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Knowledge and attitude of next to marry persons toward thalassemia in Mosul city

ABSTRACT:

Background Hemoglobin disorders are the most common clinically serious single gene disorders in the world. It is estimated that over 300,000 affected children are born each year, most with sickle cell disease, while about 60,000-70,000 are born with thalassemia major .

Aim of the study : To determine the knowledge of next to marry couples about thalassemia and what is there attitude toward such a disease.

Patients and methods : This study was a cross sectional study conducted in Mosul city, sample was taken from next to marry couples during their visit to do premarital screening at Ibnalatheer pediatric hospital (Mosul thalassemia center is one of it is departments) and asshurqi primary health center which is the place of blood sample collection for premarital screening (blood group ,HIV Ab , HBs Ag ,HCV AB,VDRL Test, and for High Performance Liquid Chromatography "HPLC" for Haemoglobinopathies). The actual period of data collection was from June 2018 up to December 2018, during this period 500 next to marry couples were collected randomly.

Results : This study reveals that the majority of sample included in this study (79%) their ages were between (20 – 40 years) and 58.6% of the study sample was female . In relation to employment state there was 54.8% of sample not employed, about 77.8 % of them lived in urban area and about 92.4% of them was from the premarrigae group while 50.4 of the study sample have pass secondary education. This study clarified the knowledge and attitude scores of thalassemia among study population which found that about 64.4 % of the sample have adequate knowledge as they have a correct answer on 11 questions from 18 questions (61 % of the total knowledge) and about 71 % of the study population have adequate attitude toward thalassemia as they have a correct answer on 5 questions from 8 questions (62.5 % of total correct answers regarding attitude . (

Conclusions : This study revealed that 79% of the study sample's age between 20 – 40 years , 58.6% were female , 92% of the sample was from premarriage group, 54.8% was unemployed , 77.8% from urban area and 83.4% have a level of education secondary and above . In relation to their knowledge and attitude this study showed that 64.4% of the sample have adequate knowledge and 71% of them have adequate or positive attitude toward thalassemia .

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Introduction

Haemoglobin disorders are the most common clinically serious single gene disorders in the world. It is estimated that over 300,000 affected children are born each year, most with sickle cell disease, while about 60,000-70,000 are born with thalassaemia major. Most affected children are born in countries with limited resources, where priority tends to be given to tackling high rates of infant and child mortality from infections and malnutrition. As a result, hereditary disorders receive little attention so that the affected children do not receive the treatment they need and dying in childhood. The haemoglobin disorders are often regarded as incurable and therefore "hopeless", and they are expensive to treat (1,2). At the same time, quality of treatment is firmly linked to both survival rates and quality of life(3. (

The term "thalassaemia" refers to a group of blood diseases characterized by decreased synthesis of one of the two types of polypeptide chains (α or β) that form the normal adult human haemoglobin molecule (HbA, α2,β2), resulting in decreased filling of the red cells with haemoglobin, and anemia Depending on which of the genes the defect occurs and the corresponding effect on the production of globin chains, α thalassaemia or β thalassaemia results..(4,5(

Prevention program for thalassaemia (3,6(

There are a number of reasons why it is important to develop prevention programs for thalassaemia:

1. The high frequency of the condition in some populations
2. To avoid fatalities from untreated thalassaemia
3. The expense and difficulty of providing optimum treatment for patients, which creates a burden on patients, families and national health services.

The Ministers of Health of 140 countries signed the Alma Ata Declaration "Health for all by the year 2000" in 1978, which recognised the need to include the prevention and control of "locally endemic diseases" in primary health care services. This includes non-communicable diseases such as hereditary disorders.

The Alma Ata Declaration emphasized that effective genetic prevention must be channeled through primary care services. Indeed, it is the right of every individual or couple to be informed of any genetic risk that may affect them. Above all, it is their right to make informed choices concerning these risks (7).

•The World Health Organization recommends several measures for the prevention of genetic diseases, such as health education, screening to identify individuals or couples at risk, genetic counseling and prenatal diagnosis (7).

•For these aspects of prevention to be applied to a population, various ethical, legal, and cultural issues have to be taken into consideration when prevention strategies are put in place as these affects marriage habits, choice of partner and reproductive behavior (8,9.(

Thalassemia in Iraq

In Iraq, there is a little data on the epidemiology and burden of thalassemia. A. Kadhim, Kamal , H. Baldawi, Kadhim & Lami, Faris study shows The total number of registered thalassemia patients in the accessible 16 (of the 19) thalassemia centers in Iraq until December 31 2015, was 11,165 representing 66.3% of all registered hereditary anemia's in these centers. The prevalence of thalassemia had increased from 33.5/100,000 in 2010 to 37.1/100,000 in 2015.(10)

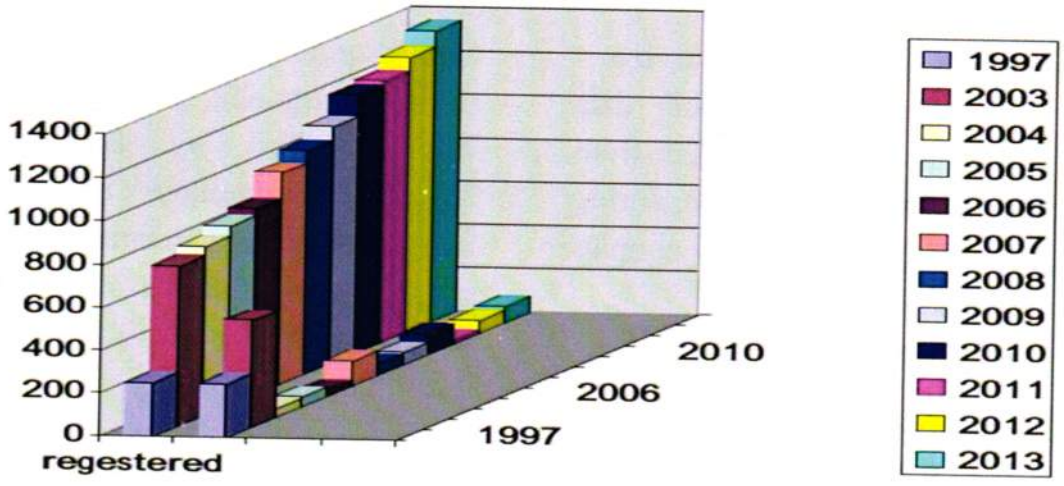
Nineveh thalassemia prevention program

Province of Nineveh:

Mosul , is the second largest city of Iraq ,in terms of population and economic growth. And is the capital of the Nineveh Province .The estimated population of the Province of Nineveh for the year 2011 (3,258,180) people, it is located on the Tigris River, which divides it into two parts.

Mosul thalassemia center established in 1997 with 250 registered thalassemic patients & by the year 2013 there was 1342regestered thalassemic patients .Table [1] The average annual increase is 50-60 new cases and about 3 - 5 new cases monthly (11).

Table (1) No. of Thalassemia patients in Mosul from 1997-2013 (11).



Aim of study:

To determine the knowledge of next to marry couples about thalassemia and what is there attitude toward such a patient.

Materials and methods

Study setting: This study was conducted in Mosul city, sample was taken from

next to marry couples during their visit to do premarital screening at Ibnalatheer pediatric hospital (Mosul thalassemia center is one of it is departments) and asshurqi primary health center which is the place of blood sample collection for premarital screening (blood group ,HIV Ab , HBs Ag ,HCV AB,VDRL Test, and for High Performance Liquid Chromatography "HPLC "for Haemoglobinopathies).

Study design :

A cross sectional study was selected in order to achieve the aim of the present study.

period of the study and sample size

The actual period of data collection has been extended from June 2018 to December 2018, during this period 500 next to marry couples were collected randomly.

Tools of data collection

The structured questionnaire were completed by the persons which consist of three parts ,namely demographic characteristics knowledge part by 18 multiple choice questions and attitude part by 8 questions(Table 1& 2) (12). Knowledge toward thalassemia level was calculated into scores by dividing the sum of the correct answers by the total items in each part . knowledge was considered adequate when the participants have a correct answers to 11 from 18 questions which represent about 60% of total knowledge .

Also, the attitude was assessed using 8 questions ,(negative and positive so if the participants answered on 5 correct answers from 8 questions which also appear to be about 60 % of attitude will included among the adequate attitude . Data analysis was performed by SPSS version 11 software and descriptive statistics were used with demographic characteristics

Ethical acceptability : the protocol was approved by Ethical and Scientific Committee in Nineveh Health sector ;an agreement was also signed by all the personals do the survey and by the places were survey is done.

Table 1 Awareness Questions (12)

	Awareness Questions	Yes	No	Dose not know
1	Did you hear about thalassemia disease? .			
2	Is thalassemia a hereditary disease ?			
3	Is thalassemia a blood disease?			
4	Does thalassemia happen after malnutrition?			
5	Do the face and shape of major thalassemia change?			
6	Do consanguineous marriages have any role in incidence of thalassemia?			
7	Can thalassemia recognized by blood test?			
8	Is thalassemia predictable?			
9	Is premarital consultation useful for refuse of a newborn with thalassemia?			
10	Is pre-marriage consultation the only way to prevent the thalassemia incidence?			
11	Is there any way to recognize major thalassemia in fetus?			
12	Does minor thalassemia recognition have any role in prevention of major thalassemia?			
13	Does minor thalassemia have any special sign or symptom?			
14	Does major thalassemia curable?			
15	Can two people with minor thalassemia marry with each other?			
16	Does a marriage between a healthy person and a carrier lead to a major thalassemic child?			
17	Do thalassemia patients need blood transfusion in all of lifetime?			
18	Did you have a relative person with thalassemia or in need of frequent blood transfusion ?			

Table 2 Attitude question (12)

	Attitude question	yes	No	doesn't know
1	Do you like to a relationship with a thalassemic person?			
2	Do you take necessary blood test for thalassemia before marriage?			
3	Do you visit a consultant before marriage?			
4	If blood test for thalassemia is positive did you visit a consultant before marriage ?			
5	If after test you understand your favorite person has minor thalassemia, do you still want to marry with him/her?			
6	Do you like to donate your blood for thalassemia patients?			
7	If there was a major thalassemia patient in your family, and you are the only chance for bone marrow transplantation, do you like to do it?			
8	Do you accept the probability of a thalassemic child just because of a family marriage?			

Results:

Table 1 demonstrates characteristic of the study population regarding the distribution of age , gender, marital state , employment state, residency, and educational state. This table reveals that the majority of sample included in this study (79%) thier ages were between (20 – 40 years) and 58.6% of the study sample was female .

In relation to employment state there was 54.8% of sample not employed, about 77.8 % of them lived in urban area and about 92.4% of them was from the premarrigae group while 50.4 of the study sample have pass secondary education .

Table 2 shows that there was (18) question regarding knowledge about thalassemia disease, in this table there was 67.8 % of study sample said that " thalassemia is a heriditory disease" while about 38.92 them said that " thalassemia not developed after malnutrition" in comparison to 33.2% answered that malnutrition is the cause of thalassemia and about 50.6% choose that " thalassemia patients need blood transfusion in all of life time. "

Table (3) include 8 questions which revealed the attitude of the study sample toward thalassemia which showed that about 79.4 % of sample reply that "if blood test for thalassemia is positive he will consult a physician before marriage" and about 77.4% they like to donate their blood for thalassemia patients.

The same table report that about 69.4 % of study sample refuse to accept the probability of thalassemic child just because of family marriage.

Table (4) clarified the knowledge and attitude scores of thalassemia among study population which found that about 64.4 % of the sample have adequate knowledge as they have a correct answer on 11 questions from 18 questions (61 % of the total knowledge) and about 71 % of the study population have adequate attitude toward thalassemia as they have a correct answer on 5 questions from 8 questions (62.5 % of total correct answers regarding attitude) .

Table (1) Characteristic of the study population

Age	No.	%
< 20 year	68	13.6%
20 – 40 year	395	79%
> 40 year	37	7.4%
Total	500	100%
Gender	No.	%
Female	293	58.6%
Male	207	41.4%
Total	500	100%
Marital state	No.	%
Previously married	0	0%
Divorced	21	4.2%
Widowed	17	3.4%
Premarriage	462	92.4%
Total	500	100%
Employment state	No.	%
Unemployed	274	54.8%
Employed	102	20.4%
Private job	124	24.8%
Total	500	100%
Residence	No.	%
Urban area	389	77.8
Rural area	111	22.2%
Total	500	100%
Educational state	No.	%
Primary	83	16.6%
Secondary	252	50.4%
University &/ higher education	165	33%
Total	500	100%

Table (2)Distribution of study population according to knowledge about thalassemia (N =500)

No.	Questions	Yes		No		I don't know	
		No.	%	No.	%	No.	%
1	**Did you hear about thalassemia disease ?**	416	83.20%	63	12.45%	21	4.2%
2	**Is thalassemia a hereditary disease ?**	339	67.80%	76	15.02%	85	17%
3	**Is thalassemia a blood disease ?**	383	76.60%	49	9.49%	68	13.6%
4	**Does thalassemia happen after malnutrition ?**	166	33.20%	192	38.92%	142	28.4%
5	**Do the face and shape of major thalassemia change ?**	226	45.20%	122	25.07%	152	30.4%
6	**Do consanguineous marriages have any role in incidence of thalassemia ?**	346	69.20%	64	13.18%	91	18.2%
7	**Can thalassemia recognized by blood test?**	380	76%	56	11.89%	64	12.8%
8	**Is thalassemia predictable ?**	266	53.20%	115	23.02%	119	23.8%
9	**Is premarital consultation useful for refuse of a newborn with thalassemia ?**	393	78.60%	42	8.50%	65	13%
10	**Is pre-marriage consultation the only way to prevent the thalassemia incidence?**	264	52.80%	122	24.71%	114	22.8%
11	**Is there any way to recognize major thalassemia in fetus ?**	203	40.60%	96	19.71%	201	40.2%
12	**Does minor thalassemia recognition have any role in prevention of major thalassemia?**	275	55%	85	17.26%	140	28%
13	**Does minor thalassemia have any special sign or symptom ?**	239	47.80%	91	18.5%	170	34%
14	**Does major thalassemia curable ?**	146	29.20%	143	28.72%	211	42.2%
15	**Can two people with minor thalassemia marry with each other ?**	111	22.20%	232	46.81%	157	31.4%
16	**Does a marriage between a healthy person and a carrier lead to a major thalassemia child?**	232	46.40%	123	24.81%	145	29%
17	**Do thalassemia patients need blood transfusion in all of lifetime?**	253	50.60%	95	18.61%	152	30.4%
18	**Do you have a relative person with thalassemia or in need of frequent blood transfusion ?**	113	22.60%	302	60.40%	85	17%

Table (3) Distribution of study population according to Attitude toward thalassemia (N =500)

No.	Questions	Yes		No	
		No.	%	No.	%
1	Do you like to a relationship with a thalassemic person?	288	57.60%	212	42.4%
2	Do you take necessary blood test for thalassemia before marriage ?	461	92.20%	39	7.8%
3	Do you visit a consultant before marriage?	262	52.40%	238	47.6%
4	If blood test for thalassemia is positive did you visit a consultant before marriage ?	397	79.40%	103	20.6%
5	If after test you understand your favorite person has minor thalassemia, do you still want to marry with him /her?	230	46%	270	54%
6	Do you like to donate your blood for thalassemia patients?	387	77.40%	113	22.6%
7	If there was a major thalassemia patient in your family, and you like to do it?	391	78.20%	109	21.8%
8	Do you accept the probability of thalassemiac child just because of a family marriage ?	153	30.60%	347	69.4%

Table (4) knowledge and attitude scores of thalassemia among study population (N=500)

Knowledge (18 items)	No.	%
Adequate (11 from 18)	322	64.4
Inadequate (less than 11from 18)	178	35.6
Total	500	100%
Attitude (8 items)	**No.**	**%**
Adequate (5from 8)	355	71
Inadequate (less than 5from 8)	145	29
Total	500	100%

Discussion

Till now no national thalassemia prevention program is applied apart from Kurdistan area & the thalassemia prevention program in Nineveh. In 2017 the 1st Iraqi thalassemia meeting discussing the application of National prevention program (11)

The Prevention Project :

After getting a result that there are about 4.8 % from Mosul population who have Thalassemia minor (trait) and 3-5 Thalassemic new birth are registered each month in the Thalassemia center ,with different circumstances delay the application of National policy against thalassemia and after attendance of 1st Pan-Middle East Conference on Haemoglobinopathies 1–2 May 2009 Damascus, Syria. Mosul Thalassemia center with the cooperation of NTS (Nineveh thalassemia society) presented a complete project for prevention of thalassemia in front of the local authority of Nineveh in 2009 aiming for community free of thalassemia (13).

On august 2011 premarital screening for thalassemia become obligatory in Mosul & by 2012 Nineveh council voted for thalassemia care low (214) which also obligate Nineveh health sector to do premarital thalassemia screening test. (11)

This study interviewed 500 premarital couples , thier knoweledge and attitude toward thalassemia was assessed by a lists of questions about knoweledge and attitude , so this study reveal that the age of most of the sample was under 40 years (92.6%) which include the summation of the number of study sample who lies in < 20 years and 20 – 40 years which was similar to other study done in Kolkata in out patient department to assess knowledge and attitude among general population toward thalassemia which found that the mean age was 45.4 while the median age was 45 years (14) , and mimic other study done in Iran which showes that the majority of sample was lie among 20 s age group and the second percent was found among 25 s age group (5).

This study showed that about 58.6 % was female which was in agreement with other study done in Serilanka which found that about 56.7 % was female but this study done on medical student in Serilanka(15) and differe from other study done in Delhi on medical students which found that about 59.46% was male (9) .

Regarding marital status this study demonstrated that about 92.4% was premarrige and this is because this study done on next to marry people so most of them not have previous history of marriage or divorced which

was disagree with other study done in Kolkata which found that about 73.60% were married and this difference may be due to type of sample in both studies here the sample collected from premarriage couples who do screening tests of heriditary diseases before marriage and the other one done among general population in tertiary care hospital in Kolkata (14).

In relation to residency this study revealed that 77.8 % from urban area which is in parallel to other study done in Delhi which found that about 74.32 % from urban area (9) .

On the other hand this study clarified that about 83.4 % (50.4 % have secondary education , 33% have university and higher education) which is agreed with other study done in Kolkata which found that the level of education of sample was between illitratre to postgraduate and about 32.24 % completed their bachalorea degree (14) .

In relation to assessment of knowledge of the study sample about thalassemia by asking 18 questions about thalassemia and record the answers of the participants and 8 questions related to their attitude to thalssemia disease and after that statistical classification of the sample according to their true answers and 11 true answers from 18 was cut off point between adequate knoweledgde which is (61.1% of the total knowledge) and inadequate knowledge , in this 64.4 % of the sample have 11 true answers (adequate knowledge) which is similar to other study done in Kolkata which found that about 57.94 % have adequate knowledge and pass the cut off point of total knowledge which is (60%) (14) and similar to other study done in Delhi which showed that the medical studenta have a good knowledge about thalassemia(9) and disagree with other study done on young people in Pakistan and this may be due to younger age of the study sample in comparison to this study and that done in Kolkata and Delhi (16).

On the other hand this study showed that about 71% of the study sample have adequate attitude toward thalassemia which was in parallel to other study done in Kolkata which also revealed that about 83.88% have positive attitude toward thalassemia (14) . This result in this study may indicate that the health education about premarital screening is good and the message about this diseas was delivered to about 64.4% of the population presented as a study sample and about 71% of them have adequate attitude

Conclusions :

This study revealed that 79% of the study sample's age between 20 – 40

years , 58.6% were female , 92% of the sample was from premarriage group, 54.8% was unemployed , 77.8% from urban area and 83.4% have a level of education secondary and above . In relation to their knowledge and attitude this study showed that 64.4% of the sample have adequate knowledge and 71% of them have adequate or positive attitude toward thalassemia .

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