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KNOWLEDGE ABOUT THALASSEMIA THROUGH PREMARITAL SCREENING PROGRAM IN DIYALA GOVERNORATE 2024

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ABSTRACT

Background: Thalassemia is one of the most common genetic blood disorders, The premarital screening program for thalassemia It is one of the most important strategies for the prevention of thalassemia and several genetic diseases, reduce the incidence of thalassemia and decrease their burden on the society that implies them. To assess the knowledge about thalassemia through premarital screening among couples attending to premarital care clinic at Baquba Teaching Hospital and Alkhalis general hospital, to assess the association between certain sociodemographic variables and knowledge about thalassemia. **Method**: A cross-section study was conducted in Diyala governorate, at Baquba Teaching Hospital and Alkhalis general hospital, during the period from March to August 2024, among the couples attending premarital care clinic at Baquba Teaching Hospital and Alkhalis general hospital, during this period. **Results:** The total of 700 people was included in the current study. The peak age 50.42% was between the age (15-24 years). Participants with primary education were 28.4%, and with university and above 27.42%, parents were relative in 50.75%, only 0.43% was having a personal history of thalassemia and family history of thalassemia was found in 0.7%. A good knowledge level was among 17.9%. **Conclusion:** Study participants were with a low proportion of good knowledge. Males, younger than 30 years, urban residents, those lower than secondary education level, Governmental occupation, had the highest proportion of poor knowledge levels.

KEYWORDS: Knowledge, thalassemia, premarital, screening program.

INTRODUCTION

Thalassemia is a significant public health issue in regions such as the Mediterranean, Middle East, Southeast Asia, and India. It results from deficiencies in the synthesis of α or β globin chains, classified into two major types: α-thalassemia and β-thalassemia.[1] This group of inherited hemoglobin synthesis disorders leads to severe anemia requiring regular blood transfusions.[2] In Iraq, thalassemia is the most common inherited anemia, with a prevalence of 35.7/100,000 and an incidence of 4.5/100,000 in 2015, constituting 66.2% of all inherited anemias.[3] The disorder was first described in a child with severe anemia and splenomegaly, originating from the Greek word "thalassa" (sea), reflecting its prevalence in Mediterranean populations.[4] Thalassemia poses financial and psychological challenges to families and creates a burden on healthcare systems, especially without preventive measures.[5] Understanding thalassemia among at-risk individuals, such as genetic carriers, is essential for effective prevention programs. Educational interventions can mitigate the health, economic, and psychological burdens faced by families in resource-poor settings.[6] Genetic screening and early detection before marriage, combined with education and family planning services, can reduce the number of affected newborns.[7] Thalassemia manifests in three clinical forms: minor, intermedia, and major. Thalassemia minor, or carrier state, typically shows mild or no symptoms. β-thalassemia is the most common autosomal recessive hemoglobin disorder, causing chronic anemia and requiring lifelong treatment, which imposes significant clinical and psychosocial burdens.[8.9] It is associated with hypochromic microcytic anemia, also called Mediterranean or Cooley anemia, resulting from decreased β-globin synthesis due to genetic mutations.[10] High-performance liquid chromatography (HPLC) is a widely used method for screening β-thalassemia.[11] Globally, around 100 million people are β-thalassemia carriers, with significant prevalence in endemic and non-endemic regions due to migration.[12]

α-thalassemia results from mutations in the HBA1 and HBA2 genes, typically involving deletions leading to reduced α-globin chain expression. This complex genetic disorder affects RNA and protein synthesis.[13] In Iraq, the high thalassemia prevalence is linked to consanguineous marriages, inadequate prevention programs, and limited legislation.[14] In 2015, 11,165 thalassemia patients were registered in 16 accessible centers, with β-thalassemia major accounting for 73.9% of cases. A significant portion of these patients were children under 15 years, with a majority born to related parents.[4] Regional variations in prevalence and an increase in cases are observed in provinces such as Diyala and Najaf.[15,16] In Najaf, the prevalence rose from 75.9/100,000 in 2018 to 94.21/100,000 in 2022, with differences noted between urban and rural populations.[16] Premarital screening (PMS) programs aim to identify carriers of genetic conditions like thalassemia and sickle cell disease to counsel couples on reproductive risks. Worldwide, around 270 million people are carriers of hemoglobinopathies, with β-thalassemia being common in Mediterranean, Middle Eastern, and Asian countries.[17] In Iraq, consanguineous marriages contribute to high thalassemia rates, with PMS programs introduced in 2008 in Duhok to mitigate these risks.[18] The aim of study is to examine couples' thalassaemia knowledge through premarital screening at Baquba Teaching Hospital and Alkhalis General Hospital. To determine if sociodemographic factors affect thalassaemia knowledge**.**

METHOD

This cross-sectional study was conducted in Diyala Governorate at Baquba Teaching Hospital and Alkhalis General Hospital between March and August 2024. The study population comprised couples attending premarital care clinics at these hospitals, and the sample was selected using a convenient sampling method. Data were collected twice weekly by the researcher, who spent five hours per day administering a structured questionnaire, taking 10-15 minutes per participant after obtaining consent and providing education on thalassemia and the importance of premarital screening. The questionnaire consisted of two parts. The first addressed socio-demographic data, including age, gender, residence (rural/urban), marital history, education level, occupation, consanguinity, and family history of thalassemia. The second part evaluated participants' knowledge of thalassemia, covering topics like awareness of premarital screening, the disease's hereditary nature, the role of consanguinity, its preventability, and available treatments. Participants also identified their sources of knowledge, such as healthcare workers, media, or personal networks. Knowledge scores were assessed using a three-point Likert scale (0 = poor, 1 = neutral, 2 = good). The total score for each participant was calculated and converted into a percentage. Scores were categorized into poor (<50%), average (50–75%), and good (>75%) knowledge levels. Data were analyzed using Microsoft Excel (version 16) and SPSS (version 26). Continuous variables were summarized as means and standard deviations, while categorical variables were presented as frequencies and percentages. Chi-square and exact tests were used to assess associations between categorical variables, with significance set at $p < 0.05$. This study provides insights into the knowledge and attitudes of couples regarding thalassemia and premarital screening, emphasizing the importance of targeted educational interventions for effective disease prevention.[19]

RESULTS

The total of 700 people was included in the current study. The peak age 50.42% was between the age (15-24years). Participants with primary education was 28.4%, and with university and above 27.42%. Self-employed was 38.5% and no consanguinity was among 66.9%, and the highest percentage of participants live in urban area. Parents were relative in 50.57%, 0.43% was having personal history of thalassemia and 0.7% was having family history of thalassemia (**Table 1**).

Table (3.1): Sociodemographic characteristics and basic of the study sample (N=700).

Variables		N.	%
Age groups	Less than 15 years	20	2.9%
	15-24 year	353	50.42%
	25-34 year	259	37.1%
	35-44 year	45	6.4%
	45-54 year	14	2.0%
	55-64 year	5	0.7%
	More than 65 years	4	0.6%
Gender	male	350	50.0%
	female	350	50.0%
Marital history	First time	638	91.14%
	Second time	62	8.85%
Educational level	Illiterate	29	4.1%
	Read and write	63	9.0%
	Primary school	199	28.4%
	Intermediate school	128	18.3%

	Secondary school	89	12.7%
	University and above	192	27.42%
Address	Urban	440	62.9%
	Rural	260	37.1%
Occupation	Governmental	334	47.7%
	Self-employed	269	38.5%
	student	97	13.9%
Consanguinity	Second degree	149	21.3%
	third degree	83	11.9%
	None	468	66.9%
Variables		**N.**	**%**
Relationship between parents	No	346	49.42%
	Yes	354	50.57%
Personal history of thalassemia	No	697	99.57
	Yes	3	0.43%
Family history of thalassemia	No	695	99.3%
	Yes	5	0.7%

More than half of the participants 71.5% they don't know that premarital screening program of thalassemia is important, and more than half of them 71% they don't know that premarital screening program reduces thalassemia for their children in the future, and those who have heard about thalassemia before 24.6%. More than half of the participants not previously heard about thalassemia 75.43%, and the main source for their knowledge was health worker 9.42%. The analysis result of Hb electrophoresis was 94.4% negative and 5.6% positive (**Table 2).**

Table 2: Knowledge about thalassemia, Source of knowledge about Thalassemia, analysis result of hemoglobin electrophoresis.

Items	answer	frequency	percentage%
thinking premarital screening program of thalassemia is important	I don't know	491	70.1%
	No	10	1.4%
	Yes	199	28.4%
Ever hear of thalassemia before	I don't know	28	4.0%
	No	500	71.4%
	Yes	172	24.6%
thinking premarital screening program reduces thalassemia	I don't know	497	17.0%
	No	3	0.4%
	Yes	200	28.6%
"Thalassemia trait "a disease	I don't know	531	75.9%
	No	93	13.3%
	Yes	76	10.9%
thalassemia is contagious	I don't know	529	75.6%
	No	118	16.9%
	Yes	53	7.6%
couples who have thalassemia trait marry and have children with thalassemia	I don't know	529	75.6%
	No	48	6.9%
	Yes	123	17.6%
thalassemia passes down through families	I don't know	520	74.3%
	No	11	1.6%
	Yes	169	24.1%
consanguineous marriage increases the risk for having thalassemia	I don't know	516	73.7%
	No	7	1.0%
	Yes	177	25.3%
thalassemia a preventable disease	I don't know	521	74.4%
	No	18	2.6%
	Yes	161	23.0%
thalassemia has any treatment	I don't know	523	74.7%
	No	15	2.1%
	Yes	162	23.1%

Source of knowledge about Thalassemia	N.	%
Health worker	66	9.42
Friends-family	51	7.29
School-university	10	1.43
Media	45	6.43
Not previously heard	528	75.43
Total	700	100%

Analysis result	N.	%
Positive	39	5.6
Negative	661	94.4
Total	700	100%

Good knowledge level was 17.9%, average knowledge level was 19.1%, and poor knowledge level was the highest percentage 63%. (Table 3).

Table (3): The level of knowledge about thalassemia in PMS(N=700).

Scales	Poor		Average		Good	
	N.	%	N.	%	N.	%
Knowledge level	**441**	**63%**	**134**	**19**.1%	**125**	17.9%

Participants younger than 30 years had the highest proportion of poor knowledge level 51.9% with statistical significance (P<0.01). Males were highest proportion of poor knowledge 33.3% without statistically significant (P=0.38). Participants living in urban area was 40.7% poor knowledge, with statistically significant (P=0.001). Participants that first time marriage was 57.8% poor knowledge without statistically significant(P=0.19). The participants had less than secondary school was 41.5 % poor knowledge level, and secondary school and above was 21.5% poor knowledge level with statistically significant (P<0.0001). Participants that governmental occupation had 29.4% poor knowledge level and self-employed occupation was 25% of poor knowledge level without statistically significant(P=0.059). Participants with no personal history of thalassemia and poor knowledge level was 63%, and good knowledge level was 17.6%, with statistically significant (P=0.031). Participants with no family history of thalassemia and poor knowledge level was 62.8%, and good knowledge level was 17.5%, with statistically significant (P= 0.028), (Table 4).

Table (4): The association between study variables and level of knowledge about thalassemia (N=700).

Variables		Knowledge level						P- value
		Poor		Average		Good		
		N.	%	N.	%	N.	%	
Age groups	< 30 years	363	51.9	109	15.6	88	12.5	**0.01**
	≥ 30 years	78	11.2	25	3.5	37	5.3	

Variables		Knowledge level						P- value
		Poor		Average		Good		
		N.	%	N.	%	N.	%	
Gender	Male	233	33.3	62	8.8	62	8.8	0.38
	Female	208	29.8	72	10.3	63	9	

Variables		Knowledge level						P- value
		Poor		Average		Good		
		N.	%	N.	%	N.	%	
Address	Urban	285	40.7	66	9.5	89	12.7	**0.001**
	Rural	156	22.2	68	9.7	36	5.2	

Variables		Knowledge level						P- value
		Poor		Average		Good		
		N.	%	N.	%	N.	%	
Marital history	First time	404	57.8	125	17.8	109	15.5	0.19
	Second time or more/widow, divorce	37	5.3	9	1.3	16	2.3	

Variables	Knowledge level						P- value
	Poor		Average		Good		
	N.	%	N.	%	N.	%	

Educational level	<secondary school	291	41.5	68	9.7	61	8.8	**0.0001**
	=>Secondary school	151	21.5	66	9.5	63	9.0	

Variables		**Knowledge level**						**P- value**
		Poor		**Average**		**Good**		
		N.	**%**	**N.**	**%**	**N.**	**%**	
Occupation	Governmental	206	29.4	63	9.0	65	9.3	0.059
	Self-employed	175	25.0	54	7.7	40	5.7	
	Student	59	8.4	18	2.6	20	2.9	

Variables		**Knowledge level**						**P- value**
		Poor		**Average**		**Good**		
		N.	**%**	**N.**	**%**	**N.**	**%**	
Personal history of thalassemia	No	441	63	133	19	123	17.6	**0.031***
	Yes	0	0.0	1	0.14	2	0.28	

Variables		**Knowledge level**						**P- value**
		Poor		**Average**		**Good**		
		N.	**%**	**N.**	**%**	**N.**	**%**	
family history of thalassemia	No	440	62.8	133	19.0	122	17.5	**0.028***
	Yes	1	0.14	1	0.14	3	0.42	

DISCUSSION

Thalassemia imposes a significant economic burden in Iraq, being the most prevalent hereditary hemoglobinopathy.[4] Knowledge about the disease is critical for the success of the national thalassemia prevention program[20], prompting the current study. The study targeted couples attending premarital care clinics in Diyala Governorate at Baquba Teaching Hospital and Alkhalis General Hospital from March to August 2024. Most participants were aged 15–25 years, a crucial group to assess for awareness, as they are in their reproductive years and need education on thalassemia and its prevention. Premarital screening (PMS) is a program combining genetic testing and counseling to identify risks of genetic diseases like thalassemia in future offspring.[17,21] Among participants, 38.5% were self-employed, and 27.42% had university-level education, differing from a Turkish study where 75.2% were employed and 33.2% held university degrees.[19] This discrepancy reflects Iraq's unstable socio-economic conditions. About 8.85% of participants were married for the second time, consistent with cultural norms in Arab countries.[22] Regarding sources of information, 7.2% of participants learned about thalassemia from family or friends, compared to 57.7% in Turkey, suggesting the need for educational strategies like including thalassemia awareness in school curricula.[19] Only 24.6% had heard of thalassemia, contrasting with 53.9% in Saudi Arabia, highlighting differences in health education.[23] Thalassemia trait prevalence was 5.6%, aligning with findings in Nineveh (4.2%) and Dohuk (4%) governorates, often identified during mandatory premarital screening.[24, 25] Consanguineous marriages were reported by 33.2% of participants, consistent with Iraq's Family Health Survey, which found a higher prevalence in central and southern governorates.[26] Only 25.3% recognized the risk of consanguinity in thalassemia, compared to 42.1% in Turkey, suggesting limited public knowledge.[19] Urban participants comprised 62.9%, reflecting better access to premarital counseling services in urban areas. Poor knowledge levels were most common among participants under 30 years old (51.9%) and those with lower education levels, similar to findings in Turkey.[19] Higher education correlated with better knowledge (39.9%) but was still lower than in Saudi Arabia, where 96.1% had higher education levels.[23] Overall, more than half of participants exhibited poor knowledge about thalassemia, particularly regarding its hereditary nature, prevention, and treatment. This underscores the importance of enhancing PMS programs and integrating education on thalassemia into younger age groups. Limitations: The study was limited to two centers in Diyala Governorate, restricting the generalizability of findings.

CONCLUSION

The study revealed that younger participants (<30 years), males, rural residents, and those with less than secondary education had significantly poorer knowledge about thalassemia. Urban residents and governmental employees demonstrated higher knowledge levels. First-time marital participants (singles) exhibited the poorest knowledge. Education and occupation significantly influenced awareness levels.

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