarital Test	Performed	56	18.4
	Not Available	160	52.6
	Marriage Outside the Court	88	28.9
Antenatal Test	No	112	36.8
	Yes	192	63.2
Believe Fatwa	No	120	39.5
	Yes	184	60.5
Abortion Agreement	No	124	40.8
	Yes	180	59.2
Total		**304**	**100**

Table 3 reveals the prevalence of complications among thalassemia patients. About 56.6% of thalassemia patients had experienced complications, while 43.4% had not. Thalassemia face, a

common physical manifestation of the disorder, was observed in 55.3% of patients. Growth retardation, a well-documented complication, affects nearly half of thalassemia patients (46.1%). Hepatic viral infections, particularly hepatitis B and C, were potential concerns (21.1%) for thalassemia patients requiring frequent blood transfusions.

Table 3. Distribution of patients' complications.

Patients' complications		Frequency	Percentage
Complications	No	132	43.4
	Yes	172	56.6
Thalassemia Face	No	136	44.7
	Yes	168	55.3
Growth Retardation	No	164	53.9
	Yes	140	46.1
Hepatic Viral Infection	No	240	78.9
	Yes	64	21.1
Total		**304**	**100**

Table 4 reveals the QoL of thalassemia caregivers, revealing that 57.9% had a "good" QoL, while 42.1% had a "poor" QoL. Factors such as caregiving burden, financial strain, and emotional stress contribute to these variations. In the general health, 68.4% reported "good" health, while 31.6% reported "poor" health. Physically, 68.4% said "poor" physical health, while 31.6% reported "good" physical health. Psychologically, 59.2% reported "poor" psychological well-being, highlighting the need for psychosocial support and mental health services. Socially, 53.9% said "poor" social relations, while 46.1% reported "good" social relations. Environmentally, 67.1% reported "poor" environmental conditions, highlighting the importance of addressing financial stress, healthcare access, and community support. Overall, 67.1% of caregivers rated their QoL as "poor," emphasizing the need for comprehensive support programs to improve the overall QoL of thalassemia caregivers.

Table 4. The thalassemia caregivers' quality of life (QoL).

Dimensions of QoL	Levels of QoL	Frequency	Percentage
General QoL domain	Poor	128	42.1
	Good	176	57.9
General health domain	Poor	96	31.6
	Good	208	68.4
Physical domain	Poor	208	68.4
	Good	96	31.6
Psychological domain	Poor	180	59.2
	Good	124	40.8
Social Relation domain	Poor	164	53.9
	Good	140	46.1
Environmental domain	Poor	204	67.1
	Good	100	32.9
Overall QoL domain	Poor	204	67.1
	Good	100	32.9
Total		**304**	**100**

Figure 1 indicates that 39.5% of thalassemia participants experienced moderate to severe burden, 34.2% experienced unbearable burden, and only 3.9% had a no-mild burden.

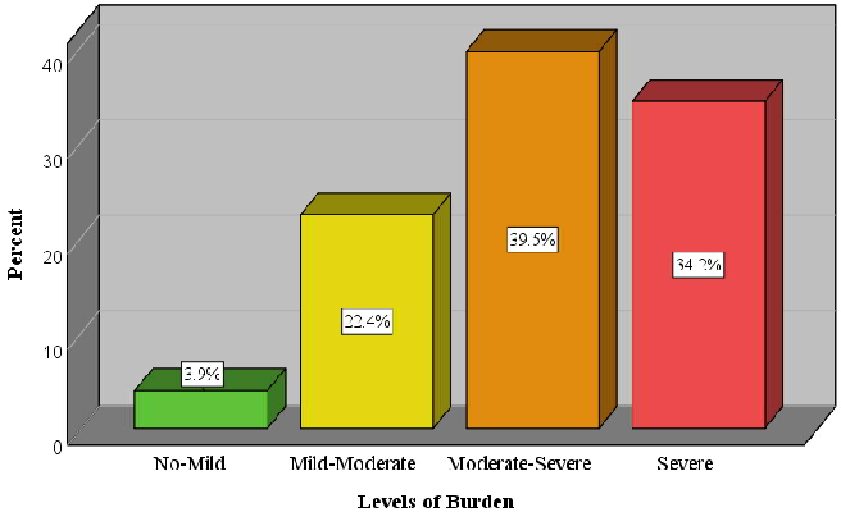

Figure 1.

Caregivers' level of burdens.

Table 5 shows a moderate negative correlation between participants' overall QoL and caregiving burdens (r: -0.52; p=0.000). The correlation between caregiving burden and the physical domain was (r: -0.35; p=0.000), with the psychological domain was (r: -0.47; p=0.000), the social domain was (r: -0.46; p=0.000), and with an environmental domain was (r: -0.41; p=0.000). The correlation between overall QoL and its domain was positive and varied. It was (r: 0.60; p=0.000) with the physical domain,(r: 0.79; p=0.000) withthe psychological domain, and (r: 0.85; p=0.000) with both the social and environmental domain. A positive moderate correlation was found between environmental and other domains: (r: 0.60; p=0.000) with physical, (r: 0.57; p=0.000) psychological,and (r: 0.62; p=0.000) with a social domain. The social domainwas correlated with physical (r: 0.52; p=0.000), psychological (r: 0.55; p=0.000), and finally correlation between mental and physical domains was (r: 0.53; p=0.000).

Table 5. The correlationamong dependent variables.

Variable		**1**	**2**	**3**	**4**	**5**	**6**
Physical Domain	r		0.53	0.52	0.60	0.77	-0.35
	p		0.000	0.000	0.000	0.000	0.000
Psychological Domain	r			0.55	0.57	0.79	-0.47
	p			0.000	0.000	0.000	0.000
Social Domain	r				0.62	0.85	-0.46
	p				0.000	0.000	0.000
Environmental Domain	r					0.85	-0.41
	p					0.000	0.000
Overall QoL	r						-0.52
	p						0.000
Caregivers' Burden	r						
	p						

Correlation is significant at the 0.01 level.

Discussion

The data arising from this study have cast a discriminating light over the terrain of complications that afflict thalassemia patients, with specific attention on thalassemia face, growth retardation, and the grim prospect of hepatic viral infection. Amidst the tapestry of these ailments, it is interesting that they have been determined to retain a prominent place, separate from other difficulties that have been reported. This study resonates with the work of Cunningham, 2008, which studied the diverse domain of thalassemia complications, validating the view that these difficulties demand primary consideration within the clinical discourse[10].

While the study conducted by Bakr et al., 2014 dug into the realm of renal complications in thalassemia patients, this particular investigation has given a remarkable revelation- the noticeable lack of individuals tormented by renal difficulties. This intriguing juxtaposition emphasizes the diversity and variability within the realm of thalassemia complications, suggesting that the nuances of the disorder are far from monolithic[11].

Furthermore, the work of Mahmoud et al., 2016 opened an intriguing concept, positing that thalassemia problems may partly be attributed to heart functional abnormalities. Nevertheless, the present study stands as a testimonial to the absence of such issues within its cohort, adding another layer of complexity to the riddle of thalassemia[12].

During this convoluted investigation of thalassemia's clinical landscape, a salient thread emerges-the critical necessity for watchful and meticulous medical treatment. The findings emphasize the inevitable truth that comprehensive, up-to-date medical therapies are indispensable to avert problems among thalassemia patients. Beyond the field of medicine, the study underlines the crucial role of nursing practitioners in social education. A clarion call is made for preventing consanguineous marriages and disseminating important counselling to persons contemplating matrimony, intending to curb the hereditary transmission of this complex ailment.

The study's complicated tapestry of findings underlines the multifaceted character of thalassemia problems. It serves as a warning that providing holistic care, reinforced by the newest medical developments, is vital in the ongoing war against the encumbrance of thalassemia's myriad afflictions. Furthermore, it underlines the crucial role of nursing professionals as educators and counsellors, contributing to the broader societal endeavour to limit the occurrence of this genetic ailment through educated choices in familial unions.

The study's findings on the QoL of caregivers revealed that a significant proportion of them reported a favourable QoL across various domains. The scores of overall QoL for more than two-thirds were <60, which is considered poor QoL. The physical domain was the most affected, followed by the environmental, psychological, and social domains. These results align with a previous study by Sharma et al. 2017that presents a study on the importance of QoL adaptation in thalassemia children[13]. It suggests that the QoLof caregivers has an impact on the health status of thalassemia children. The findings of this study are consistent with those of a previous study conducted by Askaryzadeh et al., 2023, which demonstrated a significant correlation between the quality of life of caregivers and caregiving burden[14].

The study's findings revealed varying degrees of caregiver load, classified as light, severe, and moderate. The findings of this study indicate that parents or caregivers of thalassemia children may have a significant burden. Almost three-fourths of participants either had moderate or severe caregiving burdens. The study conducted by Mevada et al., 2016 focused on examining the burden and quality of life of caregivers of thalassemia children, and these findings were found to be

consistent with the study's results[15]. Another study conducted by Sahu et al., 2023 demonstrated that thalassemia can have an impact on the load experienced by caregivers, manifesting as psychological challenges for them[16]. The present study identified varying degrees of burden experienced by caregivers and patients. These findings align with a previous study by Paramore et al., 2020, highlighting the potential burden that thalassemia can impose on caregivers, parents, and patients[17]. Consequently, the author suggested that providing training for caregivers and parents of thalassemia children is imperative based on this understanding.

The present study's findings indicate the presence of positive and negative correlations among the variables of QoLand burden, as illustrated in the table. A negative moderate correlation was found between caregiving burdens and overall QoL and its domains, which means increasing caregiving burdens lead to deterioration of QoL. Furthermore, overall, QoL correlated to its dimension positively and powerfully. In addition, a positive moderate correlation was found among different QoL domains. These results align with previous research, suggesting that a body of evidence supports such relationships. Thus, we tried to address the positive correlation and enhance the negative correlations through various methods, as previously mentioned. This study is further supported by the work conducted by another study [14]. There is a need to show more studies to support the association between the domain of variables, such as social support, and the management of carriers' QoL, as demonstrated by the work [18]. There should be an endeavour to enhance and address adverse correlations, effectively managing them to assist parents and carriers of a kid with thalassemia.

Also, this study revealed positive and negative correlations between various variables and caregiver burden. This highlights the significance of health authorities in the Kurdistan Regional Government (KRG) offering training courses for caregivers and parents, focusing on enhancing their understanding of QoL and burden-related issues. Consequently, the researcher suggests further investigation to improve the overall management of parents and caregivers and noting the existence of numerous studies on this topic.

Conclusions

Caregiving for thalassemia patients has moderate and severe burdens and deteriorates overall QoL and its dimensions; therefore, elevating caregiving burdens leads to worsening QoL among family caregivers.Thus, it is suggested to involve all caregivers in a training program that focuses on enhancing their ability to adapt their QoL to the needs of their children.

References

[1] Hulbert M.L., Shenoy S. Hematopoietic stem cell transplantation for sickle cell disease: Progress and challenges. *Pediatric Blood & Cancer.* 2018;65(9):e27263.

[2] Mutar M.T., Majid M., Jaleel A., Saad A., Abdulmortafea A., Talib H. Awareness among parents of beta thalassemia major and intermedia patients in three centres in Baghdad and Al-Nasiriyah, Iraq in 2017. *International Journal of Medical Students.* 2019;7(1):6-10.

[3] Saxena A., Sharif M., Siddiqui S., Singh S. Knowledge, practice and experiences of parents with a thalassemic child. *International Journal of Contemporary Pediatrics.* 2017;4(5):1630-1633.

[4] Punaglom N., Kongvattananon P., Somprasert C. Experience of parents caring for their children with Thalassemia: Challenges and issues for integrative review. *The Bangkok Medical Journal.* 2019;15(1):100-100.

[5] Biswas B., Naskar N.N., Basu K., Dasgupta A., Basu R., Paul B. Care-related quality of life of caregivers of beta-thalassemia major children: an epidemiological study in Eastern India. *Journal of Epidemiology and Global Health.* 2020;10(2):168.

[6] Gratão A.C.M., Brigola A.G., Ottaviani A.C., Luchesi B.M., Souza É.N., Rossetti E.S., Oliveira N.A.d., Terassi M., Pavarini S.C.I. The brief version of Zarit Burden Interview (ZBI) for burden assessment in older caregivers. *Dementia & Neuropsychologia.* 2019;13:122-129.

[7] Yu Y., Liu Z.-w., Zhou W., Chen X.-c., Zhang X.-y., Hu M., Xiao S.-y. Assessment of burden among family caregivers of schizophrenia: psychometric testing for short-form Zarit burden interviews. *Frontiers in Psychology.* 2018;9:2539.

[8] Skevington S.M., Tucker C. Designing response scales for cross-cultural use in health care: Data from the development of the UK WHOQOL. *British Journal of Medical Psychology.* 1999;72(1):51-61.

[9] Nejat S., Montazeri A., Holakouie Naieni K., Mohammad K., Majdzadeh S. The World Health Organization quality of Life (WHOQOL-BREF) questionnaire: Translation and validation study of the Iranian version. *Journal of School of Public Health and Institute of Public Health Research.* 2006;4(4):1-12.

[10] Cunningham M.J. Update on thalassemia: clinical care and complications. *Hematology/Oncology Clinics of North America.* 2010;24(1):215-227.

[11] Bakr A., Al-Tonbary Y., Osman G., El-Ashry R. Renal complications of beta-thalassemia major in children. *American Journal of Blood Research.* 2014;4(1):1-6.

[12] Mahmoud H.H., Abo Elnour S.I. Cardiac affection in pediatric patients with β-thalassemia major. *Fayoum University Medical Journal.* 2022;10(4):1-10.

[13] Sharma S., Seth B., Jawade P., Ingale M., Setia M.S. Quality of life in children with thalassemia and their caregivers in India. *The Indian Journal of Pediatrics.* 2017;84:188-194.

[14] Askaryzadeh Mahani M., Ghasemi M., Arab M., Baniasadi Z., Omidi A., Irani P.S. The correlation between caregiver burden with depression and quality of life among informal caregivers of hemodialysis and thalassemia patients during the COVID-19 pandemic: a cross-sectional study. *BMC Nursing.* 2023;22(183):1-9.

[15] Mevada S.T., Al Saadoon M., Zachariah M., Al Rawas A.H., Wali Y. Impact of Burden of thalassemia major on health-related quality of Life in Omani children. *Journal of Pediatric Hematology/Oncology.* 2016;38(5):384-388.

[16] Sahu S., Agrawal A., Shrivastava J., Tonk S. Psychiatric disorders and caregiver burden in children with transfusion-dependent β-thalassaemia and their caregivers. *World Journal of Clinical Pediatrics.* 2023;12(3):125.

[17] Paramore C., Levine L., Bagshaw E., Ouyang C., Kudlac A., Larkin M. Patient-and caregiver-reported burden of transfusion-dependent β-thalassemia measured using a digital application. *The Patient-Patient-Centered Outcomes Research.* 2021;14:197-208.

[18] Mashayekhi F., Jozdani R.H., Chamak M.N., Mehni S. Caregiver burden and social support in mothers with β-thalassemia children. *Global Journal of Health Science.* 2016;8(12):206.