Exploring Patients' Perspectives About Thalassemia and Its Treatment Modalities: Cross Sectional Hospital-Based Study

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Abstract

Objective: the study was conducted to identify the potential gap in patients' understanding, belief and behaviour towards thalassemia and its medications including iron chelation therapy (ICT).

Methods: An observational cross-sectional study performed from Feb to March 2023 on patients admitted to thalassemia centre in Najaf. The study included male and female patients diagnosed with thalassemia, taking iron chelation therapy, and accepted to participate in this study. The data were obtained by using a pretested validated questionnaire focused on sociodemographic data and 20 items used to evaluate the knowledge, attitude, and practice level (KAP).

Results: A total of 199 patients completed the study. About 73.9% of them had adequate knowledge, 78.4% showed positive attitude and 78.9% had good practice toward thalassemia and its therapy. However, 73% of them did not know that iron overload could cause diabetes and around 50% of them showed wrong belief toward importance of not missing medication doses. Additionally, third of patients experienced dose missing due to side effects. There were significant positive correlations among the total scores of patients KAP. All scores of KAP were significantly correlated with educational level while knowledge and practice scores were associated with the occupation as well as knowledge and attitude scores were also related to monthly income. Among remaining variables only male and urban residence were significantly linked to high knowledge score.

Conclusions: The study revealed overall adequate knowledge, positive attitude and good practice toward thalassemia and its therapy. Also, the study identifying specific and essential gap in patients' awareness, belief and behaviour that need a tailored patients support and educational program.

Keywords: Attitude, iron chelation therapy, knowledge, practice, thalassemia

Introduction

Thalassemia is a heterogeneous grouping of hereditary hematologic disorders (HHD). It associated with decreased synthesis of alpha or beta chains of haemoglobin (Hb) resulting in dysfunctional Hb, reduced RBC life span and haemolytic anaemia as well as ineffective erythropoiesis leading to chronic anaemia.[1] Worldwide, Thalassemia is considered one of the most widespread genetic diseases about 280 million. It is considered endemic in the Middle East, the Mediterranean region, and Southeast Asia as its prevalence in these regions ranges from 7%–10%. Annually 60 000 children with severe thalassemia are born.[2-4] In Iraq, there is about 13390 registered cases with a prevalence of 3.4/10000.[3] In Najaf province specifically, about 1022 patients recorded who consistently visit the thalassemia centre for treatment and follow-up.[5]

Thalassemia alpha or beta was classified as major, intermediate, or minor genotypes, but lately it was classified based on the clinical severity of patients determining whether they require regular blood transfusions to survive (transfusion-dependent thalassemia, TDT) or do not need transfusion of blood (non-transfusion-dependent thalassemia, NTDT).[1,6] Although blood transfusion is considered as mainstay of therapy, regular or frequent blood transfusions would cause iron overload (IOL) which might result in accumulation of iron in the heart, liver, spleen, and other tissues. Consequently, many complications might be encountered in thalassaemic patients such as hepatic, cardiac, and endocrine complications which are associated with increased disease morbidity and mortality. Therefore, removing the access iron from the body must be considered. Iron chelation therapy (ICT) is essential therapeutic option to eliminate and prevent iron overload and the patients usually require long-life treatment with regular follow up.[2,7] The understanding and awareness level of patients in their disease as well as the belief in treatment effectiveness are very fundamentals to ensure proper disease management, decrease complications and to optimize therapeutic outcomes.[8-10] Although there are several studies explored the knowledge, attitude and practice (KAP) of thalassemia among healthy populations in order to lower disease prevalence,[4,11–13] very limited studies were performed on thalassaemic patients to assess their understanding, belief and behaviour about the disease and its therapy.[14,15] The awareness level among thalassaemic patients regarding their lifelong disease and its challenges is the most effective way to decrease the disease complications, produce positive impact in their quality of life and improve their performance to deal with chronicity of their disease.[15,16] Additionally lack of knowledge about the thalassemia and its therapy will negatively affect patients adherence to the treatment.[11,14,17]

To the best of our knowledge, this will be the first study that investigates these objectives among Iraqi thalassaemic patients. Considering the importance of patients understanding, belief and practice in the disease treatment and providing the scarcity of such research on the thalassaemic patient treated with iron chelation therapy, we conducted this study to explore the patients' perspectives about thalassemia and its treatment and identifying any gap in their awareness, belief, and behaviours with focusing on iron chelation therapy.

Patients and Methods

The study design was observational cross-sectional study and conducted on the patients regularly visiting Thalassemia centre of AL Zahraa teaching hospital in Al Najaf governorate, starting from Feb 2023 till the end of March 2023. This centre is the only available health care institute for haematological diseases in Al Najaf province. The potential participants in this observational study were mainly the patients recorded in the thalassaemia centre of Al Zahraa teaching hospital. The patient randomly selected from those attending to the centre for medical counselling, routine checkups, blood transfusion, and medications. the study included male and female patients diagnosed with thalassemia, taking iron chelation therapy, and accepted to participate in the study after complete understanding the purpose of study. The total number of thalassaemic patients registered at this thalassemia centre were around 1022 patients. During the study period, we approached 220 patients.

The data of the study were collected by using pre-tested structured questionnaire which was developed by the research team based on a wide revision of many related literatures' questionnaires.[4,14] The questionnaire was reviewed and validated by two consultant physicians and four PhD academic pharmacists in the clinical pharmacy department. The questionnaire was translated into Arabic. The Arabic version was tested by running pilot study on 15 patients to ensure consistency, feasibility, and reliability. The data were collected by face-to-face interview with patients themselves or with their parents or caregivers for those under 12 years old. Each interview took 20–30 minutes to accomplish. The questionnaire was consisting of four parts, the Sociodemographic data of the patients (age, gender, weight, residence, education level, occupation, monthly income, consanguineous marriage, type of Thalassemia, frequency of transfusion and if he takes; iron chelation therapy). The second part was ten questions about the understanding of the disease, its hereditary nature, cause, treatments, the cause of iron overload and its associated complications and role of dietary iron, and finally assessing the awareness about the role and importance iron chelation therapy and its proper administration. The third part was five questions about patients' attitude toward following certain dietary instruction, belief in iron chelation therapy to lower iron overload, and patients' belief about getting new information regarding thalassemia. The fourth part of the questioner was about the patient's practice or behaviour which included five questions such as searching for new information thalassemia, visiting the hospital regularly, following certain dietary instruction, and using iron chelation agents in relation to mealtime and experiencing the impact of side effects on the adherence pattern.

Outcome measurements for tools done as follow, the response to knowledge questions were answered by either "Yes", "No" or "I don't know". The right responses were "Yes" for all the 10 knowledge questions and given 1 mark while zero mark given for "No" or "I don't know". The patients considered having good knowledge level if their total score was between 10–7, and poor knowledge level for those with total score below 7. For each attitude and practice assessment, we used five questions of four points -Likert scale answered by (strongly agree, agree, disagree, strongly disagree). The most suitable response received 4 marks, while 1 mark for the least suitable response. In all questions, "strongly agree" is the most suitable response that awarded by 4 marks except the number four question in each of practice and attitude was the reserves question in which the most suitable statement is "strongly disagree" that awarded by 4 marks. Finally, the total score was determined for each patient by collecting the mark of the right answers, with maximum score was 20. The positive attitude or good practice were considered for the patients with total score 14–20 while negative attitude and poor practice were determined for score below 14.[12]

Statistical Analyses

Data was analysed using Statistical Package for the Social Sciences (SPSS) software version 25. Descriptive statistics were conducted for all study items. Continuous variables were expressed as means ± standard deviation (SD), whereas categorical variables were expressed as frequencies and percentages. The One-Way ANOVA test was used to compare the differences in the means of continuous parameters (the total scores of knowledges, attitude, and practice (KAP)) according to patient characteristics such as education. The independent T-test was used to measure the difference in the total scores of KAP according to patient variables such gender. Pearson correlation was used to measure the relationships among the continuous KAP scores. A P-value of less than 0.05 was considered statistically significant.

Results

Thirteen patients refused to participate in the study and eight patients did not complete the study questionnaire. The remaining 199 patients who gave their consent and completed all study interviews. Baseline patients' characters of those 199 patients with thalassemia were demonstrated in Table 1. More than three-quarters of participating patients were adults (77.4%) and about half of the patients were male (51.3%) (Table 1). The majority (63.8%) were living in urban and were with primary or secondary school degrees of education (63.3%). Most of them were not employed 72.3%. About eighty one percent of the patients had parents having consanguine marriage. Almost most of the patients received blood transfusion and took Iron chelation therapy (Table 1). In general, the average mean of all patients' knowledge, attitude and practice scores were adequate: 7.5 out of 10, 15.74 and 15.23 out of 20, respectively (Table 2).

In other words, 73.9% of the patients had good knowledge, 78.4% had positive attitude and 78.9% had proper practice toward thalassemia and its therapy. At least two-thirds of the participants answered nine out of ten knowledge questions correctly. Two therapy-related items received the highest percentages of correct answers: "I know about iron chelation therapy" (87.9%) and "the mainstay of thalassemia treatment is blood transfusion" (87.4%). In contrast, only one item (iron overload causes diabetes mellitus) received 27.1% as correct answers (Table 3). Generally, the patients had a positive attitude in four items toward the thalassemia therapy. However, more than half of them (51.2%) agreed with one negative attitude item: "I believe that nothing will happen if I miss my doses" (Table 4).

In most practice questions, the patients showed good practice. 59.3% of them allocated time to find information about their conditions and about 94% of them showed very commitment regularly to visit hospital. Interesting finding

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Table 1. **The sociodemographic characteristics of the participating patients**

Characteristics	Subcategories	Frequency	Percent
Gender	Female	97	48.7
	Male	102	51.3
Age	Child	45	22.6
	Adult	154	77.4
Area of residence	Rural	72	36.2
	Urban	127	63.8
Level of education	No formal education	52	26.1
	Primary or secondary	126	63.3
	College or higher	21	10.6
Occupation	Not employed	144	72.3
	Employed (but not healthcare provider)	46	23.1
	Healthcare provider	9	4.5
Monthly income	Low	83	41.7
	Moderate	114	57.3
	Higher	2	1.0
Parents' consanguine marriage	Yes	161	80.9
Frequency of blood transfusion (per month)	1	55	27.6
	2	103	51.8
	3	41	20.6
Take iron chelation therapy	Deferasirox	177	88.9
	Deferoxamine	68	34.1
	Folic acid	187	93.9
	Calcium	99	49.7
	One alpha	104	52.2

Table 2. **The total scores of patients' knowledge, attitude, and practice**

	N	Minimum	Maximum	Mean	Std. deviation
Total knowledge score	199	1.00	10.00	7.50	1.87
Total attitude score	199	11.00	20.00	15.74	1.97
Total practice score	199	9.00	20.00	15.23	2.47

Table 3. **The frequency of correct (yes) answers for the knowledge scale**

No.	Knowledge items	Frequency	Percent
1	Thalassemia is a genetic disorder affecting red blood	164	82.4
2	The main cause of anaemia in thalassemia is destruction of red blood cells.	156	78.4
3	The mainstay of thalassemia treatment is blood transfusion.	174	87.4
4	Blood transfusion can cause iron overload	169	84.9
5	Dietary iron could cause iron overload and worse your health	153	76.9
6	Iron overload negatively affect the liver.	164	82.4
7	Iron overload negatively affect the heart.	157	78.9
8	Iron overload causes diabetes mellitus	54	27.1
9	I know about iron chelation therapy.	175	87.9
10	I am aware that taking medicines in respect to mealtime will impact its effectiveness.	126	63.3

Table 4. **Attitude scale of the participating patients**

No.	Attitude items	Strongly disagree N (%)	Disagree N (%)	Agree N (%)	Strongly agree. N (%)	Mean (SD)
1	I believe that following dietary instructions such as avoid iron-rich foods could be useful?	16 (8)	18 (9.0)	95 (47.7)	70 (35.2)	3.10 (.87)
2	I believe that iron chelation therapy has improved my quality of life.	2 (1.1)	11 (5.7)	81 (41.7)	100 (51.5)	3.44 (.65)
3	I think that regular use of iron chelation therapy reduces my ferritin level	4 (2.1)	11 (5.2)	100 (51.5)	80 (41.2)	3.32 (.67)
4	I believe that nothing will happen if I miss my doses*	39 (19.6)	58 (29.1)	58 (29.1)	44 (22.1)	2.54 (1.04)
5	I think it is important to receive information about thalassemia and its treatment.	18 (9.0)	14 (7.0)	48 (24.1)	119 (59.8)	3.35 (.96)

For all points, the positive (agree) answer is the true answer (strongly agree = 4, agree = 3, disagree = 2 and strongly disagree = 1) except item No. 4 *; the negative (disagree) answer was the true answer ((strongly agree = 1, agree = 2, disagree = 3 and strongly disagree = 4).

Table 5. **The practice scale of the participating patients**

No	Practice items	Strongly disagree, N (%)	Disagree N (%)	Agree N (%)	Strongly agree N (%)	Mean (SD)
1	I usually allocate some time to find more information and education about thalassemia.	55 (27.6)	26 (13.1)	73 (36.7)	45 (22.6)	2.54 (1.12)
2	I regularly visit the hospital to follow my condition and its treatment	1.0 (.5)	11 (5.5)	70 (35.2)	117 (58.8)	3.52 (.63)
3	I follow certain dietary instruction to help my condition.	14 (7.0)	40 (20.1)	79 (39.7)	66 (33.2)	2.99 (.90)
4	I usually use Deferasirox after foods to reduce side effects.	89 (45.9)	67 (34.5)	20 (10.3)	18 (9.3)	3.17 (.96)
5	I have ever missed a dose of iron chelation therapy due to side effects	24 (12.4)	38 (19.6)	43 (22.1)	89 (45.9)	3.01 (1.08)

Table 6. **The correlations among the total scores of knowledges, attitude, and practice**

Correlated parameters	N	Pearson correlation	P value
Knowledge and attitude score	199	0.247	0.000
Knowledge and practice score	199	0.377	0.000
Attitude and practice score	199	0.325	0.000

Correlation is significant at the 0.05 level.

that about 80% of the patients did not use deferasirox after food to reduce side effects while more than 30% of them missed the doses due to side effects (Table 5). There were significant positive correlations among the total scores of patient's knowledge, attitude, and practice (KAP) (Table 6).

In this study male patients had significantly higher total knowledge score compared to female patients (Table 7). There were significant differences in the patient knowledge total score according to area of residence (Table 7). In other words, the patients living in urban areas had significantly higher knowledge scores compared to the patients living in rural areas (Table 7). The patients with college or higher education had significantly higher total scores of knowledges, attitude

and practice compared to patients with lower education levels (Table 7). There were significant differences in the knowledge and attitude levels according to patients or caregivers' monthly income (Table 7). In other words, the low-income participants had significantly lower knowledge and attitude scores compared to those with middle income (Table 7). There were significant differences in the knowledge and practice levels according to the occupation (Table 7). In other words, the non-employed participants had significantly lower knowledge and practice scores compared to those who have occupation or having health care provider occupation (Table 7).

Discussion

In this study, we provide comprehensive insight of Iraqi patient's awareness, belief, and behaviour toward thalassemia and its therapy as well as highlighting potential gap in this perspective to help in directing and tailoring the clinical care and disease management to improve patient's outcome. The main finding of the present study revealed that the average mean of all patients' understanding, belief and practice level were adequate. In other words, 73.9% of the patients had good knowledge, 78.4% had positive attitude and 78.9% had good practice toward thalassemia and its therapy.

Table 7. **The correlation of the knowledges, attitude, and practice with patients' characters**

Patients' characters		N	Mean	Std. dev	*P*-value
Total knowledge score	Female	97	7.20	2.03	.027**
	Male	102	7.78	1.66	
Total attitude score	Female	97	15.56	1.96	.193
	Male	102	15.92	1.98	
Total practice score	Female	97	15.25	2.29	.928
	Male	102	15.22	2.63	
Total knowledge score	Rural	72	7.08	1.98	.018**
	Urban	127	7.73	1.77	
Total attitude score	Rural	72	15.61	2.29	.507
	Urban	127	15.82	1.78	
Total practice score	Rural	72	14.96	2.35	.242
	Urban	127	15.39	2.53	
Total knowledge score	No formal education	52	6.52	1.91	.000*
	Primary or secondary	126	7.81	1.70	
	College or higher	21	8.05	1.94	
Total attitude score	No formal education	52	15.15	1.78	.023*
	Primary or secondary	126	15.88	2.03	
	College or higher	21	16.38	1.80	
Total practice score	No formal education	52	14.13	2.61	.001*
	Primary or secondary	126	15.61	2.24	
	College or higher	21	15.67	2.67	
Total knowledge score	Low income	83	6.87	1.95	.000*
	Moderate income	114	7.97	1.66	
	High income	2	6.50	2.12	
Total attitude score	Low income	83	15.27	1.94	.012*
	Moderate income	114	16.07	1.94	
	High income	2	17.00	1.41	
Total practice score	Low income	83	14.76	2.63	.069
	Moderate income	114	15.58	2.31	
	High income	2	15.00	0.00	
Total knowledge score	Not employed	144	7.24	1.95	.001*
	Employed	46	7.96	1.46	
	Health care provider	9	9.22	0.44	
Total attitude score	Not employed	144	15.56	2.00	.079
	Employed	46	16.30	1.50	
	Health care provider	9	15.89	3.10	
Total practice score	Not employed	144	14.97	2.55	.031*
	Employed	46	16.07	1.90	
	Health care provider	9	15.11	2.98	

*Significant (*P*-value <0.05) according to ANOVA test, **Significant (*P*-value <0.05) according to independent samples test.

At the time of our study, there were very limited study to explore the overall perspective of patients with thalassemia about the disease and its treatment specifically about ICT. In one study conducted in Egypt on 80 adult patients showed that more than two third of patients had adequate knowledge level regarding thalassemia[18] which is consistent with knowledge level finding in our study. Also, the finding of our study agreed with the knowledge level of three fourths of patients with thalassemia major included in cross sectional study in Taiwan.[14]

Regarding general populations there were many studies conducted to explore KAP of people about thalassemia and these studies showed variable results. Iraqi general population showed accepted knowledge and awareness level toward thalassemia principle information as inherited non communicable disease according to thalassemia reports in 2018.[13] Consistently good level of awareness about thalassemia was also observed in UAE population.[19] In other cross-sectional study on Indian population, about 58% had sufficient knowledge; 84 % had positive attitude while majority (86%) had bad practice in thalassemia.[11] Although the thalassemia patients or population showed accepted level knowledge on thalassemia basic information, a significant gap or insufficient knowledge toward important aspects such as dietary irons and belief in thalassemia therapy was observed in previous study.[20,21] In our study, about 87% of the patients know the importance of blood transfusion and iron chelation therapy in thalassemia while only 27% of the patients know that iron overload could cause diabetes. Although many of the patients showed positive belief in effectiveness and benefit of ICT, surprisingly half of them believed that nothing would happen if they missed some doses which reflecting wrong perception about the consequence of forgetting occasional doses on their health. Additional practical findings that most of the patients (about 80%) will not use deferasirox after food to reduce side effects while about third of them missed some doses due to side effects. These findings highlighted valuable insight about the extent and barriers to patient's adherence which will enable to tailor the patients support and educational intervention to enhance medications adherence. Customized educational or interventional programs addressing these gaps will help to improve patient's therapeutic outcome and quality of life.[17]

The association in increasing of patient knowledge level and with the improvement in attitude and practice was observed in the present study. In other words, a higher level of understanding and awareness of patients about their conditions and treatments is associated with a more positive attitude toward managing their condition and ensuring better compliance with desired practice. This positive correlation among knowledge, attitude and practice was previously reported in several studies.[4,12] In this study, patients' independent variables were analysed to explore the association between KAP and sociodemographic factors. Among these factors, male gender, higher education level, urban residence, patients' income and being government employee or healthcare provider were significantly contributing to patients' knowledge level. These findings are consistent with other studies which reported that good KAP is more prevalent among male adult with higher education and urban residence.[11] However, other studies reported that female were associated with better knowledge than male in Bahrain study and Iran study which is not consistent with the findings of this study.[22,23]

The education level considered as main determinant factors associated with higher knowledge, positive attitude and proper practice since the individuals got higher education level and learning experience thus increased literacy and information about thalassemia from different sources.[12] The current study provided valuable and unique insight into the understanding and misconceptions of thalassemia patients regarding the condition and its treatment specifically iron chelation therapy which will enable to develop targeted educational program and patient centred care that will optimize disease management and improving patients' outcomes. However, this study is not without limitations, being cross sectional study and conducted in single centre, the results cannot be generalized to all populations and subjected to change with time.

Conclusion

The thalassemia patients in Najaf had adequate understanding, positive attitude and good practice toward the disease and its treatments. However, the study identified specific gap in patients' awareness and perception about the importance of the adherence to chelation therapy which will help in developing more effective strategy and tailored educational support to ensure optimal adherence and improve patient's outcome.

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Conflicts of Interest

There is no conflict of interest regarding the publication of the manuscript.

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Authors' Contribution

The authors confirm contribution to the paper as follows: study conception and design: Reem Ali Shaker*, Fadhil Abduljabbar Rizij Al Basrawy, Talib Abduljaleel Jasim Al-Alikhan.

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Draft manuscript preparation: Reem Ali Shaker. All authors reviewed the results and approved the final version of the manuscript.

Ethics Statements

This study was approved by several committees: The Ethical and Scientific committee of the Faculty of Pharmacy/ Kufa University (no. 5318 on Dec. 29. 2022). The Scientific Committee of Research of Najaf Health Directorate (no. 5340 on Feb. 2, 2023). The ethical committee for clinical studies/ Kufa Faculty of Medicine/ University of Kufa (no. MEC-40 on 2023). ■

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