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Awareness of thalassemia intermedia caregivers about iron overload in Baghdad

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iron over loud, Thalassemia intermedia blood, chelating agent

ABSTRACT

Thalassemia is a hereditary haemoglobinopathy, chronic disorder requiring blood transfusion for lifelong that cause financial and emotional burden on the family and society. This study was done to assess level of awareness in the caregivers of thalassemic patients to ameliorate their experience in caring their child. A cross sectional descriptive study was conducted in AL-Karama and IbnAL- Baladi thalassemia centers in Baghdad from november2020-june 2021 in which 220 caregivers of thalassemia intermedia patients were interviewed to assess their level of awareness, the practice they exert regarding to blood transfusion, iron over load and its treatment. 52% of the caregivers had good awareness, 46% had fair awareness and2%had poor awareness level. 11.8% thinks blood transfusion must be given from time to time, 28.4% thinks iron overload means increase level of iron in the body, Liver cirrhosis and heart failure was the most important complication of iron overload if not treated as 88% of care givers declare, chelating agents was one of the treatments of iron overload for 97.3%, Oral or subcutaneous chelating agents we rementioned by 99.1%as types of treatment, 98.2% know that serum ferritin and type of thalassemia was the most indicators for patients to take chelating agents, About 11.8% of patients stated that chelating agents prescribed according to patients will and his parents, burning sensation in site of injection and GIT upset was one of side effects of chelating agents in the opinion of 67.3%, 84.5% consult a doctor before stop treatment when side effect appears, 50% of studied sample stated that they are going to change treatment from one type to another if liver enzymes elevated,77.3%knows that the treatment is lifelong. Age and educational level were significant predictors in relation to level of awareness of the caregivers; Majority of caregivers had good level of awareness and enough knowledge about thalassemia, Management should include comprehensive education and increase level of awareness between caregivers and patients them selves and enhancement of management strategies existed. To assess the level of awareness among caregivers with thalassemia intermedia. To assess level of awareness about thalassemia intermedia complication (iron overload) and the types of it's treatment, it's side effect. To findout associations between socio-demographic variables and awareness inthalassemic intermedia patients.

1. Introduction

Thalassemia is defined as an inherited impairment of hemoglobin synthesis, that there is partial or complete failure to synthesize a specific type of globin chains [1].

Beta-thalassaemia Failure to synthesis beta chains (beta-thalassaemia), is the most common type of thalassaemia, and most prevalent in the Mediterranean area.

Heterozygotes have thalassaemia minor, a condition in which there is usually mild anemia and little or no clinical disability, that may be detected only when iron therapy for a mild microcytic anemia fails, while Homozygotes (thalassaemia major) either are unable to synthesis hemoglobin A or produce very little; after the first 4–6 months of life they develop profound hypochromic anaemia [2].

Alpha-thalassaemia reduced or abscent alpha chain synthesis is common in Southeast Asia. There are two alpha gene loci on chromosome 16 and therefore each individual carries four alpha gene alleles.

Thalassemia intermedia is defined as Inherited hemoglobin-related disorders, which include the structural variants (hemoglobin S, C, and E) and the alpha (α) and beta (β)-thalassemias, Screening for carriers of these traits is important to provide prenatal genetic counseling and to accurately estimate the true prevalence and public health burden of these disorders.

2. Methodology

This is a cross-sectional descriptive study conducted in thalassemia centres in Baghdad (Ibn AL-Baladi, AL-Karama). The study was held from November 2020to 1st of July 2021. A total of 220 caregivers of affected individuals with thalassemia intermedia (150 from Ibn AL-Baladi, 70 from AL-Karama) were included in thisstudy. Inclusion criteria were caregivers of patient diagnosed with thalassemia intermedia in those centres.

The aim of the interview was to measure the level of awareness of interviewed subjects about the iron over load in thalassemia intermedia patients.

The interview included information about caregivers and/or patients (age ofcaregivers, ageofpatients, ageofdiagnosis, educationallevelandoccupation).

The data was collected by interviewing the caregivers after verbal consent was obtained (those who refused were excluded) and their profile was confidential withnoobligationtoanswerit, by using aquestionnaire(15questions) that was structured under the supervision of a paediatric specialist, community medicine specialist, family medicine and haematologist.

15caregivers were interviewed as apilot study to ensure clarity of questions and time needed to complete the interview and those caregivers were excluded from the members included in the study. The scoring system of awareness was done according to the following equation

Awareness score=(no.of right answers)/(total no.of questions)x 100 .The subjects were divided into three levels of awareness:

ISSN: 0005-2523
Volume 62, Issue 08, October, 2022

1-poor awareness
If the interviewed person scored less than 50%
2 intermediate awareness:
If the interviewed scored between 50 – 75
3-Goodawareness:
If the interviewed scored75 and more.

This questionnaire includes questions related to awareness about iron overload (acomplication of blood transfusion in thalassemia patients) along with general details pertaining to age,sex,education,job and age of diagnosis).

Their awareness were assessed regarding to their answers about needs for blood transfusion, knowing iron overload, it's signs and symptoms, treatment of iron over load, their types, investigations done before blood transfusion, side effect of iron overload, change the treatment from one type to another, compliance, time taken on treatment and factors contributed to delay complications.

2.1 Ethical consideration

The research proposal was discussed and approved by the ethical and scientific committee inAL-Kindy medical college.

The agreement of health authorities in AL-Karama and Ibn AL-Baladi thalassemia centers were taken before starting data collection.

A verbal consent was taken from each interviewed person after full explanation of the aim of the study and ensuring him/her about the confidentiality of the collected data which wouldn't be used for any purpose other than current study.

2.2 Statistical analysis

The collected data were loaded into SPSSV.24 statistical program. The descriptive statistics were presented using tables and graphs.

Chisquare test was used to findout significant of association between related categorical variables. Pvaluelessthan0.5was considered as discrimination point for significance.

3. Results

This cross-sectional study show that 220 caregivers of thalassemia intermedia patients were included, themeanageofcaregivers was 36.9±10.16yearswhile the mean age of children(patients) age was 14.40 ± 4.33 years and the mean age of diagnosis of thalassemia intermedia was5.45 ±2.76 as shown in table1.

Table 1 distribution of care givers and tahalasemic patients according to age of caregivers and patients and age of diagnosis

	N	Minimum	Maximum	Mean	Std.Deviation

Caregiver Age/year	144	19	63	36.9	10.16
Child age/year	220	2	20	14.40	4.331
Age of diagnosis/year	220	2	14	5.45	2.76

Figure 1 shows that 55% caregivers were males and 45% were females.

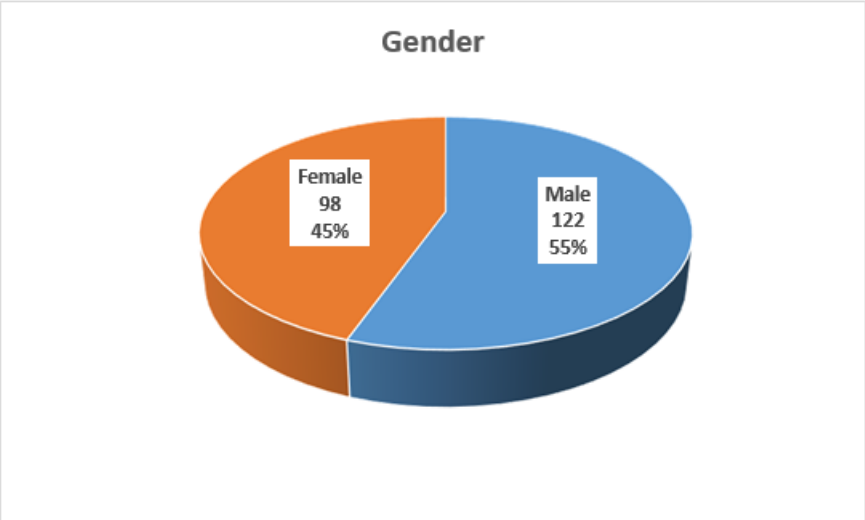

Figure 1 gender distribution of caregivers

Table 2 shows that:
30.9% of care givers were mothers of the patients while 16.4 were fathers and 52.7% were others (sister,brother,grandmother….etc)
*About 34.5% of studied caregivers had primary level of education and less, 46.8% had secondary level of education, while 18.6% had university level of education
*Regarding occupation it was found that 25.5% of caregivers were employee while 74.5% were unemployed.

Table2distributionofcaregiversaccordingtoessentialcharacteristics			
		Coun t	Column N %
Relative	Mother	68	30.9%
	Father	36	16.4%

ISSN: 0005-2523
Volume 62, Issue 08, October, 2022

	Other	116	52.7%
Education	Primary	76	34.5%
	Secondary	103	46.8%
	University	41	18.6%
Occupation	Employee	56	25.5%
	Unemployed	164	74.5%

While in Table 3:

*About blood transfusion, 82.7% of studied sample thinks that patients with thalassemia intermedia must receive blood regularly each 3 weeks, while11.8%(correct answer) from time to time and 5.5% think that thalassemia intermedia patient don't need blood transfusion.

*Iron overload means increase level of iron in the body (correct answer) was the choice of 28.4%while taking too much iron supplements was the choice of 7.3%and eating too much food containing iron was the choice of 64.2%.

*Liver cirrhosis and heart failure are the most important complication of iron overload if not treated as 88%ofstudied sample declare (correct answer), while cataract was the most important complication for11.8%.

*chelating agents is the treatments of iron overload for 97.3%(correct answer) while dialysis is the treatment for less than1%and no treatment was mentioned by1.8%of studied sample.

*About types of chelating agents; Oral or subcutaneous chelating agents were the choice of 99.1%(correct answer),while 0.9%chose drops as chelating agents.

* Serum Ferritin and type of thalassemia was the main indicators for 98.2% for patients who take chelating agents(correct answer),while serum calcium was the main indicator for 1.8%.

*About11.8%of patients stated that chelating agents prescribed according to patient will and his parents, while 87.3% (correct answer)thinks that it must be doctor decision and 0.9% stated that the treatment must be prescribed according to advice from family and friends.

*About side effects;burning sensation at the site of injection and GIT upset were the choice of 67.3%(correct answer), while it was polyuria for 28.2% and tonsillitis for4.5%.

*About 5.5% of studied sample said that must stop treatment when a side effect appears,84.5%(correct answer)consult adoctor and10%wouldchange the dose of treatment.

*About 50% of studied sample stated that they chose to change treatment from one type to another if liver enzymes elevated (correct answer), while 4.5% if they noticeedemaand45.5%if bleeding occurs.

*About 93.6% of studied sample take doctor opinion consultation about how to use treatment(correct answer),4.5%take instructions from leaflets inside,while1.8%the internet was their source of instructions.

*Taking the treatment regularly was the opinion of 99.1%(correct answer),while 0.9% think that it'sok to forget treatment some times.

*Treatment could be life-long for 77.3%(correct answer), short time according to patient condition for17.3%and5.5%stated that treatment could be up to patients desire.

*Avoiding red meat and some vegetables is factor contributed in delay complications according to the opinion of 78.2 %(correct answer), taking supplements is the factor for14.5% and taking antibiotics is the opinion of 7.3%.

Table3distributionofstudiedsubjectsaccordingontheiranswersonawarenessquestionnaire

Patient with Thalassemia intermedia must receive blood	Regular each 3 weeks		From time to time*		Nonee d	
	N	%	N	%	N	%
	182	82.70%	26	11.80%	12	5.50%
Ironoverloadmeans:	Taking to much iron supplement		Increase level of iron in the body*		Taking too much food that containing iron	
	16	7.30%	62	28.40%	140	64.20%
The most important symptom in advance cases	Blurring vision		Hematemesis		Dark color skin*	
	2	0.90%	14	6.40%	204	92.70%
The most important complications of iron overload if not treated	Liver cirrhosis and heart failure*		Gout		Catarac t	
	194	88.20%	0	0.00%	26	11.80%
One of the treatments of iron overloadis:	Chelating agents*		Dialysi s		No treatment	
	214	97.30%	2	0.90%	4	1.80%
Types of chelating agents:	Oral or subcutaneous*		Suppository		Drops	
	218	99.10%	0	0.00%	2	0.90%
Patient takes chelating	Serum ferritin and		Serum calcium		Glucose level in	

ISSN: 0005-2523
Volume 62, Issue 08, October, 2022

agentsaccordingto	type of thalassemia*				blood	
	216	98.20%	4	1.80%	0	0.00%
Treatmentsprescribedaccordingto:	Patient will and his parents		Doctor decision*		Advice from family and friends	
	26	11.80%	192	87.30%	2	0.90%
Oneof thesideeffects:	Burning sensation at the site of injection and GIT upset*		Polyia		Tonsillitis	
	148	67.30%	62	28.20%	10	4.50%
Whensideeffectsappear,youmust	Stop treatments		Consult your doctor*		Change dose	
	12	5.50%	186	84.50%	22	10.00%
Changing treatment from one typetoanother,in	Elevation of liver enzymes*		Presenceofedema		Bleeding	
	110	50.00%	10	4.50%	100	45.50%
Taking constructions about how touse treatments from:	Your doctor*		Leaflet inside		Internet	
	206	93.60%	10	4.50%	4	1.80%
In your opinion,patient should:	Take treatment regularly*		Sometimes forgetting it,is O.K		No need to take it	
	216	99.10%	2	0.90%	0	0.00%

Treatment could be:	Lifelong*		Short time according to his condition		What patient desire	
	170	77.30%	38	17.30%	12	5.50%
Factorscontributedindelaycomplications	Avoiding red meat and some vegetables*		Taking supplements		Taking antibiotics	
	172	78.20%	32	14.50%	16	7.30%
*The correct answer						

Figure 2 shows that 52% of caregivers had good level of awareness about iron over load among thalassemia intermedia patients, while 46%had fair awareness level and 2%had poor awareness level.

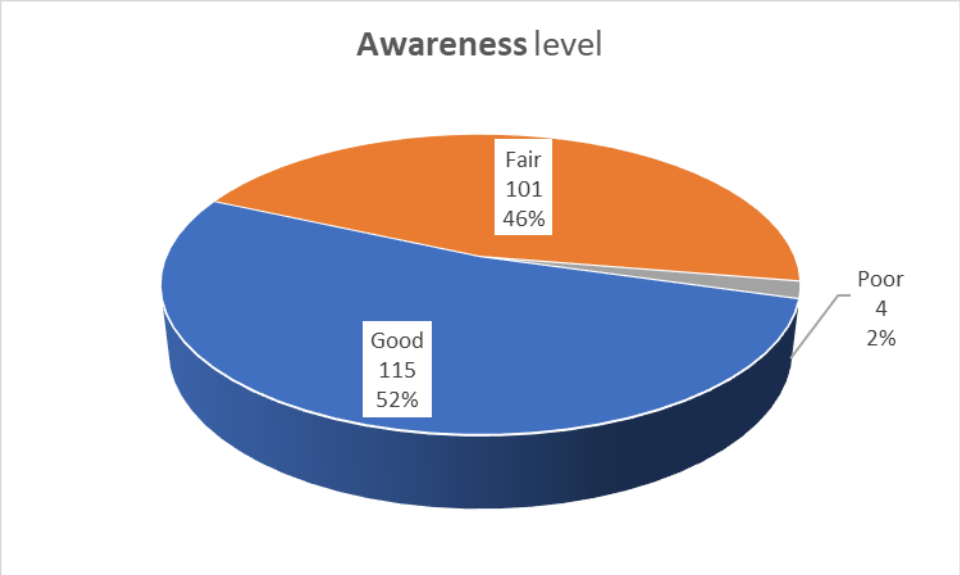

Figure 2 distributions of studied subjects according to levels of awareness about Iron overload.

Table 4shows that:

*There was no significant difference between mean age of caregivers with good awareness level and mean age of caregivers with fair or poor awareness level(Pvalue0.189).
*The mean age of children of caregivers with good level of awareness was found to be significantly higher than those who had fair or poor awareness level.
(Pvalue0.020).
*No significant difference between the mean age of diagnosis and level of awareness of caregivers.
(Pvalue0.061)

ISSN: 0005-2523
Volume 62, Issue 08, October, 2022

Table 4 differences between means of age of care givers, child age and age of diagnosis according to awareness level						
	Awarenesslevel	N	Mean	Std.Deviation	Std.Error Mean	
Care giver age	Good	115	37.76	8.673	.809	0.189
	Poor-fair	105	35.95	11.544	1.127	
Child age	Good	115	15.01	4.376	.408	0.029
	Poor-fair	105	13.73	4.202	.410	
Age of diagnosis	Good	115	5.11	2.470	.230	0.061
	Poor-fair	105	5.81	3.013	.294	

Table 5 shows:

*There was no significant association between the gender, degree of relative and occupation of caregivers and their level of awareness.
(Pvalue0.834,0.479and0.143)respectively.
*It was found that 85.7% of caregivers with university level of education significantly higher than those with secondary level of education (60.8%) and primary level of education.(P value0.001).

Table 5 association between independent categorical variables and level of awareness			
	Good	Poor-fair	

		Count	RowN %	Count	RowN %	
Gender	Male	63	51.6%	59	48.4%	0.834
	Female	52	53.1%	46	46.9%	
Relative	Mother	32	47.1%	36	52.9%	0.479
	Father	18	50.0%	18	50.0%	
	Other	65	56.0%	51	44.0%	
education	Primary	24	31.6%	52	68.4%	0.001
	Secondary	79	60.8%	51	39.2%	
	University	12	85.7%	2	14.3%	
Occupation	Employee	34	60.7%	22	39.3%	0.143
	Unemployee	81	49.4%	83	50.6%	

4. DISCUSSION

Thalassemia is a common health problem, brings much burden for a family both financially and emotionally, due to lack of knowledge about the disorder, its manifestations, survival rate, treatment availability, and psychosocial and cultural issues many barriers to optimal health care were existed, including disclosure of thalassemia status as well as to carrier testing. In this study we tried to scope some light on the level of awareness concerning thalassemia intermedia among care cavers as they are the most important cohort in need to this knowledge [41], [42].

In the present study the mean age of caregivers was about 37± 10 years and the mean age of studied patient was 14± 4 years, this diversity in age distribution is almost thes amein astudy done in Egypt concerning cultural view to wards thalassemia in which the age distribution of the participants (caregivers and patients) was relatively nonhomogeneous, with 39% of patients between 10 and 20 years of age [43].

The sample had almost equal gender distribution with a slight larger percentage of males, one third of them were accompanied by their mothers, half of them carried a secondary school degree and about 20% finished university. These results are slightly differing from a study done in Pakistan in 2015 in which (38%) of the patients who attended the transfusion centers for treatment of thalassemia, were accompanied by their mothers while (62%) were accompanied by their fathers, about half of parents were having no formal education10%were having bachelor and or master's degree [44].

ISSN: 0005-2523
Volume 62, Issue 08, October, 2022

Only 25.5% of the studied sample were employed, nevertheless, no significant association was noted between occupation of those parents and level of awareness. Employment and education are usually determining to some extent the family income and socio-economic status ,these facts are noticed in a qualitative study on children with thalassemia in Pakistan, high volume of family's problems have been reported due to unemployment and poverty, consequently, families cannot afford the cost of transporting the child to the hospital for routine treatment procedures which affect the management of thalassemia disease, so as the financial aspects are improved, a better awareness of the thalassemia disease can be achieved [45].

The observed results shows that half of the studied sample had good awareness, (46%) had fair awareness and 2% had poor awareness level. This is consistent with across-sectional study done in eastern India in2018in which the attained knowledge concerning thalassemia had affair score among caregivers and about 52.7% of them had satisfactory knowledge regarding the disease. [46], while a study done in SheikhZayedMedicalCollege/HospitalRahimYarKhana,2016 found that 60%percent of parents were unaware about the disease, 25% had a little knowledge and only 15%knew about Thalassemia and its complications [47]. Lack of awareness toward thalassemia among population and especially families of patients with thalassemia, had created many problems to them, like stigmatization, stress and under.

Socialization which affects their daily life. Those problems were mentioned also in a study done in Iran in 2017 referred to thalassemia patients' and caregivers' social problems such as psychosomatic disorders that affecting their quality of life. One of these problems was fear and anxiety of patients in the society. In addition to the needs of thalassemia children to continue education and recreational activities which is usually interrupted by the prolonged treatment sessions especially when they need blood transfusion. Supporting parents and patients in these aspects will for sure, be effective in the treatment process and cure of their children [48].

In this study, caregivers had amany wrong concepts concerning thalassemia treatment and complications, most of them thought that patients with thalassemiaintermedia must receive blood regularly each 3 weeks, a large percent declare that iron overload is acomplication of blood transfusion but had awrong opinion concerning its causes and complications ,these findings are almost consistent with the study done in Pakistan in 2015 in which(92%) parents had knowledge that iron over load is acomplication of thalassemia while about(8%)of them had no knowledge regarding the causes and treatment of this complication [45].

In the current study, more than 90% of the caregivers consulted the doctors about how to use treatment, 4.5% read the leaflets inside, while the remaining 1.8% used the internet. These results are fortunately differs from aKAPstudy done in 2011 in KlangValleyareaofMalaysiain which participants depended on Friends (31.4%), Mass media (18.6%), health caregivers (8.6%), and schools (5.7%) respectively as the main sources of information concerning the treatment of their children illness [49]. Most of the studied sample thought that chelating agents is needed and must be the doctor decision and less than1% stated that the treatment must be prescribed according to advice from family and friends. The knowledge of our sample in this study is better than the knowledge of a sample taken in astudy done by MymensinghMedicalCollegeHospital/Bangladeshin2014in which only fifty five percent of parents knew about chelating agents and stated that children should receive Desferal according to physician adviceonly [50].

Almost all the caregivers in this study stated that they should take the treatment regularly, and a small percent (5%) thought that treatment could be up to patients desire, these results are consistent with astudy

done in a selected hospital of Delhi concerning knowledge of caregivers about thalassemia in 2016 which reported that average knowledge was found among participants related to management of thalassemia among caregivers specially in aspects of timing of the drugs and physicians visits [51].

As a result, most participants stated that avoiding red meat and some vegetables is factor contributed in delay complications; there aming few percent thought that taking supplements and/or antibiotics are the key to delay complications. The variability of opinions concerning the disease course and prevention fits Complications among participants in the study may be due to differences in socioeconomic status, different proportion of gender in the sample, educational and cultural back ground, and may be due to geographical plausibility.

A study had been done in Egypt appeared to be as like as findings of this one concerning cultural views toward thalassemia showed that the cultural views and background play a major role in the management and therapeutic care for thalassemia children and if cultural views are improved, we can achieve a better awareness of the thalassemia disease and subsequently a better cure rate [43].

In the current study, the younger caregivers (less than 40years old) had significantly higher awareness level, Also, the highest level of awareness was shown by the higher educated group, this is in consistent with a comparative study done between Italians and Americans concerning knowledge of thalassemia, which stated that greater awareness and knowledge was not associated with education achievement or age group but with intensive public awareness campaigns [52].

Limitations of the study:
Due to the COVOD-19 pandemic and total closure at the time of data collection, there were some difficulties in transportation to the assigned hospitals, decrease in number of patients for follow up and receiving blood, as all health care services utilization were affected due to increase the COVID-19 patients [53]. In addition, the fear of parents to spend more time to do the interview as they wanted to leave the center as soon as possible to avoid getting any infection make the consent taking very difficult.

5. Conclusion

In this study majority of caregivers had good level of awareness and more than 50%had positive attitude and enough knowledge about thalassemia. Age and educational level were the significant predictors in relation to practice of caregivers.

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