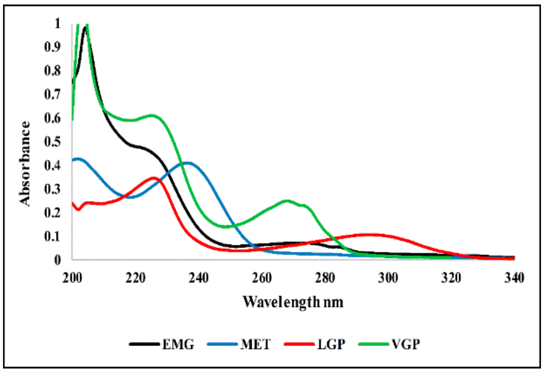
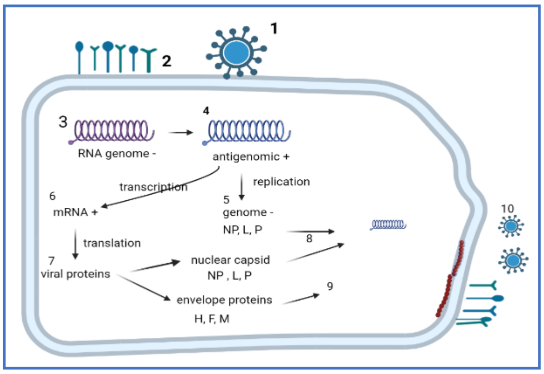
JOURNAL OF ZANKOY SULAIMANI

Part -A- (Pure and Applied Sciences)

VOLUME 26 ISSUE 1 June 2024
ISSN: 1812-4100
www.jzs.univsul.edu.iq

AUTHOR'S COPY





Journal homepage www.jzs.univsul.edu.iq
Journal of Zankoy Sulaimani
Part-A- (Pure and Applied Sciences)
ISSN:1812-4100

Knowledge of Thalassemia Caregivers Attending the Thalassemia and Congenital Blood Disorder Center, Sulaimaniyah, Iraq

Chiman Jamal Ahmed[1,2*], Karim Fatah Aziz[3], Muhamad Rashid Amin[2]

[1] *Thalassemia and Congenital Blood Disorder Center, Sulaimani Directorate of Health, Sulaimaniyah, Iraq*
[2] *College of Nursing, University of Sulaimani, Sulaimaniyah, Iraq*
[3] *College of Nursing, Hawler Medical University, Erbil, Iraq*
*Corresponding author's e-mail: chiman.ahmed@univsul.edu.iq

Article info

Original: 05/12/2023
Revised: 10/01/2024
Accepted: 12/01/2024
Published online: 20/06/2024

Keywords:
Caregiver, knowledge, thalassemia, analytical study

Abstract

Background: Thalassemia is the leading hemoglobinopathy and a common public health problem in Iraq. About 7% of the Iraqi people are carriers of this genetic disorder. **Aim:** To assess parents' accurate knowledge about thalassemia disease in Sulaimaniyah, Iraq. **Subjects and Methods:** This descriptive-analytic study was conducted on 304 caregivers of thalassemia patients at the Thalassemia and Congenital Blood Disorder Center, Sulaimaniyah, Iraq, from February to July 2022—a validated questionnaire collected caregivers' characteristics and knowledge of the thalassemia condition. **Results:** Regarding the thalassemia patients' caregivers' sociodemographic data, most of them were aged 36-49 years old (67.1%), females (59.2%), mothers (61.8%), housewives (59.2%), lacked formal education (48.7%), had not enough income (57.9%), and from urban area (78.9%), without chronic disease (76.3%). Also, most caregivers were not undergoing premarital testing (81.6%), expressed readiness for antenatal testing (63.2%), had a poor level of general knowledge about thalassemia (73.7%), and agreed to abort their fetus if they knew about the condition during pregnancy (59.2%). Regarding thalassemia caregivers' level of knowledge, most caregivers (73.7%) had poor general knowledge, 44.7% had good prevention knowledge, 65.8% had good treatment knowledge, 61.8% had good perception, and 35.5% had a fair overall understanding. There was a significant difference between knowledge level and gender, occupation, education, relation, and residency (p=0.000). Regarding antenatal tests, caregivers who had not performed these tests had a significantly lower mean knowledge level than those who had (p=0.000). **Conclusions:** There needs to be more knowledge among patients' caregivers regarding thalassemia. Thus, intensive courses and training should be given to them to improve their understanding.

Introduction

Thalassemia is one of the most common genetic blood disorders in the world that is characterized by a decrease or absence in the synthesis of the alpha or beta polypeptide chains that form the average hemoglobin molecule [1]. Thalassemia is a hemoglobinopathy and hereditary chronic disorder that needs lifetime blood transfusions in severe cases, medications and investigations, creating a financial burden and emotional on the family [2].

Thalassemia is a common disease in Iraq, with a prevalence of 35.7 per 100000. Beta thalassemia major is a condition of life-threatening with many complications and could cause death at an early age if the complications are not managed [3]. The influence of thalassemia on the body can lead to physical malformation, delayed puberty and growth retardation. Its impact on the patient's appearance, like bone deformity and short stature, also contributes to a poor self-image [4].

A parent with good knowledge concerning the disease can provide a healthier quality of care to their ward and may act as a percolator of expertise to the society in which they live. Thus, it dramatically helps raise public awareness of the disease [4].

Different strategies to prevent thalassemia include parental awareness, population screening, genetic counselling, and prenatal diagnosis [5]. Creating awareness and educating caregivers is cost-effective in preventing the disease and developing the quality of life of thalassemia patients. Our country has studies on the general population about screening and prenatal diagnosis of thalassemia. Still, very few studies emphasize the awareness and experiences of parents raising a thalassemia child [6].

As severe thalassemia affects both physical and mental health, it causes patients and their parents to suffer; therefore, prevention and control of severe thalassemia are essential [7]. Several countries, including Italy, Greece, Cyprus, the United Kingdom, France, Iran, Thailand, Australia, Singapore, Taiwan, Hong Kong, and Cuba, have comprehensive national prevention programs for severe thalassemia [8]. The process includes public awareness and health education, carrier screening, genetic counselling, prenatal diagnosis, and sometimes therapeutic abortion when a life-threateningly severe form of thalassemia is confirmed. Limited programs, including antepartum screening according to ethnic group, are available in only a few northern European countries [9]. Thus, this study is designed to investigate the level of knowledge among caregivers of patients with thalassemia and find out the relation between knowledge and their characteristics in Sulaimaniyah City, Iraq.

Materials and Methods

This quantitative-descriptive research design was conducted at the Thalassemia and Congenital Blood Disorders Center, Sulaimaniyah, Iraq. The study centred on those caring for individuals with thalassemia from February to April 2023. The study utilized a non-probability convenience sampling method to pick 304 caregivers deliberately.

Data collection

Before conducting the interviews with the caregivers, a formal agreement was obtained. 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 careers themselves. The data were obtained by administering a questionnaire through structured interviews with careers. The interview took place in the facility's dedicated and comfortable conference room during the morning hours.

Study instruments

A structured and validated questionnaire was prepared using literature and personal experience. The questionnaire was organized into three sections. Section 1 consists of sociodemographic data and caregiver-related characteristics (age, gender, education, occupation, residency, economic status, and relation to the patient). Also, it includes caregivers' chronic disease, premarital test, antenatal test, the reason for not completing the antenatal test/ premarital test, and abortion agreement. Section 2 includes 36 questions that were general information about thalassemia (12 questions), screening and prevention (13 questions), treatment (5 questions) and perception (6 questions) to assess caregivers' knowledge regarding thalassemia.

For the scoring system, only one correct answer related to their knowledge about thalassemia was selected. The correct answer was "1", while the incorrect was "zero". The percentage was calculated for each knowledge section and overall knowledge. The total score was 36 questions; the answers' score was rated as poor, fair and reasonable knowledge according to its total score and classified into poor knowledge (<50%), fair knowledge (50 - 75%), and good knowledge (>75%).

Ethical approval

The College of Medicine ethics committee approved the research 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 thalassemia patients.

Exclusion criteria

Family caregivers with severe physical or mental disorders were excluded.

Statistical analysis

Data analysis was conducted using the Statistical Package for Social Science (SPSS, Chicago, USA, version 26). Inferential statistics were utilized to make inferences about the population based on the sample. Furthermore, a correlation coefficient was used to determine the correlation among dependent variables, with a p-value of <0.05 considered statistically significant.

Results

The mean age of thalassemia caregivers was 42.43 ± 8.12 years. Most of them (67.1%) fall in the age group of 36 - 49 years: 59.2% were females, 56.6% were housewives, 61.8% were mothers of thalassemia patients, 78.9% were from an urban area, 57.9% had income less than expenditure, and 48.7% had no formal education (Table 1).

Table 1. Distribution of caregivers' sociodemographic characteristics.

Thalassemia Caregivers' Sociodemographic characteristics		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
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
Total	304	100	

Moreover, most caregivers (81.6%) had not undergone premarital testing due to the availability of the test (52.6%). Also, most thalassemia parents (63.2%) performed antenatal testing and agreed to abort their child (59.2). While 26.3 % didn't want to abort their child even if the fetus was diagnosed with thalassemia major, and 40.8% of the parents were not willing to abort their fetus (Table 2).

Table 2. Distribution of caregiving-related clinical 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 and lack of knowledge	160	52.6
	Marriage outside the court	88	28.9
Antenatal Test	No	112	36.8
	Yes	192	63.2
Reason for not performing Antenatal Test	Performed	192	63.2
	Do not believe	80	26.3
	Not applicable	32	10.5
Abortion Agreement	No	124	40.8
	Yes	180	59.2
Total		304	100

Additionally, most caregivers (73.7%) had poor general knowledge about thalassemia, 44.7% had excellent prevention knowledge, 65.8% had good treatment knowledge, 61.8% had good perception, and 35.5% had a fair overall understanding (Table 3).

Table 3. Thalassemia caregivers' level of knowledge.

Type of knowledge	**Levels of knowledge**	**Frequency**	**Percentage**
General Knowledge	Poor	224	73.7
	Fair	32	10.5
	Good	48	15.8
Prevention Knowledge	Poor	80	26.3
	Fair	88	28.9
	Good	136	44.7
Treatment Knowledge	Poor	72	23.7
	Fair	32	10.5
	Good	200	65.8
Perception	Poor	52	17.1
	Fair	64	21.1
	Good	188	61.8
Overall Knowledge	Poor	92	30.3
	Fair	108	35.5
	Good	104	34.2
Total		304	100

Regarding the association between sociodemographic characteristics of thalassemia caregivers and their knowledge, there were no significant differences in knowledge among different age groups (p=0.428) and financial status (p=0.162). In contrast, significant differences (p=0.000) were seen for each gender, occupation, education, relation to their patients, and residency. Retired/jobless caregivers had the highest knowledge (p=0.000), while those with no formal education had the lowest knowledge (p=0.000) (Table 4).

Table 4. Association between sociodemographic characteristics of thalassemia caregivers and knowledge.

Sociodemographic characteristics		**Knowledge**		**p-value**
		Mean	**SD**	
Age groups (Years)	20 - 35 years	58.43	20.55	0.428
	36 - 49 years	59.83	25.93	
	≥ 50 years	64.38	25.88	
Gender	Male	67.11	22.04	0.000**
	Female	55.76	26.15	
Occupation	Housewives	55.01	25.95	0.000**
	Paid employed	57.47	24.41	
	Self-employed	73.30	16.76	
	Retired/Jobless	100	0.00	
Education level	No formal education	55.40	27.96	0.000**
	Primary	60.48	20.87	
	Secondary	69.58	20.36	
	Institute/University	72.44	20.59	
Financial Status	Income more than expenditure	65.01	12.74	0.162
	Income equal expenditure	63.24	20.94	
	Income less than expenditure	58.07	28.32	
Relation	Mother	55.90	26.76	0.000**
	Father	67.66	20.38	
Residency	Urban	63.65	23.43	0.000**
	Rural	48.14	27.67	

**: Highly significant difference using the Chi-square test

The caregivers who performed the antenatal test had higher overall knowledge (64.4±22) than caregivers who did not complete it (53.5±28.7) (p=0.000). The caregivers with abortion agreement had a more excellent overall knowledge (63.4±20.5) than those who had not performed it (56±30.1) (p=0.01). There was no significant difference between overall knowledge and caregivers' chronic disease (p=0.077), premarital test (p=0.861) and reason for not performing the premarital test (p=0.984) (Table 5).

Table 5. Association between some caregiving-related characteristics and knowledge.

Caregivers' Characteristics		**Knowledge**		**p-value**
		Mean	**SD**	
Chronic disease	No	61.80	24.25	0.077
	Yes	55.81	27.53	
Premarital test	No	60.26	25.17	0.861
	Yes	60.92	25.25	
Reason for not performing Premarital test	Performed	60.92	25.25	0.984
	Not Available	60.21	25.87	
	Marriage Outside the Court	60.37	23.99	
Antenatal test	No	53.5	28.7	0.000**
	Yes	64.4	22	
Abortion agreement	No	56	30.1	0.01*
	Yes	63.4	20.5	

*: Significant difference, **: Highly significant difference using Chi-square test

Discussion

Caregivers' knowledge regarding thalassemia is one of the vital areas in the prevention of the disease. Very few studies related to caregivers' knowledge sociodemographic predictors help design interventions across different study settings [10]. Thus, we aimed to study the thalassemia patient's caregiver's knowledge for the first time in this locality.

The present study revealed that most caregivers were women, mothers of the patients, housewives, and did not have any formal education, were from urban areas, and did not suffer from any chronic conditions. Also, most of them did not have enough income, were mothers of patients, and did not perform premarital tests, mainly due to lack of knowledge. More than one-third of caregivers did not perform antenatal tests due to either not believing or an unavailable test, and most caregivers were ready to abort their fetus when diagnosed with thalassemia major. General knowledge regarding thalassemia was poor for almost three quarters, while the knowledge about prevention and treatment was good for nearly half and almost two-thirds, respectively. Overall knowledge is distributed similarly among poor, fair and good knowledge. The knowledge was better among retired, jobless, educated, those from urban areas, males and fathers. The finding about the knowledge of fathers agreed with a study done by Manzoor and Zakar, 2019, which revealed that fathers were more aware of the premarital screening, and they mentioned that fathers had a better understanding of disease and exhibited better-coping strategies compared to mothers [11].

The current study also revealed that the performance of antenatal tests had significant impacts on knowledge levels. Caregivers who had yet to undergo antenatal testing had less knowledge, indicating that promoting and facilitating antenatal testing was essential for the early detection of thalassemia and increasing awareness. The research findings on caregivers' knowledge showed a significant knowledge gap among thalassemia caregivers, with a significant portion having a poor or fair understanding of various knowledge in each category. Because of this, efforts should be directed toward improving overall knowledge through targeted educational initiatives to enhance caregiving for individuals with thalassemia. Moreover, the findings indicated that they have unsatisfactory knowledge regarding thalassemia as a general knowledge, while there needed to be more knowledge regarding prevention and treatments. These findings are lined with another study conducted by Inamdar et al., 2015, which revealed that caregivers did not have satisfactory knowledge about thalassemia [12].

Similarly, Salih, 2014 in Kirkuk, Iraq, found that most caregivers had good knowledge about thalassemia treatment and prevention [13]. However, Jeesh et al., 2019) indicated that patients needed more information and skills regarding the parts of thalassemia care they were receiving [14]. Also, Ishfaq et al., 2016 noted that thalassemia caregivers with their kids had extremely inadequate knowledge and skills and required health education programs to improve their understanding and abilities [15]. Similarly, Nassim et al., 2022 did not agree with the general knowledge of caregivers in this study. Still, they have similar findings regarding understanding prevention and treatment [16].

The other findings of this study indicated no significant relation between premarital test and their features. In this respect, Hashemizadeh and Noori, 2013 demonstrated that a premarital screening program was adequate for the identification and prevention of high-risk marriages [17].

It is possible to manage thalassemia major effectively by the utilization of premarital screening programs that are designed to identify carrier couples. At the same time, this study's findings showed an acceptance rate of knowledge and skills among caregivers. Other studies linked to the knowledge of caregivers preferred to increase the knowledge by using education programs and suggested that educational intervention was required to enhance their understanding and abilities [18, 19]. Furthermore, other studies found that it was vital to raise people's levels of knowledge in order to raise awareness about the preventative elements of thalassemia among the general public, as well as among family members and caregivers [15, 20].

Additionally, it was realized that increasing education and awareness among parents and those who provide care could prevent some features of thalassemia illnesses [4]. Also, it was found that the parents of children who have thalassemia need to get health education about the condition and the necessary therapy, and might require therapy and help on a psychological level [12]. It should be recommended that premarital counselling is essential for the early diagnosis and awareness of blood diseases in the family. These suggestions should be based on the studies' findings and the significance of caregivers' knowledge. Building a social and professional support network should be done. The study suggests that there is a need for educational initiatives to improve knowledge about thalassemia among caregivers in Sulaimani, Iraq, mainly targeting female caregivers, those with no formal education, and those who have not undergone antenatal testing. Alternatively, promoting awareness through religious channels or involving religious leaders may be beneficial. Increasing knowledge about thalassemia can lead to better regional prevention and management of this genetic disorder.

Conclusions

The findings revealed a lack of knowledge among caregivers regarding thalassemia. Regular counselling and education programs about knowledge and awareness should be offered to extended caregivers of existing thalassemia patients. It is suggested that special consulting units be established for the families of thalassemia children to answer their questions. Encourage the parents of these children to work as volunteers in the consulting units to help the newly diagnosed cases of thalassemia and help their parents be oriented to their new situations.

Conflict of Interest

The authors declare no conflicts of interest regarding this manuscript's publication and/or funding.

References

[1] M. A. C. Mat, L. H. Yaacob, and R. Zakaria, "Parental knowledge on thalassaemia and factors associated with refusal to screen their children," *The Malaysian Journal of Medical Sciences: MJMS*, vol. 27, pp. 124-133, 2020.

[2] K. Srinivasa and P. Pujari, "Knowledge, attitude, practices among parents of β thalassemia children regarding thalassemia," *International Journal of Advanced Community Medicine,* vol. 3, pp. 1-5, 2020.

[3] M. T. Mutar, M. Majid, A. Jaleel, A. Saad, A. Abdulmortafea, and H. Talib, "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,* vol. 7, pp. 6-10, 2019.

[4] R. K. Kalra, D. Kaur, M. Sodhi, and J. Kaur, "Knowledge, attitude and practice in parents of chronically transfused thalassemic patients regarding thalassemia in thalassemia day care unit in government medical college, Amritsar, Punjab, India," *International Journal of Contemporary Pediatrics,* vol. 6, pp. 2469-2475, 2019.

[5] F. Ishaq, F. Hasnain Abid, A. Akhtar, and S. Mahmood, "Awareness among parents of ββ-Thalassemia major patients, regarding prenatal diagnosis and premarital screening," *Journal of the College of Physicians and Surgeons Pakistan,* vol. 22, pp. 218-21, 2012.

[6] A. Saxena, M. Sharif, S. Siddiqui, and S. Singh, "Knowledge, practice and experiences of parents with a thalassemic child," *International Journal of Contemporary Pediatrics,* vol. 4, pp. 1630-1633, 2017.

[7] R. Tariq, T. Mahmud, S. Bashir, S. Akhtar, and M. Israr, "Impact Of Population Screening Programs On The Knowledge, Attitudes And Practices Regarding Prevention Of Thalassemia," *Pakistan BioMedical Journal,* vol. 4, pp. 209-214, 2021.

[8] B. Modell, M. Darlison, H. Birgens, H. Cario, P. Faustino, P. C. Giordano, *et al.*, "Epidemiology of haemoglobin disorders in Europe: an overview," *Scandinavian Journal of Clinical and Laboratory Investigation,* vol. 67, pp. 39-70, 2007.

[9] A. Cao and Y. W. Kan, "The prevention of thalassemia," *Cold Spring Harbor perspectives in medicine,* vol. 3, 2013.

[10] M. S. Hossain, M. Mahbub Hasan, M. Petrou, P. Telfer, and A. A. Mosabbir, "The parental perspective of thalassaemia in Bangladesh: lack of knowledge, regret, and barriers," *Orphanet Journal of Rare Diseases,* vol. 16, pp. 1-10, 2021.

[11] I. Manzoor and R. Zakar, "SociodemSociodemographicnants associated with parental knowledge of screening services for thalassemia major in Lahore," *Pakistan Journal of Medical Sciences,* vol. 35, pp. 483-488, 2019.

[12] S. Inamdar, M. Inamdar, and A. Gangrade, "Stress level among caregivers of thalassemia patients," *National Journal of Community Medicine,* vol. 6, pp. 579-582, 2015.

[13] Y. A. Salih, "Awareness of the Thalassemic Patients’ Parents toward Thalassemia in Kirkuk City," *Mosul Journal of Nursing,* vol. 2, pp. 58-62, 2014.

[14] A. Jeesh, Y. Aser Adnan, and M. A.-B. Al-Haboub, "The Effects of Patients' and Caregivers' Knowledge, Attitude, & Practice (KAP) on Quality of Life Among ThalassemiaMajorPatients' in Damascus-Syrian Arab Republic," *European Scientific Journal,* 2018.

[15] K. Ishfaq, T. Ahmad, S. B. Naeem, J. Ali, and S. Zainab, "The Knowledge Of Parents Having Thalassemia Child," *Isra Medical Journal,* vol. 8, pp. 79-82, 2016.

[16] M. S. Nassim, M. A. Mahmoud, H. Abu Shady, and E. A. E. R. Mohammed, "Assessment of disease knowledge gaps among beta-thalassemia major patients and their caregivers," *Egyptian Pediatric Association Gazette,* vol. 70, pp. 49-56, 2022.

[17] H. Hashemizadeh and R. Noori, "Premarital screening of beta thalassemia minor in north-east of Iran," *Iranian Journal of Pediatric Hematology and Oncology,* vol. 3, pp. 210-215, 2013.

[18] E. S. Ebtisam Mohamed and H. Amal Atia, "The effectiveness of an educational intervention on maternal management of children with beta-thalassemia," *Alexandria Journal of Pediatrics,* vol. 16, pp. 251-258, 2002.

[19] N. Ahmed, B. A. Khan, S. W. Bukhari, K. S. Khan, T. Sabir, and M. Nazir, "Knowledge, attitude and practices (KAP) of The families of B-thalassemia patients in a thalassemia Center of Karachi," *International Journal of Current Medical and Pharmaceutical Research,* vol. 6, pp. 4972-6, 2020.

[20] H. Maheen, F. Malik, B. Siddique, and A. Qidwai, "Assessing parental knowledge about thalassemia in a thalassemia centre of Karachi, Pakistan," *Journal of Genetic Counseling,* vol. 24, pp. 945-951, 2015.