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Family Support for Patient with Thalassemia Concerning Psychological Needs

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ABSTRACT

Objective: This study aimed to assess the psychological needs of children with thalassemia and examine differences in family psychological support based on parents' sociodemographic characteristics.

Methods and Materials: A cross-sectional descriptive study was conducted from February 12 to March 15, 2025, at the Babylon Center for Genetic Diseases, Babylon Teaching Hospital for Maternity and Children, Iraq. The study included 125 parents of children with thalassemia aged 5–22 years. Data were collected using a validated and modified questionnaire with two sections: sociodemographic data and psychological support items. The data were analyzed using SPSS version 26, employing descriptive statistics, Mann–Whitney U test, and Kruskal–Wallis H test to assess group differences.

Findings: Most children were over 15 years old (44.0%), and the majority of parents were aged 40–49 (40.8%), female (61.6%), and had primary-level education (34.4%). Overall, 62.4% of parents provided a high level of psychological support. Key areas included expressions of love (68.8%), listening to feelings (70.4%), and offering encouragement (77.6%). Significant differences in psychological support were found based on parental gender (p=0.045), education level (p=0.029), and residence (p=0.017), with mothers, more educated parents, and urban residents providing greater support.

Conclusion: Family psychological support plays a crucial role in the emotional well-being of children with thalassemia. Socio-demographic factors significantly influence the level of support provided. Educational interventions targeting fathers, rural families, and those with low educational attainment are recommended to enhance psychological support for affected children.

Keywords: Family support, thalassemia patient, psychological Needs.

Introduction

Thalassemia is chronic hereditary blood disorder that Greats significant physical and emotional burdens on affected individuals, particularly children. Those diagnosis with beta thalassemia major often require lifelong treatment, such as blood transfusion and iron chelation therapy. while these interventions essential for survival ,they contribute to recurrent hospital visits and persistence physical suffering ,exposing patients to severe psychological stress (Prathyusha et al., 2019).

In addition to physical challenges ,patients with thalassemia frequently experience psychological difficulties such as anxiety, depression ,and social withdrawal ,This emotional struggles often stem from the chronic nature of the illness, The need for repeated medical procedure and visible disease related complications like delayed growth and skeletal abnormalities .consequently ,psychosocial stressor can negatively influence their quality of life and treatment adherence (Sari et al., 2024).

Family support plays a crucial role in managing the psychological wellness of patients with thalassemia, parents often serve not only as providers of medical care but also as sources of emotional and psychological stability. The presence of supportive family relationships can improve patient coping mechanisms, reduce emotional distress and improve adherence to treatment regimens (Ahmadian et al., 2022; Tarım & Öz, 2022). However, the burden placed on caregivers can lead to psychological strain, which in turn mat affect the quality of support offered to the patient.

Effective family support includes emotional availability, understanding the patient mental state and providing reassurance and motivation, all of which help children adapt to their condition and reduce their psychological burden (Handayani et al., 2022; Richard et al., 2025) ,Despites its importance, their remains limited research addressing how family support, particularly, psychological support meets the emotional needs of children with thalassemia .

Therefore, this study aims to explore the level of psychological support provided by parents to patients with thalassemia and to highlight its significance in managing the psychological challenges associated with disease.

Methods and Materials

Design and sampling

A quantitative, cross-sectional descriptive design is used for the assessment the psychological needs for thalassemia patient 12February 12 May 2025. The sample of the study was selected convenience (non-probability), made up of 125 parents for patient diagnosis with major thalassemia from both sex.

Data Collection

Collection of data by using a questionnaire was modified to accomplish the goals of the current study after a comprehensive review of the relevant literature. It consists of two sections designed to cover all aspects of the study. The first part is for demographic data for the patient and their families, the Two part is about psychological needs which includes ten items.

Data Analysis

The data of the present study was analyzed electronically via the Statistical program (SPSS) version 26. The method used in this program aimed to find out the descriptive and inferential statistics such as frequencies, percentages, Mann-whitney U test, Kruskal-wallis H test, by entering data to achieve the objectives of the study.

Findings and Results

Table 1

Distribution of the Study Sample by their demographic data of(N=125)

SDVs	Classification	No.	%
Patients age (years)	<10	18	14.4
	10-15	52	41.6
	>15	55	44.0
	M ± SD	14.73±4.508	
Sex	Male	79	63.2
	Female	46	36.8
Education level	Not Read and write	46	36.8
	Primary	49	39.2
	Intermediary	20	16.0
	Secondary	5	4.0
	Institute or above	5	4.0
Birth order in family	1st	31	24.8
	2nd	36	28.8

	3rd	35	28.0
	4th ≥	23	18.4
Parents age (years)	<30	5	4.0
	30-39	36	28.8
	40-49	51	40.8
	50-59	25	20.0
	≥60	8	6.4
	M ± SD	43.62±9.448	
Parents Sex	Father	48	38.4
	Mother	77	61.6
Parents education	Not read and write	40	32.0
	Primary	43	34.4
	Intermediate	12	9.6
	Secondary	6	4.8
	Institute or above	24	19.2
Parents occupation	Employed	29	23.2
	Un employed	96	76.8
Residents	Urban	62	49.6
	Rural	63	50.4
Family income/month	Insufficient	31	24.8
	Sufficient for some extent	68	54.4
	Sufficient	26	20.8

Table 2

Distribution of Family Support in terms of psychological needs for patient with thalassemia

List	**Psychological needs Items**	**Never**		**Sometime**		**Always**		**M.s**	**Ass.**
		No.	%	No.	%	No.	%		
1	The parents express love and affection to the patient.	21	16.8	18	14.4	86	68.8	2.52	**H**
2	Listen attentively when the patient shares his or her feelings.	16	12.8	21	16.8	88	70.4	2.58	**H**
3	Offer words of encouragement, reassurance to the patient.	16	12.8	12	9.6	97	77.6	2.65	**H**
4	Avoid criticizing or blaming the patient for his or her condition.	19	15.2	15	12.0	91	72.8	2.58	**H**
5	Talk to the patient about his or her feelings and experiences.	18	14.4	25	20.0	82	65.6	2.51	**H**
6	The parents help the patient cope with stress, anxiety.	23	18.4	26	20.8	76	60.8	2.42	**H**
7	The parents encourage the patient to engage in healthy coping mechanisms such as exercise and relaxation exercise.	36	28.8	24	19.2	65	52.0	2.23	**M**
8	The parents help the patient access mental health services when needed.	35	28.0	27	21.6	63	50.4	2.22	**M**
9	The parents provide the patient with emotional support during difficulty times.	25	20.0	21	16.8	79	63.2	2.43	**H**
10	The parents believe in the patient ability to cope with his condition and live a fulfilling life.	18	14.4	24	19.2	83	66.4	2.52	H

Table 3

overall level of family support for psychological needs (N=125)

Psychological needs	**Frequency**	**percentages**	**Mean**	**SD**
Low	14	11.2		
Moderate	33	26.4		
High	78	62.4		
Total	125	100.0	24.66	5.7737

Fig.4-1.

Overall Family Support of Psychological Needs

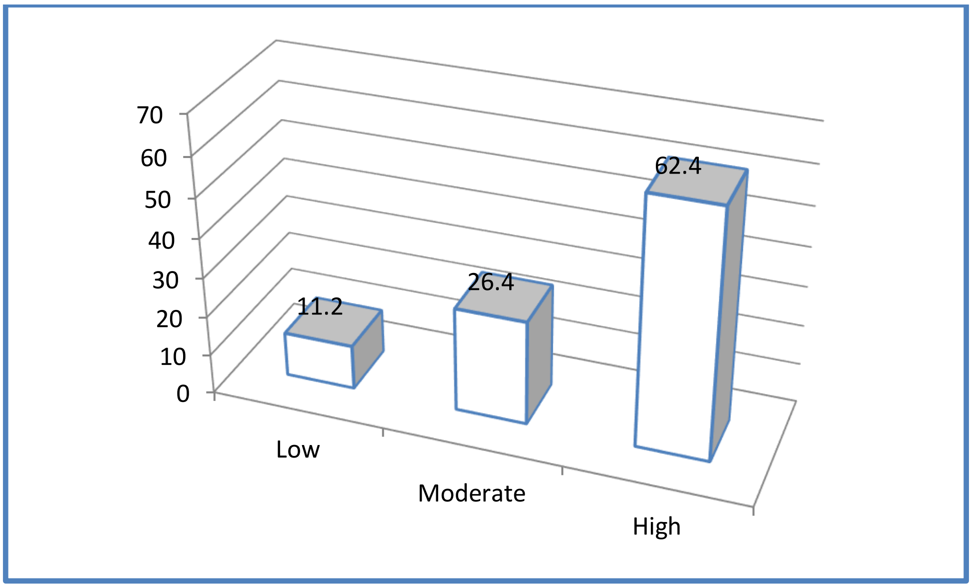

Table 4

difference between psychological support and their demographic data of parents

Variables	Classification	Psychological Needs *Ranking*	*Sig.*
Parents age	<30	66.30	
	30-39	68.93	
	40-49	55.91	.382
	50-59	70.00	
	≥60	57.56	
Parents sex	Father	63.69	
	Mother	82.57	.045
Parents Education	Not read and write	62.18	
	Primary	58.52	
	Intermediate	74.08	
	Secondary	77.50	
	Institute or above	83.23	.029
Occupation	Employed	55.14	.172
	Un employed	65.38	
Residents	Urban	88.18	.017
	Rural	57.90	
Income/ month	Insufficient	58.06	.315
	Sufficient for some	67.44	
	Sufficient	57.27	

Discussion and Conclusion

The results indicates that most of the patients are in the age group >15 years (44.0%) with a mean age of 14.73 years, and more patients are male (63.2%) .This results go in line with El-said et al., (2021) in Egypt to evaluate stress, anxiety and depression for 112 patient reveals that more than half of the studied subjects (52.7%) were males and 54.4% aged between 10 to less than 14 years.

In cross sectional study carried by Mousa, (2022) to Assessment The Quality of Life of Thalassemic Major Children in Duhok City for 88 children ,The result indicated that majority of children age more than 10 years (45.5%) .

Concerns sex, ,The result of the study showed More male patients are included (63.2%) than females patients(36.8%),This findings agree with the findings of Wardhani et al., (2021) who shown that the majority of thalassemic patients were males (52%) and age group (10-17)years .

A descriptive study conducted by Mousa, (2022) to Assessment The Quality of Life of Thalassemic Major Children in Duhok City showed the highest percentage of patients were male (60.2%).

In terms educational level of patients, the majority completed primary school (39.2%) as well as parents had primary school (34.4%),therefore this finding agrees with Eidan & Aldoori, (2022) which showed the majority of patients have primary school , A separate study conducted by Batool et al., (2017) employed a cross-sectional design involving 91 patients with thalassemia major, aged 12 to 18 years, the majority of whom had attained just a primary educational level, what is attributed to socioeconomic position for the studied sample, Therefore educated person have the ability to understand the management plan and have Enough knowledge about results not complying with the plane ,Moreover the has ability to accept child and the disease that requires treatment for long life ,which affects the level of support that is provided by parents .

Regarding patient orders in their families the current study showed a relatively balanced distribution. Specifically, 28.8% of the patients were second-born, 28.0% were third-born, and 24.8% were first-born children at birth , A similar conclusion was drawn by a study conducted in Iran by Naderi et al., (2023) which was titled “Assessment of the influencing factors on the birth of children with thalassemia major in families with more than one affected child. That study found no meaningful link between birth order and thalassemia prevalence, with infection rates being comparably high across first-, second-, and third-born children (100%, 97.9%, and 100%, respectively).

Another unpublished study conducted in karbala university by ISHFAQ et al., (2016) showed that the majority of mothers participating in the questionnaire were those who had 1-3children, and the percentage was (51.1)% of total number of children (307), While, comparative study in Babylon province conducted by Eidan & Aldoori, (2022) to assess Physical Growth and Psychosocial Development of Thalassemic and Healthy Adolescents showed adolescent's orders in their families between first and second child (64.0%).

Analysis sociodemographic of parents revealed the age group of parents with the largest group falling within the 40-49 years age range (40.8%) and the majority female (61.6%),these results particularly agree with Astarani et al., (2024) that showed the majority participants where female (85.7%) and the age group(40-49) was less than a third (28.6%) .

Regarding level of education, the results show the parents majority (34.4%) have primary school, therefore ,the result consistent with Eidan & Aldoori, (2022) that showed that (58.7%) of mothers had a primary level.

In unpublished comparative study carried out by Khurana et al., (2006) to identify the physical growth and psychosocial development of thalassemic patients and healthy adolescents, The findings showed that the age group of (31%) of mothers was (44-50),Also the majority has a primary school education(58%).

Concerning caregiver occupation, the result shows the majority caregivers unemployed (76.8%), similar to findings from a descriptive study conducted by ISHFAQ et al., (2016) to assess Mothers Knowledge Concerning Management of Children with Thalassemia, showed most of the mothers unemployed (90.2%).

In terms residence ,the results indicates that majority of caregivers from rural (50.4%),this result consistent with Batool et al., (2017) on 91patient in age 8-18 years in Pakistan shown that (50.5%) resided in rural areas.

While The current result disagrees with another study conducted by Islam et al., (2025) it shows that of the total respondents, 51% of the participants were from urban areas.

Concerns about family income for caregivers, The result indicates that most family have income sufficient for some extent (54.4%), This findings consistent with ISHFAQ et al., (2016) shows 219 of 307 participants (71.3%) with barely sufficient monthly income .

Another cross sectional study carried by Eidan & Aldoori, (2022) The finding indicates that most families have family income sufficient for some extent (47.3%) for 150 participants.

The findings of current study table (5) indicated that there is a highly significant

Differences between psychological support that provided by parents and some socio demographical data such as (sex, level of education ,residence) at $p<0.05$ researchers opinion this due to cultural and social norms to east community because traditional role to mother in caring ,The mother is closer and more embracing to the child and strong emotional correlation In addition ,the male may be busy with other things like a living or provide support to another domain .

Higher level education that effect greatly on support provided, Educated individual have deep awareness about disease and consequences ,This make him attention in provide emotional support and assistance and best ability to communicate with patient ,In addition to economic position associated with high education ,Therefore alleviated financial strain and allow to parent concentration on psychological aspect to the patient.

In concerns residence, parents residence in urban had high level from education and easy access to health psychological services such as consultation that enhance parent ability to deal with psychological stressors as well as income level relatively high in urban from rural .

Based on the interpretation and discussion of the findings, the study concludes the following: The majority of thalassemia patients were between 10 and 15 years of age, while most of their parents fell within the 40–49 age range. A significant portion of the participants and their families had only attained a primary level of education. The level of family support was found to play a crucial role in the psychological well-being of the patients. Furthermore, parental sex, educational status, and place of residence were significantly associated with the level of psychological support provided to the patients.

Recommendation

The study recommends maintaining a high level of psychological support for thalassemia patients and increasing family support, particularly for families with lower educational levels and those residing in rural areas. It also emphasizes the importance of encouraging greater involvement from fathers in providing psychological support. Additionally, further research is needed to explore the role of family support in addressing the psychological needs of thalassemia patients.

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Declaration of Interest

The authors of this article declared no conflict of interest.

Ethical Considerations

The study protocol adhered to the principles outlined in the Helsinki Declaration, which provides guidelines for ethical research involving human participants. Ethical considerations in this study were that participation was entirely optional.

Transparency of Data

In accordance with the principles of transparency and open research, we declare that all data and materials used in this study are available upon request.

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Authors' Contributions

All authors equally contribute to this study.

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