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Original Research Article

Physical Aspects of School Age Children with Thalassemia Major in Al-Najaf Al-Ashraf

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Abstract

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

The Objectives of this study is to assess physical aspect of school age children with thalassemia major andto found out the magnitude association between physical aspect and their demographic characteristics and their clinical characteristics.

A Non Probability "purposive" sample of (100) school age children with thalassemia major and their parents are included in the present study. 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 physical 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 squire, and P- value) were used to data analysis.

The present study results indicated that there was a significant relationship between thalassemia major and their physical aspects.

The study concluded that the majority of the study sample of thalassemic childrenhad negative impact on physical aspects.In addition,non-significant differences between child and their parents regard to the overall physical aspects.

The study recommends that a physical physician and psychologist should be present in all thalassemia centers in order to help in promotion a relationship between children, school representatives, the families, and the doctors and health oriented mass media should an important role in providing information to population about thalassemia and other inherited diseases.

Key words: Thalassemia major;school age children, physical aspect.

الخلاصة

مرض فقر دم البحر الابيض المتوسط الشديد من الامراض الوراثية المنتشرة في منطقة البحر الابيض المتوسط وان تقويم الجوانب البدنية للاطفال في عمر المدرسة يعد من الامور ذات الأهمية القصوى خاصة للأطفال الذين يعانون من الامراض المزمنة.

تهدف الدراسة الحالية الى تقييم الجانب البدني للأطفال المصابين بمرض فقردم البحر الابيض التوسط الشديد في عمر المدرسة و تحديد العلاقة بين الجانب البدني لعينة البحث والمتغيرات الديموغرافية والسريرية للمرض.

تم اختيار عينة غرضية (غير احتمالية) شملت (١٠٠) من العوائل واطفالهم في عمر المدرسة ومن المصابين بمرض فقر دم البحر الابيض المتوسط الشديد.قام الباحث ببناء استمارة استبيان خاصة لغرض تحقيق اهداف الدراسة الحالية تم اثبات الهدف الظاهر للأستمارة من خلال عرضها على مجموعة من الخبراء في مجالات مختلفة واما ثبات الاستمارة فقد تم التحقق منة من خلال استخدام معامل الارتباط بيرسون وكان ٠,٩١للاباء و٠,٨٧لأبناءهم . تم استخدام مقياس التائي الثلاثي لقياس اجابات الاطفال وابائهم فيما يخص الجوانب البدنية للأطفال وتم تحليل

البيانات من خلال استخدام الاحصاء الوصفي (النسبة المئوية والتوزيع التكراري) والاحصاء الاستدلالي (التحليل التائي ,معادلة مربع كاي والاحتمالية).اشارت نتائج الدراسة الحالية بأن هنالك نتائج دلالة احصائية واضحة للعلاقة بين مرض فقر دم البحر الابيض المتوسط الشديد والتأثيرات السلبية على الجوانب البدنية لعينة البحث.اشارت الدراسة الى ان غالبية عينة البحث من الاطفال يعانون من مشاكل بدنية وان مرض فقر دم البحر الابيض المتوسط يؤثر تأثيرا سلبيا على الجوانب البدنية لعينة البحث فضلا عن انه لاتوجد فروقات ذات دلاله احصائية بين استجابات الاطفال وذويهم فيما يخص الجوانب البدنية والسريرية.

الكلمات المفتاحية:الثلاسيميا الكبرى,اطفال عمر المدارس,الجانب البدني.

Introduction

Thalassemia major (TM) is an inherited blood disorder caused by deficiency in synthesis one or moreglobin polypeptide chains that is passed from one generation to another based on Mendelian laws [1,2]. Hemoglobin is a protein that consists of two alpha (α) and two beta (β) chains. Thalassemia occurs according to α or β – globin chain affected. Children whit (βTM) is normal at birth, but develop symptoms anemia in early infancy of life [3-5].World Health Organization (WHO) has calculated that about 7% of the world's populations carry a hemoglobino-pathy gene.It is estimated to affect up to 270 million people worldwide. In the Mediterranean area, there are 15 to 25 Million of healthy carriers[6]. Iraq is one of the countries in which 6-10% of the population have a hemoglobinopathy of which thalassemia is the most common[7].Consanguineous marriages which are the most preferred in Iraq contribute to increasing the incidences of genetic disorders [8,9].Children with beta-thalassemia major need a life-long treatment of regular blood transfusion and iron chelation therapy [10,11].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 [12-14].

The study was conducted to achieve the following objectives:

1- Assessment of the physical aspect of school age children with thalassemia major.

2- Find out magnitude the relationship between school age thalassemic children physical aspect with certain variable include age, gender, residential area, duration, and adherence of iron chelation therapy.

Materials and Methods

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^{ed} 2014 to August 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, constricted a questioner 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 physical aspect items. Physical aspect refers to the physical function that consists of eight items such as walking, running, sports activity or exercise, lift heavy things, take a bath or shower by himself, chores around the house, feeling pain, and energy loss.An instrument was conducted through the use of (3) level

type Likert scale for the assessment of physical aspect of major thalassemia. The rating of the instrument, was, never had problem, sometime had problem, 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 physical 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 Study Subjects by their Demographic Data

Demographic data	Rating	Frequency	%	Cumulative Percent
1.A- 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
1.B- Gender	Male	53	53.0	53.0
	Female	47	47.0	100.0
1.C- Residential Area	Urban	75	75.0	75.0
	Rural	25	25.0	100.0
1.D- Birth series	First	29	29.0	29.0
	Second	29	29.0	58.0
	Third	11	11.0	69.0
	Fourth	13	13.0	82.0
	Fifth or more	18	18.0	100.0
1.E- Socio economic status	high	12	12.0	12.0
	middle	16	16.0	28.0
	low	72	72.0	100.0

Concerning children's age, the majority of children was (10-11) years old which accounted for (39%) and the mean of age was (9.6) years with slandered deviation of (1.8) (Table 1.A).Relative to the children's gender, those who were male accounted (53%) and the reaming were female (47%) (Table 1.B).In respect to the residential area, the majority of thalassemic children (75%) were living in urban area and those who were living in a rural area accounted for (25%) (Table 1.C).The birth series of thalassemic children were distributed as (29%) for first birth series, (13%) for fourth birth of series and, (18%) for fifth or more birth of series(Table 1.D). Relative to the socioeconomic status, majority of them (72%) were low level of socioeconomic, (16%) from middle socioeconomic level, and those in the high socioeconomic level was accounted for (12%) (Table 2.E).

Table 2: Distribution of the Study Subjects by their Clinical Data

Clinical data	Rating	Frequency	%	Cumulative Percent
2.A- 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
2.B- Family History	Present	63	63.0	63.0
	Absent	37	37.0	100.0
2.C- Blood transfusion/ month	Regular	79	79.0	79.0
	Irregular	21	21.0	100.0
2.D- Number of blood transfusions / month	One time	20	20.0	20.0
	twice	71	71.0	91.0
	three times	8	8.0	99.0
	fourth times	1	1.0	100.0
2.E- Iron chelation	Regular	82	82.0	82.0
	Irregular	18	18.0	100.0

This table represents of the child clinical data, The present study reported that regarding the duration of disease, the mostly of children was more than (10) years which accounted (56 %),those who were between (8-9) years which accounted (21%),those who were between (6-7) years which accounted (22%),and those who were five years or less which accounted (1%) (Table 2.A). The family history of thalassemia was distributed (63%) for present and (33%) for absent (Table 2.B).Concerning children blood transfusion per month, the majority of children (79%) was regular attended to the hospital in order to received blood transfusion, comparing with (21%) those who were irregular attended to the hospital in order to received blood transfusion (Table 2.C).In regard to number of blood transfusion per month, most of them (71%) was attended hospital twice per month for blood transfusion and remain (29%) was attended hospital (1-4) per month for blood transfusion(Table 2.D).

Table 3: The Comparative Difference between Children and their Parents Regarding to the Overall Responses of the Physical Aspect

	Main domain	Levels	Frequency	Percent	Mean	s.d.	t	d.f	p-value
Child information	Physical	Never	1	1.0	2.4	0.52	1.271	198	0.205 NS
		Sometime	50	50.0					
		Always	49	49.0					
Parents information	Physical	Never	5	5.0	2.5	0.58			
		Sometime	32	32.0					
		Always	63	63.0					

* S.d = standard deviation , t = t-test, d.f = degree freedom and P- value = probability value.* NS : Non Significant at P>0.05.

This table indicates that were no significant differences between children and their parent's information regarding to the overall responses of physical aspect.Also this table shows that there were (50%) of the study sample were sometime had problems and (49%) that were always had problems.

Table 4: The Association Between the Study Subjects Demographic Data and their Responses to the Physical 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	9.735	0.298	6	0.639	.599	0.781	NS
Gender	6.236	0.242	2	0.044	0.000	0.030	S
Residential Area	0.907	0.095	2	0.636	0.546	0.734	NS
Birth series	2.892	0.168	8	0.941	0.953	1.000	NS
Socio economic status	3.005	0.171	4	0.557	0.483	0.677	NS

* ValueChi-square = Calculated value. Cc = Contingency Coefficient, d.f = degree freedom and P-value = probability value. * Sg : Significant at P<0.05 ; NS : Non Significant at P>0.05

This table revealed that there were no significant association between the study sample physical status and their demographic data at p-value more than 0.05; but there were a significant association between the study sample physical status and their gender.

Table 5: Association between the Study Subjects Clinical Data and their Responses to the Physical 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	5.627	0.231	8	0.689	0.688	0.852	NS
Family History of thalassemia	2.496	0.156	2	0.287	0.266	0.454	NS
Blood transfusion	1.923	0.137	2	0.382	0.314	0.506	NS
Number of blood transfusion	13.075	0.340	6	0.042	0.041	0.159	Sg
Iron chelating	2.837	0.166	2	0.242	0.219	0.401	NS

This table shows that there were no significant association between the study sample physical status and their clinical data at p-value more than 0.05; but there were a significant association between the study sample physical status and number of blood transfusion.

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 was 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 [15].While the cross sectional study of [16] which tested the Psychological problems and Quality of Life in Children with Thalassemia, 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. In another study conducted to Determine Quality of life of Adolescent with thalassemia major in Iraq indicated that majority of the study subjects are males [17].Generally speaking, these finding supported and agrees 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 HawlerThalassemia 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[6].In regard to birth series, the study results indicated that the thalassemia major was highly incidence rate among the first and second child of birth series and 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 study which was conducted on a sample of 100 school-age thalassemic children out-patient Hematology clinic at Zagazig University Hospitals in Egypt, the study results revealed that the majority of them among first and second of birth order as well as the mostly of them not sent to school because of severity of their disease [18]. The findings of the present study revealed that majority of children's parent married and most of them consanguinity marriage.In a descriptive study, of (144) caregivers of thalassemia children who attended Hiwa hospital, to assess level of caregiver's coping to their child condition was conducted by [19] the study findings indicated that majority of study samples were married and there were majority of them consanguinity marriage . Concerning to the socio-economic status and incidence of thalassemia major, these findings revealed that a highly present of incidence was appeared among families with low socio-economic status (Table 1). [20] stated that the majority of thalassemia major appears among families of low socio-economic level. 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 a study which was conducted by [18, 21].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.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 physical complication of disease.This results also supported by [22], they 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.The data analysis manifested that the majority of thalassemic children had regular received blood transfusion and iron chelation therapy.[15] tested the regularity and irregularity of blood transfusion as well as, 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. Generally speaking, regular blood transfusion and regular iron chelation therapy is so important for thalassemic children in order to improve their physical and psychosocial status.The study results indicated that that majority of the study sample appears family history with thalassemia (Table 2).The results of present study agree with the result of the study which was conducted by [23]. They found that more than half of parents that participates as samples for their study, was carried of thalassemia gens.The findings of the present study indicated that there were no significant differences between children response and information of their parents regarding the overall children physical aspect of thalassemia, this findings revealed that majority of thalassemic children had suffered a bad and poor overall physical status ,in addition, the bad and poor physical status of thalassemic children confirmed by children's parents, they mention that their children faced many problems regarding to the all item of physical aspect domain such as walking, running, lifting heavy things and taken shower or bath by himself (Table-3). In a cross sectional study of (49) children with thalassemia major who were interviewed for determination of the relationship between bad felling of physical aspects and thalassemia major disease, the study finding indicated that there were highly correlation between child's physical aspect and incidence of thalassemia, and these was considered as important factors determining the child's physical aspects [24]. In another study which was conducted to identify effects and burden of thalassemia major among (60) school age children .The results show significant effects on child's physical status regarding ,walking running ,showering, and lifting things. That means there are a bad and burden effects of thalassemia on children physical status and this study results agrees with results of the present study [25]. The study results revealed that there were no significant association between the study sample physical status and all item of demographic data except children's gender(Table 4).These results indicate that there is a significant association between the responses of male and female toward the physical domain and this result comes because of physiological differences between these two sexes (male and female)and when the disease affects the human body, this effect present among sexes with different manner. In astudy which was conducted to evaluate quality of life in children with β-thalassemia major at center for special disease in Iran. The results show that there were no significant relationship between physical health status and other demographic data [26]. While the results of the study which was conducted by [14] in order to assess of poor physical and mental health related quality of life in beta-thalassemia major showed statistically non-significant relationship between overall responses of physical aspect, except gender of thalassemic children. This present study shows that there were no significant association between the study sample physical status and their clinical data of thalassemic children at p-value more than 0.05.While the study results indicate that there were a significant association between the study subject physical aspect and number of blood transfusion at p-value less than 0.05.(Table 5).This result comes because that the number of blood transfusion plays a dual effect by which the body refreshed with a new fresh blood to enhance its function if

there is a deficient in the number of blood transfusion so that Patient problems specifically the physical problem will affected by the number of blood transfusion. In addition, the results of the present study agrees with the study which was carried out at Zagazig city in Egypt in order to assess the quality of life of school age thalassemic children,the study findings indicated that were asignificant association between physical health status and number of blood transfusion per month as well as iron chelation therapy[18]. Additional support was provided in a cross sectional study which was conducted to identify quality of life among (46)children with β-thalassemia major treated in Western Saudi Arabia, the study finding revealed that there were a significant association between physical function of those children family history of thalassemia as well as with number of blood transfusion per month [21].

Conclusion

The study was concluded that there were no significant differences between children response and information of their parents regarding the overall children physical aspect of thalassemia, as well as that majority of thalassemic children had suffered a bad and poor overall physical status. Also, the study results indicated that there were significant associations between thalassemic school age children physical aspect with their gender and their number of blood transfusion.

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