

## Psychosocial Aspects of School Age Children with Thalassemia Major in Al-Najaf Al-Ashraf الجوانب النفسية الاجتماعية لأطفال عمر المدرسة المصابين بالثلاسيميا الكبرى في النجف الإشرف

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### الخلاصة:

**خلفية البحث:** مرض الثلاسيميا الكبرى من الامراض الوراثية المنتشرة في منطقة البحر الابيض المتوسط وان تقييم الجوانب النفسية الاجتماعية للاطفال في عمر المدرسة يعد من الامور ذات الأهمية القصوى خاصة للاطفال الذين يعانون من الامراض المزمنة.  
**الهدف:** تهدف الدراسة الى تقييم الجوانب النفسية الاجتماعية للاطفال المصابين بمرض الثلاسيميا الكبرى في عمر المدرسة وتحديد العلاقة بين الجوانب النفسية الاجتماعية لعينة البحث والمتغيرات الديموغرافية والسريرية للمرض.  
**المنهجية:** تم اختيار عينة غرضية (غير احتمالية) شملت (100) طفل مع اباؤهم في عمر المدرسة ومن المصابين بالثلاسيميا الكبرى. بدأت الدراسة في الثاني من ايلول 2014 لغاية الثاني من اب 2015 في النجف الاشرف - مستشفى الزهراء التعليمي للولادة و الاطفال- مركز الثلاسيميا وقام الباحث ببناء استمارة استبيان خاصة لغرض تحقيق اهداف الدراسة الحالية تم اثبات الهدف الظاهر للاستمارة من خلال عرضها على مجموعة من الخبراء في مجالات مختلفة واما ثبات الاستمارة فقد تم التحقق منه من خلال استخدام معامل الارتباط بيرسون وكان 0,91 للاباء و0,87 للابناء. تم استخدام مقياس التائي الثلاثي لقياس اجابات الاطفال و اباؤهم فيما يخص الجوانب النفسية الاجتماعية للاطفال وتم تحليل البيانات من خلال استخدام الاحصاء الوصفي (النسبة المئوية والتوزيع التكراري ) والاحصاء الاستدلالي (التحليل التائي، معادلة مربع كاي ومعامل الاحتمالية)  
**النتائج:** اشارة نتائج الدراسة الحالية بأن هنالك نتائج دلالة احصائية واضحة للعلاقة بين مرض الثلاسيميا الكبرى والتأثيرات السلبية على الجوانب النفسية الاجتماعية لعينة البحث. كذلك انه لا توجد فروقات ذات دلالة احصائية بين استجابات الاطفال وذويهم فيما يخص الجوانب النفسية الاجتماعية والسريرية.  
**الاستنتاج:** اشارة الدراسة الى ان غالبية عينة البحث من الاطفال يعانون من مشاكل نفسية اجتماعية وان مرض الثلاسيميا الكبرى يؤثر تأثيرا سلبيا على الجوانب النفسية الاجتماعية لعينة البحث فضلا عن ان الجانب العاطفي كان اكثر جانب متأثر متبوعا بالجانب الاجتماعي والجانب المدرسي.  
**التوصيات:** أوصت الدراسة بوجود طبيب نفساني واجتماعي في مركز الثلاسيميا للمساعدة في توفير صلة بين الاطفال، والمدارس، والأسر، والأطباء. الاستفادة من وسائل الإعلام الجماهيري الموجه للصحة في توفير المعلومات للسكان حول الثلاسيميا وغيرها من الأمراض الموروثة.  
**مفردات البحث الرئيسية:** الجوانب النفسية الاجتماعية، الثلاسيميا الكبرى.

### Abstract:

**Background:**Thalassemia major is a prevalent hereditary disease in Mediterranean region, the assessment of physical aspect of school age children, especially in those with chronic illness such as thalassemia is particularly important.

**Objectives:** Objective of study to assess psychosocial aspects of school age children with thalassemia major. And found out the magnitude association between psychosocial aspects and their demographic characteristics and their clinical characteristics.

**Methodology:** A Non Probability "purposive" sample of (100) school age children with thalassemia major and their parents are included in the present study. The study was conducted from period of September 2<sup>nd</sup> 2014 to August 2<sup>nd</sup> 2015 in Al Najaf Al Ashraf / Al-Zahra Maternal and Child Teaching Hospital / Thalassemia center. Researcher constructed special questioner to achieve objectives of the present study. Validity of the study instrument was determined through the panel of experts and the reliability of the study questionnaire was determined through Alpha correlation coefficient was computed for the determination of the internal consistency reliability which was  $\alpha = 0.87$  for the standardized alpha of the internal scale of the assessment of child psychosocial aspects and  $\alpha = 0.91$  for standardized Alpha of the internal scale of the assessment of parents proxy information. Data analyses through use descriptive (frequency and percentage) and inferential statistical analysis procedures (t-test , chi square, and P- value) were used to data analysis.

**Results:** The present study results indicated that there was a significant relationship between thalassemia major and their psychosocial aspects. Also non-significant differences between child and their parent's responses regard to the overall psychosocial aspects.

**Conclusions:** The study concluded that the majority of the study sample of thalassemic children had negative impact on psychosocial aspects. In addition, the emotional domain is the most affected one, followed by the social domain, and then the school domain.

**Recommendations:** The study recommends that a psychologist and sociologist in the center thalassemia is a must be present to help in providing a link between patients, school, the families, and the physicians. And health oriented by mass media in providing information to population about thalassemia and other inherited diseases.

**Key words:** Thalassemia major; school age children, psychosocial aspects.

## **INTRODUCTION**

Thalassemia major (TM) is an inherited blood disorder caused by deficiency in synthesis one or more globin polypeptide chains that is passed from one generation to another based on Mendelian laws<sup>(1,2)</sup>. Thalassemia occurs according to  $\alpha$  or  $\beta$  – globin chain affected. Children with  $\beta$ TM is normal at birth, but develop symptoms anemia in early infancy of life<sup>(3,4)</sup>. World Health Organization (WHO) has calculated that about 7 percent of the world's populations carry a hemoglobinopathy gene. In the Mediterranean area, there are 15 to 25 Million of healthy carriers<sup>(5)</sup>. Iraq is one of the countries in which 6-10% of the population has a hemoglobinopathy of which Thalassemia is the most common<sup>(6)</sup>. Severe complications of  $\beta$  Thalassemia major involved all the human dimensions (physical, psychological, emotional, spiritual, and school functioning) also lead to impairment at the psychosocial level among patients and their families<sup>(2,7)</sup>. Thalassemia major causes destructive effect on emotional aspect through they feel different from others and illness result in anger, sadness, sleep disturbed, afraid, then anxiety, and depressed. In addition, disturbed social relationships and mental health, eventually leading to poor school performance<sup>(8)</sup>. Children with beta-Thalassemia major need a life-long treatment of regular blood transfusion and iron chelation therapy<sup>(9)</sup>. Thalassemia major had negative impact on many aspects of life and becomes increasingly evident through the school age children when they would the independence. Children feel differences between themselves and others which are associated either to the physical aspect such as facial appearance, growth failure, bone deformities or their inability including loss of energy to accomplish daily tasks and prior physical activities that used to enjoy<sup>(10,11)</sup>.

## **OBJECTIVES**

- 1- Assess psychosocial aspects of school age children with thalassemia major.
- 2- Find out magnitude the association between school age thalassemic children psychosocial aspects with certain variables include age, gender, residential area, duration, and adherence iron chelation therapy.

## **METHODOLOGY**

Descriptive cross sectional design was carried out in Al Najaf Al Ashraf / Al-Zahra Maternal and Child Teaching Hospital / Thalassemia center from period of September 2<sup>nd</sup> 2014 to August 2<sup>nd</sup> 2015. A non-probability "purposive" sample of 100 of both gender of school age children, they were medically diagnosed with thalassemia major and attending in Al-Zahra Maternal and Child Teaching Hospital/thalassemia center. Through extensive review of literature the researcher, constructed a questionnaire and use of information existed on the assessment phase. The questionnaire was used as mean of data collection. It was comprised of (3) main parts: Part one include demographic data sheet, part two include clinical data, and part three include psychosocial aspects items. The nature of interview was included as child and parent proxy information. Psychosocial aspects refer to the emotional

function, social function, and school function that consists of (17) items. An instrument was conducted through the use of (3) level type Likert scale for the assessment of psychosocial aspects of thalassemia major. The rating of the instrument, was, 1= never had problem, 2= sometime had problem, 3= always had problem. The study instrument validity used to investigate the clarity, relevancy, and adequacy of the questionnaire in order to achieve objectives of the present study. Content validity for the early developed instrument was determined through the use of panel of (16) experts. Alpha correlation coefficient was computed for the determination of the internal consistency reliability which was  $\alpha = 0.87$  for the standardized alpha of the internal scale of the assessment of child psychosocial aspects and  $\alpha = 0.91$  for standardized Alpha of the internal scale of the assessment of parents proxy information. The sample of the pilot study was excluded of the study's original sample. The data of the present study are analyzed through the use of Statistical Package of Social Sciences (SPSS) version 16, performed through the use of descriptive statistical data analysis approach; such as (Frequencies, percentages), and inferential statistical data analysis (Chi-Square, p-value, and t-test).

**RESULTS**

**Table (1). Distribution of the child sample by their demographic data. (No=100)**

Demographic data	Rating	Frequency	Percentage	Cumulative Percent
Child age	6-7	19	19.0	19.0
	8-9	22	22.0	41.0
	10-11	39	39.0	80.0
	12	20	20.0	100.0
Gender	Male	53	53.0	53.0
	Female	47	47.0	100.0
Residential Area	Urban	75	75.0	75.0
	Rural	25	25.0	100.0
Child School level	Miss school	21	21.0	21.0
	First class	10	10.0	31.0
	Second class	15	15.0	46.0
	Third class	14	14.0	60.0
	Fourth class	18	18.0	78.0
	Fifth class	12	12.0	90.0
Socio economic status	Sixth class	10	10.0	100.0
	high	12	12.0	12.0
	middle	16	16.0	28.0
	low	72	72.0	100.0

Table 1 shows that the mostly of children age was ranged (10-11) years which represents (39%) and the mean of age was (9.6) years with standard deviation of (1.8). Also results shows that more than half of sample (53%) reported the males more than females regard to the gender. As a result shows that the majority percentage of subjects (75%) represented from urban area and regard the child school level the study results revealed that (21%) not sent to school and (18%) in fourth class. Also regarding the socioeconomic status, sample accounted low income with percentage of (72%).

**Table (2). Distribution of the child sample by their clinical data**

Clinical data	Rating	Frequency	Percent	Cumulative Percent
Duration of disease occurrence by years	<= 5.00	1	1.0	1.0
	6.00 - 7.00	22	22.0	23.0
	8.00 - 9.00	21	21.0	44.0
	10.00+	56	56.0	100.0
Blood transfusion/month	Regular	79	79.0	79.0
	Irregular	21	21.0	100.0
Iron chelation	Regular	82	82.0	82.0
	Irregular	18	18.0	100.0

Table2 represents of the child clinical data, The present study reported that regarding the duration of disease occurrence were more than (10 years), accounted more than half (56 %) of the study sample. Also regarding the Blood transfusion, (79%) reported regular attending, also this study indicated that which Iron chelation was regular attended, accounted (82%) of the study sample,

**Table (3) Varmix rotated method with a single extracted component for the studied domains**

Studied Domain	Component
Emotional domain	.791
Social domain	.787
School domain	.427

Table3 shows that the emotional domain is the most affected one, followed by the social domain, and then the school domain.

**Table (4) The comparative difference between children and their parents regarding to the overall responses to the psychosocial aspects**

	Main domain	Levels	Frequency	Percent	Mean	s.d.	t	d.f	p-value
Child information	Psychosocial	Never	20	20.0	2.0	0.65	0.106	198	0.916
		Sometime	57	57.0					
		Always	23	23.0					
Parents information	Psychosocial	Never	22	22.0	2.0	0.68			NS
		Sometime	54	54.0					
		Always	24	24.0					

Table4 revealed that there were no significant differences between children and their parents regarding to the overall responses of psychosocial aspect domain.

**Table (5): Association between the study subjects demographic data and their responses to the psychosocial aspect.**

Demographic data	Value chi-square	C.C.	df	P-value	Monte Carlo Sig. (2-Sided) 95% Confidence Interval		Sig.
					Lower Bound	Upper Bound	
Child age	30.834	0.485	6	0.002	0.000	0.030	HS
Gender	5.141	0.221	2	0.077	0.041	0.159	NS
Residence	1.555	0.124	2	0.460	0.402	0.598	NS
Child primary school level	56.682	0.601	12	0.000	0.000	0.030	HS
Socio economic status	28.020	0.468	4	0.000	0.000	0.030	HS

Table5 indicated that there were no significant association between the study sample psychosocial status and their demographic residence at p-value more than 0.05; But there were a significant association between the study sample psychosocial status and their age, child primary school levels, and socio-economic status, the study results indicate that there is a high significant association at p-value less than 0.01.

**Table (6) Association between the study subjects clinical data and their responses to the psychosocial aspect.**

Clinical data	Value chi-square	C.C.	Df	P-value	Monte Carlo Sig. (2-Sided) 95% Confidence Interval		Sig.
					Lower Bound	Upper Bound	
					Duration of disease occurrence	26.502	
Blood Transfusion	3.303	0.179	2	0.192	0.122	0.278	NS
Iron Chelating	0.461	0.068	2	0.794	0.804	0.936	NS

Table 6 revealed that there were no significant association between the study sample psychosocial status and their clinical data at p-value more than 0.05; but there were high significant association between the study sample psychosocial status and their disease duration at p-value less than 0.01.

## DISCUSSION

Through an overview of the study findings, the sample demographic characteristic indicated that the majority of school age children with thalassemia major were males and aged between (10\_11) years old. In a study which tested the physical and psychosocial aspects of school age children with thalassemia major consisting of face to face interview indicated that children's age mostly ranged between (10 -11) years old <sup>(9)</sup>. While the cross sectional study by Shaligram, et.al.,(2007)who tested the (Psychological problems and Quality of Life in Children with Thalassemia)<sup>(10)</sup>. Thirty-nine children Aged (8-16 year), were assessed for psychological problems using the Childhood psychopathology Measurement Schedule and QOL was assessed using the EQ-5D in Indian, revealed that most of children with thalassemia major were boys and aged between (8-12) years old.

Generally speaking, these findings supported and agree with the findings of the present study. Regarding to the resident area, the majority of sample were from urban area. A quasi-experimental study, of (100) caregivers of thalassemic children who was attended to the Hawler Thalassemia Center in Erbil, North of Iraq, the study aimed to enhance the knowledge and practices of thalassemia children caregivers, the study findings indicated that the majority of thalassemic children are live in urban area<sup>(5)</sup>. Regarding to the child primary school level the study found that the most of them at the level of the primary school student, as well as; majority of them didn't sent to study in their school because of their instable and bad health status regarding to their illness. A descriptive design was by directed on a sample of 100 children aged (6-12) years at out-patient thalassemia center at Zagazig University Hospitals in Sharkia Governorate, Egypt, the study results indicate that the mostly of subjects not sent to school related to this severity of their disease<sup>(8)</sup>. Concerning to the socio-economic status and incidence of thalassemia major, the findings revealed that a highly present of incidence was a private among families with low socio-economic status. (Table 1). another study emphasized that the majority of thalassemia major appears among families of low socio-economic level<sup>(11)</sup>. Results of the present study indicated that the duration of thalassemia major among children was onset before ten years ago and most of them attended health center, twice per month for blood transfusion. Supported for this findings was found in previous studies which They revealed that onset of thalassemia major among children, was discovered during the first years of life and they frequently attended health centers every 2-3 weeks for blood transfusion<sup>(12,8)</sup>. Scientifically speaking, the early detection and early diagnosis of thalassemia cases reflects positive point for the child's health progress, that is because early diagnosis may decreases the clinical complication of disease. This results was supported by another study which stated that iron chelation therapy can reduces the iron level in the blood and this leading to an increase of life span of children with thalassemia major<sup>(13)</sup>. The data analysis manifested that the majority of thalassemic children had regular received blood transfusion and iron chelation therapy. In a study was done earlier it was tested the regularity and irregularity of blood transfusion and iron chelation therapy among thalassemic children, they indicated that most of parents and their thalassemic children take care for regular receiving blood transfusion and iron chelation therapy especially among non-neglected families<sup>(9)</sup>. Generally speaking, regular blood transfusion and regular iron chelation therapy is so important for thalassemic children in order to improve the physical and psychosocial status of those children (Table 2). In order to determine which was the most highly effective domain on a psychosocial status of studied sample the researcher used a test of varmix rotated method with a single extracted component for the studied domains. According to the statistical Eigen value this study finding shows that the emotional domain is the most highly affected one, followed by the social domain and school domain. (Table 3). In an experimental study of (86) school age Iranian children with thalassemia major it was found that the thalassemia major had a strong negative impact on emotional aspect of children more than social, and school achievement aspect<sup>(14)</sup>. Additional support was found study of (269) UAE children; It was conducted to assess the physical and psychosocial health of thalassemia children. The study result indicated that there were the most affected dimensions with emotional being affected more than any dimension by social, physical, and school achievement<sup>(15)</sup>. The results of the present study revealed that there were no significant differences between children response and information of their parents regarding the overall children psychosocial aspect of thalassemia, these findings revealed that majority of

thalassemic children had always suffered problem of overall psychosocial status. (Table 4). In a study was conducted to identify effects and burden of thalassemia major on Psychosocial aspects of (70) thalassemic children, the study results indicated that the majority of the study sample had negative impact on the different psychosocial life aspects<sup>(11)</sup>. In a cross sectional study of (75) with thalassemia major in Malaysian families who were tested physical and psychosocial aspects of thalassemic children. This study results revealed that there were no significant differences between children response and information of their parents regarding to the responses of overall psychosocial aspect of thalassemia, also the study result indicated that there majority of the thalassemic children had always suffered problems related to the psychosocial status; in addition, child self-report were lower than parents proxy report<sup>(16)</sup>. The present study revealed that there were a significant association between the study sample psychosocial status and their age, child primary school levels, and socio-economic status, the study results indicate that there is a high significant association at p-value less than 0.01. (Table 5). The psychosocial domain represent to two main dimensions psycho and social one, and these dimensions affected by both the social and developmental stages. Age and child primary school levels represent to a different developmental stages that may affect psycho and social dimensions of the patients and the gender and the socio economic status also affected the psychosocial status dimensions because the male and female so that patient responses might be different due to these circumstances. In a cross-sectional study were conducted of (75) children with thalassemia major in Thailand family. The study results showed that there was a significant association between psychosocial status of thalassemic children and their age, education level and non-significant with gender and socio economic status supported the present study results<sup>(17)</sup>.

While, a cross-sectional survey was conducted in Thailand which include (315) Thalassemic children and the study investigated physical and psychosocial health of their sample<sup>(7)</sup>. Another study Supported the present study, the study result indicated that there were a significant relationship between the study subjects overall psychosocial health and there age but not significant with others<sup>(5)</sup>. These study findings revealed that there were significant associations between the study sample psychosocial aspects and their disease duration, the study results indicate that there is a high significant association at p-value less than 0.01 (Table 6). This result comes because of might the adaptation strategies play an important role in changing patient's responses toward the psychosocial aspects. In addition, when the duration of the disease increase the possibility of adaptation may increase, otherwise when the duration of disease decreased the possibility of the adaptive also decrease. Within this issue the patient response will be charged. The present study results, agrees with a study results revealed that there was a significant relationship between the study subjects psychosocial health and there duration of thalassemia occurrence<sup>(7)</sup>. Also the present study supported by a previous study findings shows that there were a significant relationship between the study subjects psychosocial status and their frequency of transfusion at p-value (0.034) and frequency of chelation therapy at p-value (0.031)<sup>(16)</sup>. In another study, a cross-sectional descriptive-analytical study was conducted on (40 ) children over 7 years of age with thalassemia major in Mazandaran, Iranian families by<sup>(18)</sup>.

They study found that there were a significant Correlation relationship between study sample psychosocial health and age at diagnosis of thalassemia major. In additional, another study, the result revealed that there were non-

significant relationship between psychosocial health of thalassemic children and their clinical data and age at onset, this study results were disagrees with the results of the present study<sup>(19)</sup>.

## **CONCLUSION**

The study concluded that the findings of the present study revealed that majority of thalassemic children had suffered poor psychosocial status. In addition, the emotional domain is the most affected one, followed by the social domain, and then the school domain.

## **RECOMMENDATIONS:**

- 1- A psychologist and sociologist in the center for Thalassemia is a must to help in providing a link between patients, school, the families, and the physicians.
- 2- And people should be health oriented by mass media in providing information to population about thalassemia and other inherited diseases.

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