

# Assessment of Daily Living Activities of Thalassemic School Age Children at Thalassemia Center in Ebn-Albaldy Maternal and Child Hospital at Baghdad City

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**Abstract-** Thalassemia is an inherited blood disorder that it is prevalent most commonly in Mediterranean regions. Thalassemia occurs due to the deficiency or absence one of the globin chains that form of the human hemoglobin ( may be affects alpha or beta globin chain ).It had a chronic negative impacts on many aspects in the life of thalassemic child including the activities of daily living and becomes unable to do it independently.

**Methodology:**A descriptive study was carried out at the thalassemia center in Ebin-AL-Balady hospital for maternal and child care at Baghdad city for the period from 12th of November to 23th of August 2016 in order to to assess the activities of daily living for school age children with thalassemia and to find out the relationship between these activities of daily living and their socio-demographic characteristics. The none-probability( purposive ) sample of 100 thalassemic school age children were selected from this center and they attended for management.A pilot study is performed for the period from 11th to 25th of February 2016 to test the reliability of the internal consistency of the study questionnaire through Alpha correlation coefficient which was  $r=0.87$ . Data was collected based on a researcher-made questionnaire by interviewing the hospitalized children and their parents .The study instrument consisted from four parts ; Child's demographic data , Child's clinical characteristics and the fourth part is concerned with the activities of the daily living for the thalassemic school age children where in this part there are (60) items questions which included (8) domains of the activities of daily living . The data was analyzed through application of the descriptive statistical data analysis approach (frequency and percentage tables and mean of score ) and inferential statistical data analysis approach (Chi-Square , ANOVA test , t-tests and Spearman correlation coefficient) . Validity of the study instrument was determined through the panel of experts from different specialties to meet the objectives of the study .

**Results:** The study results indicated that there is a moderate level (1.79) towards the activities of daily living of the thalassemic school age children. While, There are a moderate relationship between the activities of daily living of the thalassemic school age children with their socio-demographic characteristics except (gender and residency).The mean of score (MS) is considered Low<(1.66), Moderate = (1.66-2.33), and High when is >(2.33).

**Recommendation:** The study recommended the necessity to provide highlighting the information about thalassemia and any inherited diseases (may be by mass media or genetic

counseling .provide a detailed scientific information about the disease in an appropriate illustration way for the children with thalassemia , provide the link unit in the thalassemia centers present between the patient ,school , the families and the physicians to help the children and their families ( especially from low socio-economic glasses or in major life events e.g. death of the parents that cause many psychological problems or stressors . provide further researches are needed to investigate the affecting of the disease on daily living activities.

**Index Terms-** Daily Living Activities, Thalassemic School Age Children,Maternal and Child Hospital.

## I. INTRODUCTION

Thalassemia is one of an inherited blood disorders of hemoglobin synthesis characterized by anemia that can be varied from mild to severe which involve the absence or decrease in genes responsible synthesis of one of globin chains(alpha or beta ) as correspond to errors in the genes on the appropriate chromosome 16 and 11 respectively that form the blood hemoglobin<sup>(1)</sup>. There are two main forms of thalassemia ;beta  $\beta$ -thalassemia major also called Cooley's or Mediterranean anemia , is the most common type, fatal alpha  $\alpha$ -thalassemia major which result death in utero .Other types are thalassemia intermedia(with mild anemic symptoms) and thalassemia minor (asymptomatic anemia type)<sup>(2)</sup>. Thalassemia occurs most often in people who live in the Mediterranean basin and those who live in tropical and subtropical regions of Asia and Africa<sup>(3)</sup>. The rate of  $\beta$ -Thalassemia carriers around the world is about 1.5% of the global population (between 80 to 90 million people) where Cyprus and Sardina have the greatest rate of the thalassemia carriers .in addition ,there are 60.000 asymptomatic individuals born annually and the great of them in the developing countries<sup>(4)</sup>. Thalassemia a chronic illness that may not be considered as terminal illness that it requires an adaptation to daily living activities due to its long life treatment and care to reduce its impacts on the child's physical ,psychological and cognitive development through early childhood that may cause functional or social limitations or minimal effects on quality of life during the middle childhood especially school age period,where the child with chronic illness (such as thalassemia) during this age becomes increasingly more independent and has an increased understanding about his condition and he can participate in certain aspects of his care<sup>(5)</sup>. The activities of daily living can

be subdivided into ;personal activities of daily living which associated with basic self –maintenance (such as eating ,showering ,toileting ,dressing ...) and those activities it usually used to assess and anticipate the stages of growth and development in children. Other activities as instrumental activities of daily living that include domestic tasks that it often use to measure or evaluate the disabilities or the dependency of the old patients like cooking ,cleaning ,shopping ,laundrying ,and access tasks like driving and mobile use . Specifically, the health professionals often use the ability to perform the Activities of Daily Living to measure the functional status (Berdian et al,2013). Moreover ,the activities of daily living are children’s ability to do things independently . but, the young children often need to help from adults to doing it with adequacy of performance in the functions of the movements or playing ,feeding, sleeping, showering, socialization and playing independently at home, school, community or work environments <sup>(6)</sup>.

II. METHODOLOGY

Objectives of the study

1. To assess the daily living activities for the thalassemic school age children at the thalassemia center in Ibin-AL-Balady hospital for maternity and child care at Baghdad City.

2. To find out the relationships between the school age children who have thalassemia and their demographic characteristics of age, gender, residency and studying in the school.

**Design of the study:**A descriptive study was conducted on hospitalized school age children who have thalassemia at The Thalassemia Center of Ibn-Albalady Hospital for Maternal and Child Care in Baghdad city to assess their daily living activities during the period (12th of November to 23th of 3 August 2016).

**Setting of the study:**This study conducted at the thalassemia center of the Ebin-Abalady Hospital for maternal and child care in Baghdad city. This center was established at 1983 as a first specialized center in the Iraq and Arabic region to provide the specific health services for few patients from Baghdad city and other governorates .These services provided to the patients freely and it included ; blood transfusions , and receiving drugs for iron chelation therapy such as desfral or deferiprone.Recently ,this center has (1632) registered patients including of them (1032)major thalassemia, (476) minor thalassemia, and(124) sickle cell anemia from all age groups (due to latest statistics from this center until 3 January of 2015).

**Sample of the study:**A none–probability(purposive) sample of 100 thalassemic school age children who had hospitalized for management and registered in the thalassemia center of the Ebn-Albalady hospital for maternity and child care in Baghdad city.

**Study instrument:** A questionnaire consisted of three parts and covering sheet that included statements to introduce the investigator and the purpose of the study which includes the followings parts:

*Child’s demographic data*

*Child’s clinical characteristics*

*Activities of the daily living for the thalassemic school age children*

**Validity and Reliability:** The content validity of the instrument was established through a panel of (15) experts, the reliability of the items were based on the internal consistency of the questionnaire was assessed by calculating Cronbach s' Alpha which as= 0.87.

**Statistical analysis:** The statistical data analysis approach by using (SPSS-ver.20) is used in order to analyze the data of the study. A descriptive statistical data analysis approach used to describe the study variables : Frequencies, percentages and mean of score; and inferential statistical data analysis approach: used by application of the Chi-square test.

III. RESULTS

**Table 1: Distribution of the children according to their demographic Characteristics**

No.	Characteristics	F	%	
1	<b>Gender:</b>	<b>Male</b>	<b>54</b>	<b>54</b>
		<b>Female</b>	<b>46</b>	<b>46</b>
		<b>Total</b>	<b>100</b>	<b>100</b>
2	<b>Age group:</b>	<b>6 – 9 years</b>	<b>39</b>	<b>39</b>
		<b>10– 13 years</b>	<b>34</b>	<b>34</b>
		<b>Total</b>	<b>100</b>	<b>100</b>
5	<b>Residence:</b>	<b>Urban</b>	<b>74</b>	<b>74</b>
		<b>Rural</b>	<b>26</b>	<b>26</b>
		<b>Total</b>	<b>100</b>	<b>100</b>
6	<b>Continuous Studying in the school:</b>	<b>Yes</b>	<b>71</b>	<b>71</b>
		<b>No</b>	<b>29</b>	<b>29</b>
		<b>Total</b>	<b>100</b>	<b>100</b>
8	<b>School absenteeism</b>	<b>Yes</b>	<b>67</b>	<b>33</b>
		<b>No</b>	<b>33</b>	<b>67</b>

This table shows that more than half of the children was male (54%) with age group of 10 - 11 years old (39%). 74% of children are resident in urban area that are continuous in their school, 61% of them are pretend the school continuously with absenteeism in their school (67%).

**Table 2: Distribution of the clinical Characteristics which Displayed among School-age Children with Thalassemia**

No.	Characteristics	F	%	
1	<b>Age of onset:</b>	<b>0 – 6 months</b>	<b>32</b>	<b>32</b>
		<b>7 – 12 month</b>	<b>41</b>	<b>41</b>

		<b>13 – 24 month</b>	<b>22</b>	<b>22</b>
		<b>25 and more</b>	<b>5</b>	<b>5</b>
		<b>Total</b>	<b>100</b>	<b>100</b>
<b>2</b>	<b>Number of transfusion:</b>	<b>No need</b>	<b>7</b>	<b>39</b>
		<b>Every two weeks</b>	<b>19</b>	<b>19</b>
		<b>Every three weeks</b>	<b>61</b>	<b>61</b>
		<b>Monthly</b>	<b>13</b>	<b>13</b>
		<b>Total</b>	<b>100</b>	<b>100</b>
<b>3</b>	<b>Regular Iron chelation therapy</b>	<b>Yes</b>	<b>67</b>	<b>37</b>
		<b>No</b>	<b>33</b>	<b>63</b>
		<b>Total</b>	<b>100</b>	<b>100</b>
<b>4</b>	<b>Level of hemoglobin:</b>	<b>4 – 6 mg/dl</b>	<b>42</b>	<b>42</b>
		<b>7- 9 mg/dl</b>	<b>52</b>	<b>52</b>
		<b>10 – 11 mg/dl</b>	<b>6</b>	<b>6</b>
		<b>Total</b>	<b>100</b>	<b>100</b>
<b>5</b>	<b>Level of ferritin:</b>	<b>1000 – 3000 mg/dl</b>	<b>31</b>	<b>31</b>
		<b>3100 – 5000 mg/dl</b>	<b>55</b>	<b>55</b>
		<b>5100 – 7000 mg/dl</b>	<b>14</b>	<b>14</b>
		<b>Total</b>	<b>100</b>	<b>100</b>
<b>6</b>	<b>Respiratory infection:</b>	<b>Yes</b>	<b>43</b>	<b>43</b>
		<b>No</b>	<b>57</b>	<b>57</b>
		<b>Total</b>	<b>100</b>	<b>100</b>
<b>7</b>	<b>Chest pain:</b>	<b>Yes</b>	<b>38</b>	<b>38</b>
		<b>No</b>	<b>62</b>	<b>62</b>
		<b>Total</b>	<b>100</b>	<b>100</b>
<b>8</b>	<b>Joint pain:</b>	<b>Yes</b>	<b>71</b>	<b>71</b>
		<b>No</b>	<b>29</b>	<b>29</b>
		<b>Total</b>	<b>100</b>	<b>100</b>
<b>9</b>	<b>Jaundice:</b>	<b>Yes</b>	<b>37</b>	<b>37</b>
		<b>No</b>	<b>63</b>	<b>63</b>
		<b>Total</b>	<b>100</b>	<b>100</b>
<b>10</b>	<b>Paleness:</b>	<b>Yes</b>	<b>75</b>	<b>75</b>
		<b>No</b>	<b>25</b>	<b>25</b>
		<b>Total</b>	<b>100</b>	<b>100</b>
<b>11</b>	<b>Cyanosis:</b>	<b>Yes</b>	<b>55</b>	<b>55</b>
		<b>No</b>	<b>45</b>	<b>45</b>
		<b>Total</b>	<b>100</b>	<b>100</b>
<b>12</b>	<b>Generalized fatigue:</b>	<b>Yes</b>	<b>76</b>	<b>76</b>
		<b>No</b>	<b>24</b>	<b>24</b>
		<b>Total</b>	<b>100</b>	<b>100</b>
<b>13</b>	<b>Anorexia:</b>	<b>Yes</b>	<b>55</b>	<b>55</b>
		<b>No</b>	<b>45</b>	<b>45</b>
		<b>Total</b>	<b>100</b>	<b>100</b>
<b>14</b>	<b>Urinary tract infection:</b>	<b>Yes</b>	<b>45</b>	<b>45</b>
		<b>No</b>	<b>55</b>	<b>55</b>
		<b>Total</b>	<b>100</b>	<b>100</b>
<b>15</b>	<b>Dwarfism:</b>	<b>Yes</b>	<b>41</b>	<b>41</b>
		<b>No</b>	<b>59</b>	<b>59</b>
		<b>Total</b>	<b>100</b>	<b>100</b>
<b>16</b>	<b>Hepato-splenomegaly:</b>	<b>Yes</b>	<b>27</b>	<b>27</b>
		<b>No</b>	<b>73</b>	<b>73</b>
		<b>Total</b>	<b>100</b>	<b>100</b>
<b>17</b>	<b>Cardiac disorders:</b>	<b>Yes</b>	<b>29</b>	<b>29</b>
		<b>No</b>	<b>71</b>	<b>71</b>
		<b>Total</b>	<b>100</b>	<b>100</b>
<b>18</b>	<b>Skin problems:</b>	<b>Yes</b>	<b>46</b>	<b>46</b>

		<b>No</b>	<b>54</b>	<b>54</b>
		<b>Total</b>	<b>100</b>	<b>100</b>

No: Number, F: Frequency, %: Percentage

The clinical characteristics for children in this table reveals that thalassemia appear with age of onset 7 – 12 months (41%). The number of blood transfusion was every three weeks (61%). The level of hemoglobin refers to 6 – 9 mg/dl for (52%) of children while fertilin level was  $\geq 1300$  ng/dl for (55%) of them. Major (58%) of them have complications. Regarding chronic disease, the results shows that less than half of children having

respiratory infection (43%), 38% having chest pain, 71% having joint pain, 37% having jaundice, 75% having paleness, 55% having cyanosis, 76% having generalized fatigue, 55% having anorexia, 45% having urinary tract infection, 41% having dwarfism, 27% having Hepato-splenomegaly, 29% having cardiac disorders, and 46% having skin problems.

**Table 3: Assessment of the activities of daily living for school age children with thalassemia (N=100)**

List	Items	Always	Sometimes	Never	MS	RS	Ass.
1	Clothing	F %	F%	F %			
1.1	I wear my clothes difficultly	9	68	23	1.86	62.0	L.S
2.1	I need to help from other whenever I need to clothing	5	40	55	1.50	50.0	L.S
3.1	I keep and arrange my clothes difficultly	9	61	30	1.79	59.6	L.S
4.1	I need to help from other to keep and arrange my clothes	9	37	54	1.55	51.6	L.S
5.1	I have difficulties to care my general appearance	16	70	14	2.02	67.3	M.S
6.1	I need to help from other to care my general appearance	16	27	57	1.59	53.0	L.S
2	<b>Transferring (motor activities)</b>						
1.2	I walk alone difficultly	12	63	25	1.87	62.33	L.S
2.2	I run alone difficultly	21	55	24	1.97	65.66	L.S
3.2	I lift the heavy things difficultly	14	64	22	1.92	64.0	L.S
4.2	I have difficulties to up staring	16	58	26	1.90	63.33	L.S
5.2	I have difficulties to going to school	18	58	24	1.94	64.66	L.S
6.2	I have fatigue and generalized weakness with any work	33	50	17	2.16	72.0	M.S
7.2	I feel bodily weakness	35	47	18	2.17	72.33	M.S
8.2	I need to help from other to perform the sport activities	33	41	26	2.15	71.66	M.S
3	<b>School activities</b>						
1.3	I have school absenteeism	22	51	27	1.95	65.0	L.S
2.3	I perform my school home-work difficultly	24	53	23	2.01	67.0	M.S
3.3	I feel that my attention is dropping during the lesson	26	55	19	2.07	69.0	M.S
4.3	I have difficulties to understand my lessons	21	46	33	1.88	62.66	L.S
5.3	I have difficulties to go to the school-picnics	11	56	33	1.78	59.33	L.S

6.3	I have difficulties to coping in school and other pupils	21	52	27	1.94	64.66	L.S
7.3	I have difficulties in understanding my school administration about my health status	34	38	28	2.06	68.66	M.S
8.3	I have low grades in school-examinations	32	48	20	2.12	70.66	M.S
4	play and hobbies						
1.4	I have difficulties in playing with other kids	17	52	31	1.86	62.0	L.S\
2.4	I have difficulties in playing which it needs a lot of energy	12	56	32	1.80	60.0	L.S
3.4	I have difficulties to play with my the favorite hobbies	14	51	35	1.79	59.66	L.S
4.4	I like to play with sister\brother only	14	55	31	1.83	61.0	L.S
5.4	I like to find other hobbies that it doesn't need a lot of energy	23	47	30	1.93	64.33	L.S
5	personal hygiene						
1.5	I have difficulties in taking bath or shower by my self	19	65	16	1.83	61.0	L.S
2.5	I need to help by others in taking bath or shower by my self	15	53	32	1.73	57.66	L.S
3.5	I have difficulties in drying and dressing my body and hair	12	64	24	1.68	56.0	L.S
4.5	I need to help by others in drying and dressing my body	14	55	31	1.83	61.0	L.S
5.5	I have difficulties in preparing my hair style	11	69	20	1.71	57.0	L.S
6.5	I need to help by others in preparing my hair style	8	54	38	1.70	56.66	L.S
7.5	I have difficulties in toilet training alone	9	81	10	1.59	53.0	L.S
8.5	I need to help by others in toilet training	8	80	12	1.58	52.66	L.S
9.5	I have difficulties in fingernails care alone	15	55	30	1.72	57.33	L.S
10.5	I need to help by others in fingernails care	11	57	32	1.69	56.33	L.S
11.5	I have difficulties in brushing teeth	9	68	23	1.66	55.33	L.S
12.5	I need to help by others in brushing teeth	13	57	30	1.73	57.66	L.S
6	Eating and drinking						
1.6	I have difficulties eating and drinking alone	8	32	60	1.48	49.33	L.S
2.6	I need to help by others to eating and drinking	7	41	52	1.55	51.66	L.S
7	Sleeping						
1.7	I go to bed regularly	16	61	23	1.73	57.66	L.S
2.7	I have difficulties in sleeping	13	51	36	1.77	59.0	L.S
3.7	I wake up through sleep	10	52	38	1.72	57.33	L.S
4.7	I use drugs during sleeping	7	36	57	1.50	50.0	L.S

8	Social communication						
1.8	I have good relationships with my family only	14	47	39	1.75	58.33	L.S
2.8	I like the isolation and to be alone	13	47	40	1.73	57.66	L.S
3.8	I afraid from any social communications with others	16	49	35	1.81	60.33	L.S
4.8	I have compassion with others	15	38	47	1.68	56.0	L.S
5.8	I have difficulties in participating the social Occasions	18	51	31	1.87	62.33	L.S
6.8	I like to talk about my self	11	35	54	1.57	52.33	L.S
7.8	I have few friends	17	47	36	1.81	60.33	L.S
<b>Total</b>		<b>858</b>	<b>2570</b>	<b>1972</b>	<b>1.79</b>	<b>59.66</b>	<b>L.S</b>

Mean of Score (MS) = Low Less than (1.66), Moderate = (1.66-2.33), High= More than (2.33).

This table demonstrated the total mean of score for school age child indicate that there is moderate level (1.79) towards the activities of daily living of the thalassemia.

Table 4: Analysis of Variance for Daily Living Activities with Child's Age group (N=100)

ADL	Sources of Variance	Sum Square	df	Mean Square	F	P ≤ 0.05
Clothing	Between Group	0.446	2	0.223	0.057	0.745
	Within Group	382.944	97	3.948		
	Total	383.390	99			
Transferring (Motor)	Between Group	6.319	2	3.160	0.371	0.837
	Within Group	827.041	97	8.526		
	Total	833.360	99			
School	Between Group	11.073	2	5.536	0.462	0.031
	Within Group	1162.317	97	11.983		
	Total	1173.390	99			
Play and hobbies	Between Group	0.508	2	0.254	0.049	0.752
	Within Group	498.082	97	5.135		
	Total	498.590	99			
Personal hygiene	Between Group	4.990	2	2.495	0.157	0.855
	Within Group	1538.800	97	15.864		
	Total	1543.790	99			
Eating and Drinking	Between Group	1.971	2	0.986	0.312	0.038
	Within Group	306.589	97	3.161		
	Total	308.560	99			
Sleeping	Between	8.166	2	4.083	2.250	0.011

	<b>Group Within Group Total</b>	<b>175.994 184.160</b>	<b>97 99</b>	<b>1.814</b>		
<b>Social</b>	<b>Between Group Within Group Total</b>	<b>41.538 759.622 801.160</b>	<b>2 97 99</b>	<b>20.769 7.831</b>	<b>2.352</b>	<b>0.076</b>
<b>Total</b>	<b>Between Group Within Group Total</b>	<b>210.470 14581.570 14792.040</b>	<b>2 97 99</b>	<b>105.235 150.325</b>	<b>1.2300</b>	<b>0.049</b>

*ADL: Activity of Daily Living, df: Degree of freedom, , P: Probability value  $p \leq 0.05$ .*

This table indicates that there is a significant relationship between daily living activities and age group among children with thalassemia at  $p \leq 0.05$ .

**Table 5: Significant differences between Daily Living Activities with Child's Genders (N=100)**

Daily Living Activities	Gender	M	SD	T	Df	$p \leq 0.05$
<b>Clothing</b>	Male	10.26	1.793	-0.917	98	0.362
	Female	10.37	2.174	-0.899	4.637	0.371
<b>Transferring (Motor)</b>	Male	15.59	2.723	1.043	98	0.030
	Female	16.65	3.027	1.028	3.743	0.037
<b>School</b>	Male	15.52	3.033	0.605	98	0.547
	Female	16.15	3.876	0.609	4.474	0.544
<b>Play and hobbies</b>	Male	9.43	2.043	0.625	98	0.533
	Female	8.96	2.458	0.621	2.891	0.536
<b>Personal hygiene</b>	Male	20.61	4.118	0.457	98	0.649
	Female	20.13	3.769	0.457	3.472	0.649
<b>Eating and Drinking</b>	Male	6.22	1.690	0.149	98	0.882
	Female	6.00	1.862	0.150	1.329	0.881
<b>Sleeping</b>	Male	6.78	1.369	-0.171	98	0.865
	Female	6.65	1.370	-0.170	3.624	0.866
<b>Social</b>	Male	12.26	2.960	0.149	98	0.882
	Female	12.17	2.735	0.150	2.329	0.059
<b>Total</b>	Male	96.67	11.972	-0.171	98	0.084
	Female	97.09	12.642	-0.170	3.624	0.008

*M: Mean, SD: Standard deviation, t: t-test, df: Degree of freedom, Sig: Significance, P: Probability value*

This table depicts that there is no significant relationship between daily living activities and child's gender at  $p \leq 0.05$ .

**Table 6: Significant differences between Daily Living Activities Child's Residence (N=100)**

Daily Living Activities	Residence	M	SD	T	df	Sig.	$P \leq 0.05$
<b>Clothing</b>	Urban	10.12	1.767	-1.628	98	0.107	N.S
	Rural	10.85	2.412	-1.405	34.895	0.169	N.S
<b>Transferring (Motor)</b>	Urban	16.00	2.833	-0.463	98	0.644	N.S
	Rural	16.31	3.134	-0.441	40.282	0.661	N.S
<b>School</b>	Urban	15.61	3.359	-0.989	98	0.325	N.S
	Rural	16.38	3.678	-0.947	40.607	0.349	N.S
<b>Play and hobbies</b>	Urban	9.03	2.120	-1.382	98	0.170	N.S

	Rural	9.73	2.539	-1.267	37.966	0.213	N.S
<b>Personal hygiene</b>	Urban	20.34	3.536	-0.222	98	0.825	N.S
	Rural	20.54	5.022	-0.188	34.112	0.852	N.S
<b>Eating and Drinking</b>	Urban	6.12	1.751	0.015	98	0.988	N.S
	Rural	6.12	1.840	0.015	41.989	0.988	N.S
<b>Sleeping</b>	Urban	6.86	1.427	1.812	98	0.073	N.S
	Rural	6.31	1.087	2.063	57.254	0.044	S
<b>Social</b>	Urban	12.16	2.730	-0.341	98	0.733	N.S
	Rural	12.38	3.201	-0.316	38.549	0.754	N.S
<b>Total</b>	Urban	96.24	10.466	-0.850	98	0.397	N.S
	Rural	98.62	16.356	-0.691	32.480	0.494	N.S

*M: Mean, SD: Standard deviation, t: t-test, df: Degree of freedom, Sig: Significance, P: Probability value, N.S: Not significant, S: Significant*

This table shows that there is no significant relationship between daily living activity and child's residence except sleeping activities which is significantly related with children who are resident in rural area at  $p \leq 0.05$  respectively.

**Table 7: Significant differences between Daily Living Activities with Child's Studying in the School (N=100)**

Daily Living Activities	Studying	M	SD	t	df	Sig.	$P \leq 0.05$
<b>Clothing</b>	Yes	10.37	2.106	0.445	98	0.657	N.S
	No	10.17	1.605	0.498	67.811	0.620	N.S
<b>Transferring (Motor)</b>	Yes	16.01	2.935	-0.354	98	0.724	N.S
	No	16.24	2.862	-0.358	53.292	0.722	N.S
<b>School</b>	Yes	15.65	3.506	-0.735	98	0.464	N.S
	No	16.21	3.310	-0.753	54.922	0.455	N.S
<b>Play and hobbies</b>	Yes	8.96	2.289	-1.778	98	0.079	N.S
	No	9.83	2.037	-1.868	58.163	0.067	N.S
<b>Personal hygiene</b>	Yes	20.35	3.727	-1.149	98	0.882	N.S
	No	20.48	4.517	-1.138	44.364	0.891	N.S
<b>Eating and Drinking</b>	Yes	6.20	1.825	0.682	98	0.497	N.S
	No	5.93	1.624	0.717	58.153	0.476	N.S
<b>Sleeping</b>	Yes	6.75	1.381	0.302	98	0.763	N.S
	No	6.66	1.344	0.306	53.386	0.761	N.S
<b>Social</b>	Yes	12.37	3.030	0.803	98	0.424	N.S
	No	11.86	2.341	0.894	66.890	0.375	N.S
<b>Total</b>	Yes	96.65	12.778	-0.270	98	0.788	N.S
	No	97.38	10.939	-0.289	60.402	0.774	N.S

*M: Mean, SD: Standard deviation, t: t-test, df: Degree of freedom, Sig: Significance, P: Probability value, N.S: Not significant*

This table reveals that no significant relationship has reported between daily living activities and children studying in the school at  $p \leq 0.05$ .

#### IV. DISCUSSION

##### Part I: Discussion of Socio-demographic Characteristics of the thalassemic school age children of the(100) participants

Results indicate that more than half of the current study sample were male (54%). This agrees with the study done by (Dakhakhny, et al, 2011) a study about (Quality of life of school

age thalassemia children at Zagazig ,Egypt) which reported that the majority of them were males (56%)<sup>(8)</sup>.

The present study found that the major of them (39%) aged between (10-11) years old for both sexes .This finding agree with the results of the study done by (Wahuni et al ,2011) a study which about ( Quality of life assessment of children with thalassemia at the north Sumatra in Indonesia ). It mentioned that the mean age in both sexes was 10.5 years and most commonly in boys (67.8%)<sup>(9)</sup>.

The current study found that more than three quarters of the studied sample were urban (74%) .This finding is consistent in line with the results of the (Gharaibeh et al , 2009) a study about ( The psychological burden of patients with beta thalassemia major in Syria ) which it revealed that most of them were from urban origin(72%)<sup>(10)</sup>.

The current study shown that the most commonly of them had school absenteeism (61%) .this finding agree with the results of the Qadir & Hussein ,(2012) a study which about (effectiveness of an educational health programme on mothers` knowledge and practices of thalassemic children receive desferal therapy in Howler thalassemia center\ Erbil city) which it revealed that the most (58%)of them have school absenteeism more than 2 days per week<sup>(10)</sup>.

## **Pare II: Discussion of the clinical Characteristics which Displayed among School-age Children with Thalassemia**

The present study shows that the age of the disease onset between the 7th month – 1st year of age was (41%) . this finding agree with the results of the study done by the Caocci et al. (2012) whose they studied (Health related quality of life in middle eastern children with beta thalassemia ). it stated that the median age (range) for disease when diagnosed was 8th months of life<sup>(10)</sup>.

In another study which done by the Datta et al. (2011) a study which about ( quality of life of school age thalassemic children at Zagazig city). It revealed that the majority of the children were diagnosed as thalassemia major by the first year of life. In the other hand , the finding of the current study contrasts the results of the (Ghazanfari et al ,2011) a study which it studied the (Quality of life assessment of children with thalassemia in the north Sumatra in Indonesia) where it revealed that more than half of the children diagnosed at  $\geq 2$  years of age. The present study showed that the number of blood transfusion per month was (81%) every 3 weeks (61%) and the majority of them are receiving iron- chelation therapy (67%) .This finding is in consistent with the result of the Ayoub et al.(2013) a study about ( quality of life among children with beta thalassemia major treated in western Saudi Arabia ) where It found that the frequency of blood transfusion of the children with thalassemia major every 3 weeks was (84.8%) and major of them on iron chelation (87%). The finding of the current study showed that the majority of the transfusions and iron chelation were routinely performed(81%) and (68%) respectively .This finding supported by the results of the Wahuni et al.(2011) whose studied the (Quality of life assessment of children with thalassemia in the north Sumatra in Indonesia) . It stated that the majority of transfusions (91%) were routinely transfusions while the iron chelation was 2 thirds (78%) of them. The present study found that majority of Hemoglobin (Hb) levels for latest records (52%)

are between 6g/dl – 9g/dl , while the majority of Iron levels for latest record (normal range 7-15 ng/ml)(Ferritin tests) are between 1300neq/dl – 5000neq/dl(55%) .This finding supported by the study of the Cocci et al.(2012) a study which about (health related quality of life in middle eastern children with beta thalassemia ).it mentioned that more than half of them had hemoglobin level (Hb)  $\geq 7$  g/dl and  $\leq 9$  g/dl , and 2 thirds approximately of them had ferritin test  $\geq 1300$  ng/ml . A serum ferritin level above 2500 ng/ml is associated with cardiovascular diseases and mortality (Borgna et al. 2004) this indicate the need for regular transfusions to maintain these values in acceptable results to improve their physical and psychological status .the present study showed that the majority (58%) of thalassemic children suffer from complications due to the disease and its treatment<sup>(11) (12) (13) 914)</sup>.

## **Part III: Discussion of the assessment of the daily living activities of school age children with thalassemia**

Study results reveals that all the domains of the activities of daily living ( clothing , transferring ,school activities , play and hobbies , personal hygiene ,eating and drinking ,sleeping and social communication) which distributed on three levels of the scales ( always ,sometimes and never) are affected moderately (total mean of score =1.79) toward the school age children with thalassemia. This finding supported by the results of the study done by Fan (2008) which studied the (self-care behaviors of school-age children with heart disease ) who found that the total levels of three subscales of self-care behaviors of school-age children with heart disease were in moderate level , the child during this age become more cognitive and responsible for self-care and thus , they achieve success and interest in and able to do it for their own health condition in moderate level of self-care behaviors. The thalassemic children although are physically affected ,they have normal intellectual development . thus ,the activities of their caring within age appropriate development are within normal and they can do it where thalassemia is considered as chronic illness and the thalassemic children must live their life with this disease familiarly in flexible treatment process .

Concerning the clothing activities , the findings of the present study shown that more than half percent of the scales of these domains are sometimes (as in children`s wearing clothes a lonely have sometimes (68%) , keeping and arranging clothes difficulty have sometimes (61%) effect , caring the general appearance have sometimes (70%) effect ) , while the rest have over half percent are never ( as in wearing clothes with help have never (55%) effect ,keeping and arranging clothes with help have never (54%) effect , and caring the general appearance with help have never (57%) . This agree with the results of the Van-Hoof et al.( 2009) as a quantitative study about (How do adolescents with chronic fatigue syndrome perceive their social environment). It found that the majority of the children have difficulties and need help in clothing and to care the general appearance due to their health conditions.

Regarding the transferring activities, the findings of the present study shown ; that the walking have 63% sometimes affect children , the running have (55%) sometimes affect , lifting the heavy things have (64%) sometimes effect , the ability to have the up-stair have 58% , going to school have (58%) affect ,fatigue and generalized weakness have (50%) affect , bodily

weakness have (47%) sometimes affect, perform the sport activities with help have (41%) sometimes effect. These findings agree with the results of the study by Caocci et al. (2012) which studied (health related quality of life in middle eastern children with beta thalassemia). They found that the majority of the thalassemic children had many problems related to all the items of physical activities domain such as walking, running, taking shower and lifting heavy things<sup>(11)(15)</sup>.

Concerning the school activities, all of the scales of this domain are sometimes more than half percent; the school absenteeism have (51%) sometimes effect's children, school homework have (53%) sometimes effect, attention during the lesson have (55%) sometimes effect, understanding the lesson have (46%) sometimes effect, going to school-picnic have (56%) sometimes effect, coping in the school life have (57%) effect, understanding the school subject have (38%) sometimes affect, low grade in school-examination have (48%) sometimes affect. This finding agree is in consistent with the results of the study done by Grossman et al (2011) which studied (Behavioral profile and school performance of thalassemic children in Eastern India). It mentioned that more than half (53%) of them not going to school, majority (70%) of them had felt that thalassemia had negative impact on their school performance, two thirds (38%) of them faced deprecatory from their peers and teachers. In another study done by the Shah et al (2015) they observed all of the school problems in all cases (100%) associated with school dropout due to frequent hospitalization<sup>(16)(17)(18)</sup>.

The findings of the playing and hobbies activities in the present study shows that all of the scales is more than half percent sometimes; playing of the children with others children have (59%) sometimes, playing in the sports or games with heavy energy have (56%) sometimes, playing with the favorite hobbies have (51%) sometimes, play only sister /brother have (55%) sometimes, finding other sports or games which doesn't heavy energy have (47%) sometimes. These findings agree with the results of the study done by Khurana et al (2006) a study about (psychological burden in thalassemia) which revealed that two thirds of the children were unable to play in outdoor with children in same level, majority of them complained of fatigue and bodily weakness due to their health conditions and remain dependent on their parents or siblings with few peers from the same age group<sup>(19)</sup>.

Regarding the personal hygiene activities, the finding of the present study shows; that in taking bath or shower have (65%) sometimes, the need for help to take showering or bathing have (53%) sometimes, hair dressing and drying have (64%) sometimes, hair dressing and drying with help have (55%) sometimes, hair styling have (69%) sometimes, the need for helping by others in hair styling have (54%) sometimes, using of the toilet have (81%) sometimes, using the toilet with help have (80%) sometimes, finger care have (55%) sometimes, finger care with help have (57%)\_sometimes, brushing of the teeth have (68%) sometimes, brushing of the teeth with help have (57%) sometimes,

Regarding the eating and drinking activities of the present study, all of the scales of this domain are never percent of the studied sample; this findings of the present study showed; that eating and drinking have (60%) never, the need for help for eating and drinking have (52%) never. These findings indicate

that the majority of them are able to do this without any aids or help by others because of these activities don't need energy or cause fatigue to them (Abdel-Rahim et al, 2005) whose they studied (Nursing care for tenth grade nursing students)<sup>(20)</sup>.

Concerning the sleeping activities, the finding of the present study shown that regular sleep pattern have (61%), difficulties in sleeping have (51%) sometimes, insomnia or wake up through sleeping have (52%) sometimes, using of the drugs for sleeping have (57%) never.

Regarding the social communication, the finding of the present study reveals that good relationships with my family only have (47%) sometimes, the isolation and still alone (47%), communications with others (49%), compassion with others (47%) never, participating the social Occasions (51%) sometimes and talking on self (54%) never and few friends (47%). This result agree with the results of the study done by Khurana et al (2006) a study about (psychological burden in thalassemia). It mentions that the majority of the thalassemic children had feelings of different and inferior with low of the self-esteem due to their physical abnormalities, lack of communication and withdrawal from their peers where they not like to discussing their illness and its related problems with peers because they did not trust them and felt that the disease had little impact on their families<sup>(19)</sup>.

#### **Part IV: Discussion of the association with the activities of daily living of school age children**

The finding of the present study shows that there is indicate to a significant relationship ( $P \leq 0.05$ ) between the activities of daily living of the school age children with thalassemia with their age. This finding is in consistent with the study done by Hamamy et al. (2013). It mentioned that the older school-age children had more increased in their abilities to independent to complete of their health care tasks such as filling prescription or recognize symptoms of illness.

The present study shown that there is indicates between the activities of daily living of the school age children who have thalassemia with their gender. This finding agree with the results of the study done by Ismail et al. (2002) which stated that girls had more control self-care behaviors than boys. Thus, more responsible and motivated to learn new skill earlier and more independent than boys at the same age (22).

The present study reveals that there is significant relationship between daily living activity and child's residence except sleeping activities which is significantly related with children who are resident in rural area at  $p \leq 0.05$  respectively. This finding agree with the results of study of the (Khairkar al., 2005) a study which about (rural and urban differences in access to and utilization of services among people in Alabama with hemoglobinopathies disorders). It mentioned that there are some differences in the activities of the urban children and rural children.<sup>(23)</sup>

#### **V. CONCLUSIONS**

The majority (39%) of the sample was the age group (10-11) and More than half of the children are male (54%). Also, two thirds 61% of them have school-absenteeism. Thalassemia appears in more than fourth (41%) of them with age of onset 7 –

12 months (41%) and The level of hemoglobin in more than half (52%) of them refers to 6 – 9 mg/dl .while, the ferritin level was  $\geq 1300$  ng/dl in (55%) of them. There is moderate level (1.79) towards the activities of daily living of the thalassemic school age children. there are moderate relationship between the activities of daily living of the thalassemic school age children with their socio-demographic characteristics except (age and gender) are in low level (Mean of Score (MS) = Low Less than (1.66), Moderate = (1.66-2.33), High= More than (2.33).

## VI. RECOMMENDATIONS

1. Provide highlighting the information about thalassemia and any inherited diseases (may by mass media or genetic counseling ) to explain the consanguineous marriages and their disadvantages especially in the families with high risk.
2. Provide a detailed scientific information about the disease in an appropriate illustration way for the children.
3. Provide the link unit in the thalassemia centers present between the patient ,school , the families and the physicians to help the children and their families ( especially from low socio-economic glasses or in major life events e.g. death of the parents that cause many psychological problems or stressors).
4. Provide further researches are needed to investigate the affecting of the disease on daily living activities with manage it in different ages.

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