African Journal of Biological Sciences

Research Paper Open Access

Assessment of Parental Attitudes About Beta Thalassemia In Dhi Qar Governorate (Iraq)

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Article Info

Volume 6, Issue 8, April 2024
Received: 12 Feb 2024
Accepted: 23 March 2024
Published: 08 April 2024

Abstract

Thalassemia is a genetic disorder that prevents the body from producing enough functional globin chains. There is no globin production at all in children with beta-thalassemia major. beta thalassemia major is a life-threatening blood disorder that can only be treated with regular blood transfusions. O**bjectives:** assessing parental attitudes regarding beta thalassemia in a hereditary anemia center in Thi-Qar Governorate (Iraq). **Methods:** A descriptive analytical study was designed to assess parents' knowledge and beliefs about thalassemia in genetic disease center in Nasiriya city, and the study started from December 29, 2021 to December 21, 2022, A non-probability (targeted) sample consisting of (300) from the parents of Thalassemia patients who used to attend the Genetic Diseases Center for clinical examination and blood transfusion. **Results:** Study results show that there is There is a huge difference in the overall key areas involved Parents' attitudes of beta thalassemia major. In addition there is a statistic The relationship between parents' attitudes in relation to their ages.There is also a highly significant relationship during the parental incubation period.knowledge in relation to their educational level.

Keywords: Assessment, Parental Knowledge, Parental Attitudes, Beta Thalassemia

Introduction:

Haemoglobinopathies constitute the most common recessive monogenic disorders worldwide (1–3). These disorders can be divided into two categories: thalassemia syndromes and structural hemoglobin variations) (2). A set of inherited hemoglobin synthesis disorders known as thalassemia hypochromic microcytic anemia that ranges in severity that can be caused by partial or whole failure in the generation of one or more globin chains (4). Globin chain synthesis is controlled by two beta and four alpha genes. Each gene mutation produces a distinct phenotype of variable severity, with beta gene abnormalities creating the more serious effects known as Cooley's anemia. Due to its widespread occurrence, inherited hemoglobinopathy

caused by mutations in beta genes, β thalassemia, is the most frequent type of thalassemia in the world (4,5). About 4.4% of every 10,000 newborns are diagnosed with thalassemia (6); boys and females are equally affected. Annual symptomatic cases are estimated at 1/100,000 worldwide and at 1/10,000 in the European UnionOn the other hand, there is a paucity of trustworthy data on carrier rates in many populations, particularly in areas of the world that are now experiencing an outbreak of the disease. or are predicted to experience high levels of transmission. Iraqi population is characterized by a high consanguinity rate, thus a high prevalence of hereditary diseases such as β –Thalassemia (6). As a matter of fact, according to *Kadhim et al*, in a study of As of the end of 2015, the thalassemia prevalence rate in Iraq was 37.1/100,000 individuals, and the male to female ratio was 1.1:1. This information is based on all thalassemia patients who were registered at the available 16 (of the 19) thalassemia facilities in Iraq. - Thalassemia major accounted for 73.9 percent (8246) of all forms of thalassemia and had a prevalence of 27.4 cases per 100,000 people in the study. (6). The number of persons in Iraq who are affected with Thalassemia was calculated by the Iraqi Ministry of Health. in Iraq at 22,000 for the year 2019 (17).

It represents a real public health problem, with a high morbidity, an economic and social burdens, for the patients, their families as well as the health authorities. In fact, transfusion-dependent beta thalassemia is associated with lifelong anemia that requires transfusions, small stature, facial defects, delayed or missing puberty, and the concomitant stigmas and psychosocial issues that come along with those conditions (10–11). Besides, an estimate by the Thalassemia International Federation (TIF) reports that fewer than 10 percent of global patient communities in the developing world can access the optimal standard of care (9).

Several published studies concerning the economic burden of this disease, for the households as well as the health care systems; showed that β-thalassemia had significantly high healthcare resource utilization, medication costs, which affects patients' quality of life (12–13). Given the prevalence, the medial social and economic impacts of transfusion dependent β-thalassemia, The World Health Organization (WHO) suggests using preventative diagnostics and promising new technologies to improve health. programs (13). As a matter of fact, prevention strategies has proven to be effective in some Mediterranean countries such as Greece, Cyprus and Italy (13).

The main strategies that have been adopted by national programs that have shown success and effectiveness are a national policy on prevention indicating national approval, control, and support; public awareness programs; a screening program to identify carriers; genetic counselling services; pre-natal diagnosis as a choice for at-risk couples; pre-implantation diagnosis; and new emerging technologies. (13).

In fact, the risk of developing thalassemia can be reduced by receiving preventive medical care. Education regarding the hazards of having a child who is born with thalassemia, in conjunction with services for family planning, is a useful strategy for informing the behaviors of those who are at risk for the condition. Blood tests performed in a clinical laboratory can determine whether or not a person has thalassemia. Screening and genetic counselling have been linked to several benefits, one of which being a reduction in the number of babies affected by thalassemic disorder (14).

However, despite all these efforts to reduce the burden of β-thalassemia in countries where it is highly prevalent, such as Iraq, there is still an important lack of knowledge and awareness about it, among general population as well as thalassemic children's parents (5,15–16).

The province of Dhi Qar is Dhi Qar is a governorate in southern Iraq, in the Arabian Peninsula. It has an estimated population of 2 150 338. In this governorate, thalassemic patients are managed in the Center for Genetic Blood Diseases in Dhi Qar. According to the Iraqi Ministry of Health the number of beta-thalassemia cases in the Center for Genetic Blood Diseases in Dhi Qar exceeded 840 people in 2022 (18).

In light of the previous informations, the purpose of this study was to:

- investigate parental knowledge, beliefs, and attitudes regarding beta Thalassemia at Hereditary Anemia's Center in Dhi Qar Governorate (Iraq).
- determine the factors associated to parental knowledge and attirudes regarding Thalassemia at Hereditary Anemia's Center in Dhi Qar Governorate and their demographic characteristic.

Method and Materials

This study is a part a non-probability (targeted) sample consisting of (300) from the parents of Thalassemia patients who used to attend the Genetic Diseases Center for clinical examination and blood transfusion.

Measures:

The Pearson correlation coefficient was used to find out the significant relationships and variance between the variables of the study, which we were able to make an estimate of its reliability.

Stages of Change Scale

The study tool also includes theoretical measures for evaluating parents' attitudes towards beta thalassemia (a short form), which includes nine questions, each question represents of the parents' attitudes towards beta thalassemia.

Results and Discussion

Parental attitudes about Beta thalassemia

Table III: Assessment of parental attitudes regarding beta thalassemia

Items	Agree		Neutral		Disagree		M.S.	S.D.	Ass.
	F	%	F	%	F	%			
1. The patient can survive if thalassemia is left untreated	65	20.9	57	18.3	189	60.8	2.40	0.812	H
2. Do not associate with the partner if he is a carrier of the disease	121	38.9	87	28.0	103	33.1	2.06	0.848	M
3. There are risks of Pregnant couple for thalassemia	130	41.8	87	28.0	94	30.2	2.12	0.842	M
4. The best way to prevent Thalassemia is the examination Prenuptial	150	48.2	79	25.4	82	26.4	2.22	0.837	M
5. A child with thalassemia major can be diagnosed before birth	118	37.9	105	33.8	88	28.3	2.10	0.809	M
6. The pregnant mother must inform the doctor and conduct a prenatal examination	124	39.9	116	37.3	71	22.8	2.17	0.775	M

7. Prenatal examination necessary for the diagnosis of thalassemia	148	47.6	124	39.9	39	12.5	2.35	0.693	H
8. If it is found that the fetus has thalassemia, a specialist doctor should be consulted to determine the fate of this affected fetus	120	38.6	125	40.2	66	21.2	2.17	0.755	M
9. Supports the existence of a prenatal examination law for the purpose of diagnosis with thalassemia	95	30.5	113	36.3	103	33.1	1.97	0.799	M

No. = number of variables, F=frequencies, % = Percentages, M.S.= mean of score, Std. Dev.= standard deviation, Ass. = Assessment; Assessment levels: (1.00-1.67) = Low; (1.68-2.33) = Moderate; (2.34-3.00) = Good.

Results of the table (3) reveals that there is moderate level of mean score in more items related to assessment of parental attitudes regarding Beta Thalassemia at the study sample participants, while the items (1. The patient can survive if thalassemia is left untreated & 7. Prenatal examination necessary for the diagnosis of thalassemia), demonstrated a good level of assessment.

Table V: Overall assessment of parental attitudes regarding beta thalassemia

Levels of assessment	Frequency	Percent
Low : (1.00 - 1.66)	19	6.1
Moderate: (1.67 - 2.33)	194	62.4
Good: (2.34 - 3.00)	98	31.5
Total	311	100.0
$\bar{x} \mp$ Std. Dev	2.17 ± 0.396	

Arithmetic Mean ($\bar{x}$) and Std. Dev.= Standard. Deviation.

Table (**V**) reveals that the more than half of the parents have a moderate level of attitude assessment, and one-third of them was good level, regarding beta thalassemia at the study sample (n=311; 194(62.4%) & 98(31.5%)) respectively, with mean and standard deviation (2.17 ± 0.396).

Discussion

The analysis of data shows that the more one-third of study sample concerning age group were within (1-5 years) it presented 125(40.2%). Addition, residence showed that more than half of participants were live in urban as their percentage reached 173(55.6%). With regard to educational level of father, it appears 86(27.7%) of the sample were primary graduate. In regarding to the subjects level of education of mother, the results show that more than two-third of participants were illiterate and primary graduate 210(67.6.8%). In addition, occupation status show more than half of study sample 162(52.1%) were free business. Addition, family type demonstrate half of participants were nuclear family as their percentage reached 158(50.8%). Relative with child of participants in study sample were more than the half 162(52.1%) were the mother. The results of this table show that the more of three-quarters of the study sample were not suffer family history of thalassemia, it presented 241(77.5%).

Also in regarding to the number of children with beta thalassemia, the results show that 137(44.1%) of sample, they were have one child. Additional support is found by(7 ,8) revealed that the most of his samples were between the ages was 28.62±7.12 years.

Conclusion

According to the present study, the following findings and conclusions are:

It showed that the evaluation level is high. The majority of the participants in our study were aware that thalassemia is a genetic disease.

The study revealed the most items related to evaluating parents' attitudes towards beta thalassemia among the participants in the study sample, while the items (1). The patient can survive if the thalassemia is left untreated and (7). Prenatal screening required for thalassemia). Diagnosis of thalassemia) showed a good level of evaluation.

The study showed that there is a highly significant relationship between the demographic characteristics of the parents and their attitudes. The significant related variables were: the place of residence, the father's education level, the mother's education level, occupational status, and family type, while the age and relationship variables with the affected child did not show any significant association.

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