

## Assessment of mother's practices toward their thalassemic children who receiving desferal therapy in thalassemia center in Babylon Maternal and child Hospital

تقييم ممارسات الأمهات نحو أطفالهم المصابين بالثلاسيميا الذين يتم معالجتهم بالديسفرال في مركز الثلاسيميا في مستشفى بابل للام و الطفل

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### الخلاصة :

**الأهداف:** تهدف تقييم ممارسات الأمهات حول معلومات الديموغرافية والصفات الشخصية. **المنهجية:** دراسة وصفية أجريت في مستشفى بابل للطفل والولادة في مركز الثلاسيميا تم استعمال استمارة استبانة لغرض تحقيق اهداف عن طريق استمارة استبانة ما بين 4 كانون الثاني ولغاية 26 من شهر مايس 2012 ليل البيانات

**النتائج:** ظهرت أن معظم الأمهات تتراوح أعمارهن ما بين (30-39) (25 41 %) (28 29 %) ومستواهم التعليمي تقرأ وتكتب ، وكذلك تبين النتائج علاقة بين عمر الأم والمستوى التعليمي مع ممارسات الأمهات حول إعطاء الديسفرال ولكن ليس هناك علاقة بين مهنة الأم والممارسات ، **التوصيات:** توصي الباحثة بأجراء تثقيف صحي للأمهات ودور وسائل الأعلام المختلفة لتثقيف الأمهات وعوائلهن حول مرض البحر الابيض المتوسط. الثلاسيميا وكيفية أء الديسفرال.

### Abstract:

**Objectives:** the study aimed to assess the practice of mothers' toward Desferal therapy, and to find out association between mother's practices with their demographic information.

**Methodology** A descriptive study was conducted at thalassemia center in Babylon Maternal and child Hospital, Data was gathered by using a questionnaire for the period from December 4th to March 26th 2012, data were analyzed through descriptive and inferential statistical.

**Results:** The results shows that most of mother's age between (30-39) years which present (41.25%), regard to the level of mother's education the highest percentage were read and write( 29.28%), level of education read and write, also the results shows that there is significant relationship between practice of mothers with desferal therapy with age of mothers' and level of education. , but there is no significant relation between practice of mother's with desferal therapy and occupation of mother.

**Recommendations:** the researcher recommended health education should be done through different mass media to educated the mother's and their families regarding chelating therapy for thalassemia children.

**keywords:** Assessment, mother's practices, thalassaemic children, desferal therapy Babylon Hospital

## INTRODUCTION:

Thalassemia is a chronic , congenital hemolytic anemia in which the chief defect seems to be an inability to produce cells capable of normal incorporation of hemoglobin (1). The term thalassemia, which is derived from the Greek word thalassa, meaning sea and mia blood is applied to a variety of inherited blood disorders characterized by deficiencies in the rate of production of specific globins' chains in Hgb, the name

appropriately refers to descendants of or those people living near the Mediterranean Sea, who have the highest incidence of the disease, namely Italians, Greeks and Syrians (2). There are two primary types of Thalassemia, Alpha thalassemia disease and Beta thalassemia disease. Beta thalassemia major (also called Cooley's Anemia) is a serious illness. Symptoms appear in the first two years of life and include paleness of the skin, poor appetite, irritability, and failure to grow. Proper treatment includes routine blood transfusion primarily in the areas surrounding the Mediterranean Sea, Africa and Southeast Asia. Due to global migration patterns, there has been an increase in the incidence of thalassemia in North America in the last ten years, primarily due to immigration from Southeast Asia. B- Thalassemia is the most common of the thalassemias and occurs in four forms. Two heterozygous forms, thalassemia minor, an asymptomatic silent carrier, and thalassemia trait, which produces a mild microcytic anemia. Thalassemia intermediate, which is manifested as splenomegaly and moderate to severe anemia. A homozygous form, thalassemia major (also known as Cooley anemia), which results in anemia that would lead to cardiac failure and death in early childhood without transfusion support (3). The objective of supportive therapy is to maintain sufficient Hgb levels to prevent bone marrow expansion and the resulting bony deformities, and to provide sufficient RBCs to support normal growth and normal physical activity. Transfusions are the foundation of medical management. One of the potential complications of frequent blood transfusions is iron overload, because the body has no effective means of eliminating the excess iron, the mineral is deposited in body tissues (4).

The iron-chelating compound desferrioxamine (DFO) was discovered accidentally, as early as the 1960s, the era of modern and effective iron-chelating therapy started only 30 years ago with the introduction of subcutaneous DFO infusions by portable pumps. Today, long-term DFO therapy is an integral part of the management of thalassemia and other transfusion-dependent anemia, with a major impact on well-being and survival (5). Starting desferal therapy should be commenced after the first 10-20 blood transfusions or when serum ferritin levels reach 1000 ng/ml, indicating saturation of the transferrin (3).

Without iron-chelating therapy, the accumulation of iron progresses relentlessly, and when about 20 g of iron have been retained in the body, significant clinical manifestations of iron toxicity may be anticipated. The most important complications of transfusion siderosis are cardiac, hepatic and endocrine disease. Pathologic findings in the heart include dilated, thickened. (6)

Iraq is one of the countries in which thalassemia is an important health problem. Babylon City is one of the areas where this problem exists because of its high carrier rate and frequency of consanguineous marriage. Thalassemia center serves about 733 cases regular register patients, on a daily attendance to follow-up and have blood transfusion of about (20-45) patients per/day and about 493 of children on chelating therapy.

Iron chelating therapy is therefore necessary to prevent or decrease the iron burden and has dramatically reduced the mortality and improved the quality of life in regularly transfused children.

## **OBJECTIVES:**

The study aims to

1. Assess mother's practices of thalassemic child toward Desferal therapy.

2. Find out association between's mother's practices with their demographic characteristics which are age , educational level, and residential and occupation of mother's

## METHODOLOGY:

**1. Design and the setting of the study:** descriptive study was carried out in maternal and child thalassemic center in Babylon maternal and child hospital

**2. The sample of study:** non-probability sample(purposive) was selected at thalassic centre in maternal and child hospital Babel, the sample consisted of (140) mother's having thalassemic child mothers , the criteria of the sample selection: mother's who have children were diagnosed as thalassaemic major and receive Deferral therapy. The questionnaire was used as a mean of data collection , the data collection was carried out at maternal and child Babylon hospital from the period of 4<sup>h</sup> of Decembers 26<sup>th</sup> of March 2012, questionnaire concerning mother's practices and comprised of 25 items. The items were Scrod to 3 likert points rating scale as ( always, sometimes and never ) and levels of scale were scored as (3 for always, 2 for sometimes and 1 for never.

**3.Ethical consideration:** Data collection is done by researcher who kept the confidentiality and anonymity of the data. The form for data collection was applied without mentioning the name of mothers, their address, or any other information and taking a verbal agreement were obtained from participants in the study

**4.Statistical Analysis:** Data were analyzed through the applying the Descriptive data analysis and inferential data analysis measurement of by frequencies, percentage and T, Test and chi- Square, the test used to determine the significant relation of mother's practice and to their demographic characteristics at  $p < 0.05$

## RESULT :

**Table(1 ) Demographic characteristics of mother's with thalassemic children**

Item	No	Percentage
<b>Mothers age</b>		
29 or less	18	12.87
30-39 years	64	45.71
More than 40	58	41.42
<b>Total</b>	<b>140</b>	<b>100</b>
<b>Mother's education level</b>		
Illiterate	17	12.14
Read and write	41	29.28
Primary	39	27.85
Intermediate and secondary	39	27.95
Institute and college	4	2.85
<b>Total</b>	<b>140</b>	<b>100</b>
<b>Mother's occupation</b>		
Employed	23	16.42
Unemployed	117	83.58
<b>Total</b>	<b>140</b>	<b>100</b>
<b>Residential area</b>		
Rural	41	29.28
Urban	99	70.72
<b>Total</b>	<b>140</b>	<b>100</b>

Table (1) shows that the most of mother's age were (30-39years ago) which presents of (85.71%). With regard to the level of mother's education, the highest percentage was

read & write (29.28).

Regarding the mother's occupation, the majority of mother's were unemployed which presents (83.58%). In respect to residential area most of mother's were from urban areas(70.72%).

**Table( 2) Distribution of mother's according to their practice regard desferal therapy**

No.	Practice of mother's	Yes 3		Sometimes 2		Never 1		M.s	Severity
1	Prepare equipment	F	%	F	%	F	%		
a	Did you prepare butterfly measurement (25-27)	140	100	0	0	0	0	3	HS
b	Alcohol for sterilization	102	72.86	7	5	31	22.14	2.50	HS
c	Adhesive tap	88	62.86	2	1.42	50	35.72	2.27	MS
e	Injection or syringe	140	100	0	0	0	0	3	HS
f	Desferal pump programme	140	100	0	0	0	0	3	HS
2	Prepare the area for injection	77	55	26	18.58	37	26.42	2.28	MS
3	Wash your hand	10	7.14	20	14.28	110	78.71	1.32	LS
4	Adjust butterfly needle to syringes fill with desferal solution	33	23.58	20	14.28	87	62.14	1.61	LS
5	Did you choose the correct location for injection	23	16.42	52	37.15	65	46.43	1.7	MS
6	Did you sterilize the area for injection from inside to out	22	15.71	34	24.28	84	60	1.55	MS
7	Did you take your precaution to touch the needle when you remove the cover	8	5.71	11	7.87	121	86.42	1.19	LS
8	Did you pinching the skin around the area	11	7.86	10	7.14	119	85	1.20	LS
9	Did you insert the needle at an angle of 45 degree	34	24.29	30	21.42	76	54.29	1.7	MS
10	Did you check desferal therapy	33	23.58	20	14.28	87	62.14	1.61	LS
11	Did you late desferal pump running	72	51.43	23	16.43	45	32.14	2.19	MS
12	Did you examine the area for the present of redness in area of injection	7	5	21	15	112	80	1.25	LS
13	Did you give desferal therapy for period of (8-12)	55	39.28	60	42.86	25	17.86	2.21	MS
14	Did you stop the pump at the end when desferal finish	78	55.71	22	15.71	40	28.58	2.27	MS
15	Did you clean the area with alchol soulation at the end of procedure	61	43.58	10	7.14	69	49.28	1.94	MS
16	Did you throw a needle at the end of procedure	32	22.86	55	39.28	53	37.86	1.85	MS

This table represent the practice of mother's about desferal therapy it is clear that the mean score was high severity in items (1,a,b,e,f) while moderate severity in items (1, c, 2, 5, 6, 9, 11, 13, 14,15,16) The highest percentage (100%) respondent to preparing Alcohol for sterilization and desferal pump programme. But majority of mother's they have low practice to given desferal therapy to their children

**Table (3) mother's practice with desferal therapy**

Items	Sample	Mean	Mean of score	Standard deviation	Expected Z	Critical	Significant
Practices	140	33.788	32	4.5	4.84	1.96	Sig

Table (2) show that there is significant relationship between **practice of** mother practices regarding desferal therapy at  $p < 0.05$ .

**Table (4) Association between mothers practices for desferal therapy with their regarding age.**

Ages	Always 3		Sometimes 2		Never 1		Total	
	F	%	F	%	F	%	F	%
29 or less	14	11.29	1	14.28	3	33.33	18	12.85
30-39 years	60	48.37	1	14.28	3	33.33	64	45.78
More than 40	50	40.34	5	71.42	3	33.34	58	41.25
	124	100	7	100	9	100	140	100

$X^2_{Obs} = 3.23$      $Df = 4$      $Crits = 0.711$      $P = < 0.5$

The findings indicated that there were significant relationship between mother practices for desferal therapy regarding age.

**Table(5) Association between practice of mothers with their education level.**

Education level	Practices						Total	
	Always 3		Sometimes 2		Never 1			
	F	%	F	%	F	%	F	%
Illiterate	17	12.8	0	0	0	0	17	12.14
Read& writ	39	29.3	0	0	2	25	41	29.28
Primary school	35	26.3	1	33.3	3	37.5	39	27.85
Secondary school	34	25.6	2	66.7	3	37.5	39	27.95
Institutes & college	4	3.2	0	0	0	0	4	2.85
Total	129	100	3	100	8	100	140	100

$X^2_{Obs} = 5.82$      $Df = 8$      $x^2 \text{ crit: } 2.73$      $P = < 0.05$

Table (5) shows there is significant relationship between level of mother's education with their practice of desferal therapy

**Table(6) Association between mothers practice and occupation of mother's**

Mothers occupation	sample	Means of score	practice	Deviation	Expected	Critical
Employed	23	36.73	31.75	0,99	79.76	1.96
Unemployed	117	32.44	16.05			

DF= 138 P<0.05

Table showed that there no significant relationship between occupational of mothers with their practice regarding deferral therapy.

**Table(7) Association between mothers practice and their residential areas**

Variable Residential	sample	Means of score	Practices	Deviation	Expected z	Critical
Urban	41	32.51	17.97	4.144	3.80	1.96
Rural	99	33.30	16.86			

Df= 138 p<0.05

Table (7) indicated that there is significant relationship between mother's practice and residential area.

## DISCUSSION:

The finding of the present study showed table (1) that the majority of mother's age ranged from 30-39 years These results agree with the study done by (5). Who found that the most of mothers in his study were between (32- 37). But the results with study done by (6)who found that (54%) of his study mother's age 40 years ago and more. (29.28%) of the study read and write, (7) stated that (45%) of the study from primary school . Also the majority of the study were (83.58%) unemployed and (70.72%) from the urban areas, the study supported by (8). Indicated that in his study was (80%) unemployed and ( 62.5%) from urban areas.

Table (2) represent the practice of mother's about desferal therapy it is clear that the mean score was high severity in items (1,a,b,e,f) while moderate severity in items (1,c,2,5,6,9,11,13,14,15,16) The highest percentage (100%) respondent to preparing Alcohol for sterilization and desferal pump programme. But majority of mother's they have less practice to given desferal therapy to their children. It means which mean that mother's have in sufficient practice regarding deaferal therapy.

The analysis of the study results has indicated that their significant association between mother's practice (table 3) . This results support by the study done by (9) that there is signification relationship between practice of mothers, but the results disagree with the study done by ( 8). That their no significant relationship.

The study done by (10) which is evaluated 500 mothers with their children receiving chelating therapy , A total of 45% of them were awareness of chelating therapy. The study disagrees with study done by (11) (13) which indicated that when assessing the mother' regarded chelating therapy that found the majority of mothers had deficit and in proper practices towards it.

Regarding demographic characteristics of thalassaemic mothers' children indicated that there is significant relationship between age of mother's with their practice Table( 4) This result agree with study done by( 11) with thalassemia his sample was 120 mother's, the research found that there is signification relation between age of mothers with their practice at  $p < 0.01$  . But the study disagree with the study done by (12). Which stated that there is no signification relationship between age of mother's with their practice regarded desferal therapy There was significant relationship between education level of mothers' with practice (Table 5) this results supported by( 12) and by( 11 ) that indicated when they assess the information practice with desferal therapy who noted significant relationship between level of education and practice. Also there is no significant relationship between occupation al of mothers with their practice regarding desferal therapy at  $p < 0.05$  ( Table 5) . This was inconsistent with the results who reported that all mothers in his study didn't acquired any practice about thalassemia(13)

There were significant relationship between mother's practice with their residential area at  $p < 0.5$ .( Table 6 ). This study disagrees by (13). Who found in his study that assess ( 200) mother's about desferal therapy ,study results indicated that there is no significant relationship between practice of mother's with their residential area. While she study supported by (12). Who stated that there is significant relationship between mother's practices with their residential area when assessing 150 of the mothers.

## CONCLUSION:

According to the findings of present study the researcher concluded

1. Majority of mothers aged between (30-38) years.
2. (High percent)of mothers their education level was read and write
- 3.High percent)of mothers their occupation was unemployed and 70.72% from rural area
- 4.The study shows that there are significant relation between age of mothers and level of education with their practice toward desferal therapy at probability  $< 0.05$ , but there is no significant relationship between occupation of mothers and practice toward desferal therapy.

## RECOMMENDATION:

1. Health education programmers should be done for thalassemia mothers
2. Screening should be applied for the following groups:
  - a. Carrier
  - b. Pre-marital
- 3 Mass media should play a role in educating the family or the mother's concerning thalassemia.
4. Advanced study should be conducted for large samples

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