

FACTORS CAUSING DISRUPTION OF SCHOOLING IN THALASSAEMIC PATIENTS AND THE RANK OF THESE FACTORS⁺

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Abstract

A descriptive analytical study was conducted on 100 thalassaemic patient who were attending the Thalassaemic Center in Baghdad Al-Karama Teaching Hospital for the period from 2nd of January to 2nd February 2004 to identify the factors causing disruption of schooling in thalassaemic patients and the rank of these factors. The tools of our study are :-

- 1-Thirteen items which are concerned with demographic information .
- 2- Eight factors affecting disruption study, scoring is on a three-point Likert scale (always 3; Sometimes 2; and never 1).

Descriptive statistical procedure was applied to the data analysis. The results of the study reveal that the inability to coordinate between the schooling and treatment is the main factor affecting disruption of study and decrease in physical activities and patient-teacher relationship have minimum effect . From the results of the present study, the researcher recommends proper job opportunity and educational programs for thalassaemic patients .

المستخلص

دراسة وصفية تحليلية أجريت على ١٠٠ مريض مصاب بفقر دم البحر الأبيض المتوسط الذين يراجعون مركز فقر دم البحر الأبيض المتوسط في مستشفى الكرامة التعليمي في بغداد للفترة من الثاني من كانون الثاني ولغاية الثاني من شباط للتعرف على العوامل المؤثرة في التلكؤ في التحصيل الدراسي لمرض فقر دم حوض البحر الأبيض المتوسط وأولوية هذه العوامل . تكونت ادوات الدراسة من شعبتين هما :-

- ١ - (١٣) فقرة تتعلق بالمعلومات الديمغرافية .
- ٢ - (٨) عوامل مؤثرة بالتلکؤ في الدراسة موزعة على مقياس لكرد الثلاثي (دائما :٣، احيانا :٢، ابدا :١)

وتم تطبيق الإحصاء الوصفي لتحليل المعلومات . اظهرت نتائج الدراسة بان عدم التوافق بين الدراسة والعلاج هو من العوامل الرئيسية المؤثرة في التلكؤ بالدراسة ، وان عامل ضعف القابلية والعلاقة بين المريض والمدرس ذو تأثير ضعيف . وبناءا على نتائج الدراسة اوصت الباحثة بتوفير فرص العمل والبرامج التنقيفية لمرضى فقر دم البحر الأبيض المتوسط .

Introduction:

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Thalassaemia refers to a genetic disorder in which there is inadequate synthesis of globin chain subunits of the hemoglobin tetramer ; in α & β - thalassaemia [1]

Ineffective erythropoiesis and chronic hemolysis stems reduced Oxygen –Carrying ability cause fatal increase in iron absorption and red marrow expansion that is reflected in Skeletal abnormalities of the frontal , molar and maxillary bones [2 and 3]

The World Health Organization has suggested that the number of thalassaemic patients will rise if no preventive or educational measures are taken [4]. In Iraq (Baghdad) the number of thalassaemic patients reached 2200 patients in 2003 (Statistics Record of Al-Karama and IBN-AL-Balady Centers).

Patients with thalassaemia have to face a life time of medical treatment and daily reminders of their potential vulnerability and dependence on the medical team . Schooling may be interrupted, Social life restricted [5].

[6] report that the integration of child with a hemoglobin disorder into school constitutes a critical step in psychological development. In addition [7] mentions that the school staff should avoid allowing special privileges to children with hemoglobin disorders , except those who are medically indicated in order to minimize the patients dependency .

Importance of the Study

Thalassemic patients suffer from many problems associated with school life . For this reason the researcher tries to identify the factors that affect this issue.

Objectives of the Study

The researcher tries :-

- 1- to identify the factors causing disruption of schooling in these patients
- 2- to find out the rank of these factors .

Material and Method:

Design of the Study :

A descriptive analytical study was carried out to achieve the aims .

Setting of the Study :

The present study was conducted in Thalassaemic center in AL-Karama Teaching Hospital in Baghdad .

Sample of the Study :

A non-probability (purposive) sample of 100 thalassaemic patients who were attending thalassaemia center in Baghdad .

Criteria of Inclusion :

- 1-patients' age 6 years a
- 2- is diagnosed as thalassaemic .

Data Collection :

The data were collected through interviewing using a questionnaire format constructed by the researcher for the purpose of the study. The data were collected from 2nd of January 2004 –2nd February 2004 .

Study Instrument :

The study instrument was constructed particularly by the researcher for the purpose of the study , the construction was based on the extensive review of the relevant literature and related studies

Section I :

Thirteen items which are concerned with demographic information such as age , sex, level of education , occupation and continuous study .

Section II:

Questionnaires consisting of 8 items was constructed by researcher to describe the factors affecting disruption of study. Scoring is on a three –point Likert scale (always 3; Sometimes 2 ;and never1;)

Validity of the Instrument

The validity of the instrument was established through a panel (5) of experts . They were as follows (1) in field of education,(3) teacher from Ministry of Education ,(1) psychologist.

Statistical Analysis :

Description statistics

- frequencies .
- percentage .
- mean of scores
- weight of the items (Rank) .

Analysis of Data and Results:

The results of this study were analyzed through the application of statistical procedures which were manipulated and interpreted

Table 1: Demographic Characteristics of the patients.

Patients characteristic	F	%
<u>Age (year)</u>	37	37
- 6-11	25	25
- 12-17	30	30
- 18-23	8	8
- 24-29		
<u>Sex</u>	63	63
- Male	37	37
- Female		
<u>Level of education</u>	20	20
- Illiterate	22	22
- Read &% write	38	38
- Primary	10	10
- Intermediate	6	6
- Secondary	4	4
- Higher education		
<u>Occupation</u>		20
- Student		5
- Worker	20	18
- General	5	25
- Business	18	32
- Housewife	25	
- Unemployed	32	
<u>Continual study</u>	20	20
- Yes	80	80
- No		

The demographic characteristics of (100) thalassaemic patients indicated that the majority of them (37%) are (6-11) years old , (63%) are male , most of them (32%) are unemployed ,(38%)of them hold primary school certificate , high percent of them (80%) have disrupted the study .

Table 2 :Factors affected for disruption study

<i>Factors</i>	Always		Sometimes		Never		Mean of scores
	F	%	F	%	F	%	
1-School administration	40	50	22	27.5	18	22.5	2.27
2-Patients-teacher relationship	15	18.75	25	31.25	40	50	1.68
3-Not have attention to continuous study .							
4-Inability to coordinate between treatment and study .	28	35	35	43.75	17	21.25	2.13
5- Fear from injury .	48	60	22	27.5	10	12.5	2.47
6-Shy from changes in body image	27	23.75	38	47.5	15	18.75	2.15
7-Decrease in physical activities.							
8- Uncertain future .	35	43.75	28	35	17	21.25	2.22
	28	35	20	25	32	40	1.9
	25	31.25	36	45	19	23.75	2.07

The finding indicates that the thalassemic patients get high mean of score (2.47) concerning the inability to coordinate between treatment and study and low mean of score (1.9) concerning decrease in physical activities .

Table 3: Rank ordering of factors according to weight by 100 thalassemic patients .

Factors affecting	Wight	Rank
1-Inability to coordinate between treatment & study	198	1
2-School administration	182	2
3-Shy from changes in body image .	178	3
4-Fear from injury .	172	4
5-Not have attention to study .	171	5
6-Decrease in physical activities .	152	6
7-Uncertain future .	166	7
8-Patients –teacher relationship .	135	8

The results show rank ordering of 8 factors according to weight of the items by 100 thalassemic patients it is revealed that inability to coordinate between treatment and study ,school administration , shy from changes in body image....etc) have the highest rank. The least factor is patients –teacher relationship.

Discussion of the Results:

1-Discussion of socio - demographic characteristics of thalassaemic patients (table: 1)

Through the data analysis of present study , the findings show that 37% of thalassaemic patients are (6-11) years old , these results agreed with [8] who states that initial screening or follow –up blood should be obtained on all patients who with blood disorder , this test may lead to patient have a stressful period with hospitalization .Most of the sample subjects of present study (63%)are males.

Thirty eight percent of sample are primary school graduates .These results indicate that the effect of disease and scheme of treatment lead them to disruption and leaving their school. These findings are confirmed by [7] who mentions that the meaningful integration in to the workforce is especially problematic for thalassemic patients who have inadequate schooling

Thirty two percent of sample were unemployed. These results agree with [10] on 90 thalassaemic patients in Italy of 14-22 years to find the psychosocial aspect of chronic illness , the results reveal that the 33.7% of them have problems in finding a job .

The findings show that most of the sample (80%) have disruption in study. These results are confirmed by [4] who reports that the regular visits to hospital and out - patient clinic are the norm , schooling may be interrupted and social life restricted .

2-Factors causing on disruption of schooling :

The finding of present study indicates that thalassaemic patients get high mean of score (2.27) concerning [3] school administration (table 2). These results are supported by [4] who states that the long term disability may cause social and school maladjustment and school problem may include low self –esteem and psychiatric problem. In addition most of school administrations do not have broad information and medical knowledge about chronic illness

Shyness from changes in body image has high mean of score (2.22) in the present study . These findings are confirmed by [5] who reports that the physical deformity in thalassaemic patients (especially of facial appearance) causes social and psychological problems and these are important obstacles to the integration into the normal life . In addition they have to face the reactions of others .

3-Ranking of factors affecting patients

Regarding priority of thalassaemic patients factors by using rank (table 3), it is revealed that the first three factors (Inability to coordinate between treatment and study, school administration, and shyness from changes in body image ...etc) rank on top of the list . Because the patients are affected by many physical and psychosocial problems the teacher – patient relationship is very important . The teacher not only teaches and advises but also gives the emotional support and friendly relationship

Conclusions and Recommendations:

Conclusions:

1-Disruption of schooling of the patients is affected mostly by in cooperative school administration and shyness from body image as well as inability to coordinate between schooling and treatment.

2-Decrease in physical activities and patients–teacher relationship have minimum effect on patients disruption of schooling

Recommendation :

Based on the results of study findings the researcher recommends the following ;-

- 1) planning and developing health policies and legislation to support comprehensive care in all community fields .
- 2) preparing job opportunity for thalassaemic patients according to physical ability .
- 3) planning and preparing course training for educational staff for patients with chronic disease .

- 4) planning and developing educational program for thalassaemic patients regardless of their physical state to increase their understanding of their disease , in order to be more able to adapt to life difficulties .
- 5) further and more expanded studies on a large sample of thalassemic patients .

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