

Assess the Knowledge and Practice of Thalassemic Patient about Complications of Iron Overload and Desferal Compliance

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الخلاصة

الهدف: تهدف الدراسة الوصفية التي أجريت للتعرف على معارف وممارسات المصابين بالثلاسيميا حول عقار الديسفيرال والمضاعفات الناتجة لديهم نتيجة تراكم الحديد في الجسم .

المنهجية: شملت عينة الدراسة المرضى المصابين بالثلاسيميا وكان عددهم ٥٠ (مصاباً). وأجريت الدراسة في مركز ابن الأثير لفقر الدم الوراثي للفترة من ٢١/٥١/٢٠٠٢ ولغاية ٤/٧/٢٠٢٠ وقد تضمنت الدراسة ثلاث مراحل الأولى تقييم معارف المصابين بالثلاسيميا حول استلام الديسفيرال والثانية تقييم ممارسات المصابين بالثلاسيميا حول استلام الديسفيرال و الثالثة المضاعفات الناتجة عند المصابين بالثلاسيميا نتيجة تراكم الحديد في الجسم.

النتائج: أظهرت الدراسة وجود اختلاف ذو دلالة معنوية عالية عند مستوى (150.005) لمعارف المرضى المصابين بالثلاسيميا وكذلك وجود اختلاف ذو دلالة معنوية عالية أيضاً عند مستوى (160.005) لممارسات المرضى المصابين بالثلاسيميا.

التوصيات: أوصت الدراسة بضرورة تطوير وزيادة معرفة وممارسة المصابين بالثلاسيميا لتقليل المضاعفات الناتجة عن عدم استلام الديسفيرال بالشكل المطلوب، وعمل دورات خاصة لمرضى الثلاسيميا حول كيفية استخدام الديسفيرال بالصورة العلمية الصحيحة

Abstract

Objectives: To assess the knowledge and practice of thalassemic patients about desferal administration and complications of iron overload.

Methodology: The present study composed of (50) thalassemic patient who are registered in center and was performed in Ibn Al-Atheer center for congenital anemia for the period from 15/12/2006 to 1/4/2007.

Results: The result of the study showed highly significant difference at (160.05) for knowledge of thalassemic patients and also appear highly significant difference at ($P<0.05$) for practice of thalassemic patients.

Recommendations: The study recommends that there is necessity to increase the knowledge and practice of thalassemic patient about desferal administration to minimize the complications of iron overload.

Key Words: Thalassemia, Iron Overload, Desferal Compliance

Introduction

Thalassemia is an inherited disease. Its symptoms and manifestation are not evident until at least the second half of the first year of life when the predominant fetal hemoglobin (Hbf) in early infancy falls due to the physiological switch off mechanism affecting the gamma chains production. In the normal individual, beta chains will be produce to replace gamma chains and the adult hemoglobin (HbA) will replace (Hbf). In patients with beta thalassemia major, this does not occur and due to the lack of ability to produce beta chains, excessive free alpha chains will accumulate and cause most of the symptoms and manifestation of the disease (1).

Thalassemia minor is usually so mild that treatment is not required, however clients who carry the thalassemia trait need genetic counseling (2). All families with a child of thalassemia should be tested for the trait and referred for genetic counseling (13). Thalassemia is known as Cooley's anemia in the United States (5). The term thalassemia (literally anemia of the sea) came into use note the association of the disease with the Mediterranean region (3). The objective of this study was to assess the knowledge and practice of the patients about the better compliance of desferal and the second to identify the association between desferal compliance and complications.

Methodology

A descriptive study was carried out to assess the knowledge and practice of thalassemic patients during desferal administration and complications result from iron overload.

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The sample of the study was collected from Ibn-Al-Atheer center for congenital anemia which is regarded as thalassemic ward for patients for the period from 15/12/ 2006 to 1 / 4 / 2007. The sample consists of 50 thalassemic patients selected purposively. For the purpose of data collection, the investigators have constructed a tool that consists of (4) parts; the first deals with demographic characteristics of the study such as (age, sex, education), the second consist of (11) question that aim to assess knowledge of patients about desferal injection, while the third one consists of (10) questions that assess practice of patients about desferal injection.

While the forth part consist of (14) question to assess the complications result from iron overload. The content validity of the questionnaire was established through a panel of (5) experts. A pilot study was carried out to check the reliability of the questionnaire (0.89).

The data collected through the use of interview, and were analyzed through the application of descriptive statistical analysis that include frequency, percentage, person correlation coefficient in addition chi-square to determine the association of knowledge to determine the association of knowledge and practice and there variable.

Results

Table (1) Socio-demographic characteristic of thalassemic patients.

	Characteristics of thalassemic patient		No.	0/
1	Age	10-20	30	60
		21-30	17	34
		3140	3	6
		Total	50	1000
2	Sex	Male	29	58
		Female	21	42
		Total	50	1000
3	Social status	Single	50	100 %
		Married	0	0
		Total	50	1000
4	Level of education	Read & write	18	36
		Primary school	28	56
		Intermediate school	2	4
		Institute and college	2	4
		Total	50	1000/

Table (1) shows high percentage of thalassemic patient age from (10-20) years, while the majority of the sample with regard to social status are single (100%). It also appears from table (1) the high percentage with regard to level of education of thalassemia patient (56%) was primary school.

Table (2) Distribution of patients' knowledge about desferal injection.

	Item	Never		Some-times		Always	
		F	O/	F	O/	F	O/
1	You know the correct site of injection.	10	20	4	8	36	72
2	Prepare the desferal for administration.	24	48	2	4	24	48
3	Ascertain the expire date of desferal.	22	44	2	4	26	52
4	Know the concentration of desferal.	24	48	2	4	24	48
5	Observe the side effect when receive desferal.	36	72	10	20	4	8
6	Desferal administration must be not less than 8 hrs daily.	37	74	4	8	9	18
7	You receive desferal for 5day/week.	25	50	6	12	19	38
8	You receive desferal only at night.	14	28	10	20	26	52
9	You receive desferal during the day work.	24	48	14	28	12	24
10	You want to receive desferal.	12	24	8	16	30	60
11	You obligated to receive desferal by the parents or medical staff.	16	32	1	2	33	66

This table shows that there is significant difference between patients knowledge about desferal injection at P value =0.005, $\chi^2=113.183$, 11220

Table (3) Distribution of patients practice about desferal injection.

	ε	Never		Sometime		Always	
		F	O/	F	%	F	O
1	Hand washing during desferal preparation.	6	12	3	6	41	82
2	Sterilize the site of desferal.	6	12	2	4	42	84
3	Put the scalp vein by your self.	37	74	2	4	11	22
4	The parents or nursing staff help to put the scalp vein.	6	12	0	0	44	88
5	Connect the scalp vein with infusion pump.	4	8	1	2	45	90
6	Change the site of injection from time to time.	1	2	2	4	47	94
7	Change the scalp vein daily.	0	0	0	0	50	100
8	Control the infusion pump to push desferal.	7	14	6	12	37	74
9	Sterilize the site of injection after the removal scalp vein.	8	16	5	10	37	74
10	Hand washing after desferal administration	4	8	3	6	43	86

Table (3) show that there is a significant difference between patients practice about desferal injection at: P value = 0.05, $\chi^2=167.530$, 01-18

Table (4) Distribution of the patients about complications from iron.

		Never		Sometime		Always	
		F	00	F	O	F	O/
1	Have shortness of breathing	38	76	3	6	9	18
2	Become fatigue during work	25	50	12	24	13	26
3	Have palpitation	23	46	19	38	8	16
4	Suffer from chest pain	35	70	10	20	5	10
5	Have you jaundice	44	88	2	4	4	8
6	Have you hepatitis B.	46	92	1	2	3	6
7	Have you hepatitis C.	44	88	4	8	2	4
8	Have you hepatitis B and C	45	90	4	8	1	2
9	Have hepatomegaly.	36	72	4	8	10	20
10	Have splenomegaly.	22	44	3	6	25	50
11	Have hepatosplenomegaly.	26	52	19	38	5	10
12	Have diabetes mellitus.	50	10	0	0	0	0
13	Have you delayed maturation.	29	0	2	4	19	38
14	Suffer from tetany (due to hypoparathyroidism)	44	88	2	4	4	8

This table show that there is significant difference about patients complications at:

P value = 0.005 $\chi^2 = 206.410$ • 1-26

Discussion

The results had revealed that (58%) of sample were male and the remaining were female, most of them were (10-20) year old. Relative the their level of education status those who were primary school (56%), regarding to the knowledge about desferal injection. It shows that the majority of thalassemic patients (74%) receive desferal less than 8 hrs daily, this is agreement with coile (Table 1, 2) (5). Highly significant difference between patients practice about desferal injection Table (3).

Hand wasning is one of the most effective ways to reduce the number of micro organism on the hand, patients must wash their hand before and after any procedure (7) The scope and complexity of patients practice require skills for solving the problems (9). (58%) of patients suffering from delay puberty, this result is agreement with oliveri (11) that caused from iron accumulation in the endocrine glands Table (4).

A detailed family history may also reveal a history of anemia and delayed growth and maturation (12). While, the table shows (50%) of thalassemic patient have splenomegaly, this result is agreement with Clemente (3).

Recommendation :

According to the result of the study, the researchers put the following recommendation

1. The necessity of mass media to develop the knowledge and practice of thalassemic patients for desferal administration.
2. The patients should be taught about the importance of desferal and should be educated about the correct does, concentration and route of administration

3. Nursing staff should not only work in the thalassemic center to care patient with thalassemia but also to provide them with knowledge and practice about desferal administration to decrease the complications.

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