IOSR Journal of Nursing and Health Science (IOSR-JNHS)
e-ISSN: 2320–1959.p- ISSN: 2320–1940 Volume 4, Issue 5 Ver. II (Sep. - Oct. 2015), PP 75-82
www.iosrjournals.org

Self-Efficacy among Thalassemic Adults Patients at Hereditary Anemia's Centers in Baghdad

Mohammed Abdul Zahra Hussein, Assist Prof. Dr. Khalida Alwan Mansour
[1,2]*University of Baghdad / College of Nursing*

Abstract:
Background: *Thalassemia is an autosomal recessive congenital disease originating from the countries of the Mediterranean region. Deficiencies in globin chain synthesis may lead to severe anemia requiring regular blood transfusions and iron chelating therapy starting at an early age*
Objective: *A descriptive analytic study design was carried out to assess Self-Efficacy among Thalassemic Adult Patients in Baghdad City- Iraq.*
Methodology: *A descriptive design study was carried out in Hereditary Anemia's Centers. The study was started from February 10th, 2014 to August 3rd, 2015. Non-probability (purposive) sample of (100) Thalassemic Adult Patients) was selected from the Hereditary Anemia's Centers in Baghdad city. The study instrument was composed of three parts, Socio demographic characteristic, clinical characteristic and chronic disease self-efficacy scales (CDSES). Data were analyzed through the application of descriptive and the inferential data analysis approach by using SPSS version 20*
The results: *Self-Efficacy in adult thalassemia patients was very low self- efficacy in the exercise and manages symptom domains, lower self-efficacy was in managing disease, do Chores, social / recreational activities, and control/Manage depression domains.*
The finding revealed that there are a statistical significant with level of education, economic status and type of chelation therapy, and a high statistical significant between self-efficacy with effect of disease on education.
Conclusion*: Self-Efficacy in adult thalassemia patients was ranging between very low and moderate level.*
Recommendation*: Continuous programs of health education of patients about early detection any abnormal clinical manifestation and how to be managed*

I. Introduction

Thalassemia is the most prevalent genetic disorders worldwide. It is hereditary hemolytic anemia resulting from malformation in hemoglobin production [(1)]. Beta Thalassemia (β -TM) is the most prevalent autosomal hereditary disease [(2 ،3)]. Forms of thalassemia belong to a group of genetic diseases named hemoglobinopathies that compromise the normal make of chains of alpha and betaglobins, which form hemoglobin. Thalassaemia is classified according to which hemolytic chain of the hemoglobin molecule is influenced. In α- thalassemias, prevalent of α globin chain are affected, while in β- tha-lassaemia prevalent of the β globin chain is affected [(4)]. Thalassemia major, as well known as Cooley's anemia and Mediterranean anemia, is the most complicated form of Beta-thalassemia, since both mutations of both Beta-globin alleles results in severely impaired Beta-globin chain production [(5)]. Patients with Beta-thalassemia intermedia have Slight to moderate anemia and in most conditions do not require blood transfusions [(6)]. The disease results in a severe anemia that prevents to survive, and in peculiar bone modification which can be detected in the osteological specimens coming from archaeological sites. Anyway, a confirmed diagnosis cannot be made just by a macroscopic examination of the material, but there is a need of elegant techniques, that let to discriminate between the modulations that are unspecific and those that are typical of thalassemia [(7)]. The happen of thalassemia in Latin America, southeast of Brazil and the Caribbean is heterogeneous, about 1% to 2% of the population. It was introduced by Portuguese, Spanish and Italian immigrants. The spread of thalassemia major (TM), which is the most severe clinical form, [(8)]. The feel self-efficacy reflects the person's belief in his/her own skills to tactic and perform confirmed activities to achieve specific goals [(9)]. Self-efficacy is the belief in one's capacity to execute a route of action for a required function pertaining to day to day symptom and disease management [(10)]. Patients with maximum self-efficacy levels are more probable to start or maintain a specific function even in the face of existing barriers. Several self-management programs swimmingly targeted self-efficacy resulting in promotion health outcomes [(11).]

Objectives of the study:

1. To assess the self-efficacy of adult thalassemic patients.
2. To identify the relationship between self-efficacy with demographic characteristic of adult thalassemic patients.
3. To identify the relationship between self-efficacy and clinical characteristic for adult thalassemic patients.

II. Methodology

A descriptive analytic study design was carried out to assess self-efficacy among Thalassemic Adult Patients at Hereditary Anemia's Centers in Baghdad City. The study was started from February 10th, 2014 to August 3rd, 2015. Non - probability (purposive) sample of (100) Thalassemic Adult Patients who were attending the hospital / Hereditary Anemia's Centers for clinical examination and blood transfusion.

The study instrument was composed of three parts which: Part 1. Socio-demographic information was included; age, gender, marital status, level of education, occupational, economic. Part 2. Clinical characteristics which including age at diagnosis, the times of blood transfusion, age at blood transfusion, Hemoglobin concentration, Ferritin concentration, S. bilirobin, Age at splenectomy. Part 3. The patient self-efficacy measured by Chronic Disease Self-Efficacy Scales (CDSES) [(12)], were adopted by the researcher with some modification for assessing self-efficacy of the thalassemic adult patients. It contains (10) Domains: The researcher using (8) domains according to the objective of the study.(Routine exercise, get help from family and friends, communicate with physician, manage disease, do chores, social/recreational activities, manage symptoms, control/manage depression) The self-efficacy scales were rated and scored by assigning each thalassemic adult patients response an ordinal value, five level types option scale as (strongly disagree, (1), disagree (2), uncertain (3), agree (4) strongly agree (5)).The highest score of self-efficacy Scales obtained, the high self-efficacy of adult thalassemic patient.

The validity of the questionnaire was determined through a panel of (16) experts. The reliability of the present study instrument was determined through Test-Retest. The result of reliability coefficients for the patients self-efficacy was (r=89). Data were collected through the use of questionnaire format designed and interview techniques. Data were analyzed through the application of descriptive and the inferential data analysis approach by using SPSS version 20.

III. Results

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

Table (1) Distribution of thalassaemic patients, according to demographic characteristics (n= 100)

Demographic Variables			F	%
1	**Age**	18-22	45	45.0
		23-27	33	33.0
		28-32	14	14.0
		33-37	5	5.0
		38-44	2	2.0
		45-above	1	1.0
		Mean ± SD 24.49±5.26		
3	**Sex**	Male	52	52.0
		Female	48	48.0
4	**Marital state**	Single	91	91.0
		Married	9	9.0
5	**Education**	Illiterate	14	14.0
		Read and write	13	13.0
		Primarily graduate	27	27.0
		Medium graduate	18	18.0
		Secondary graduate	11	11.0
		Institute graduate	3	3.0
		College graduate	14	14.0
6	**Occupation**	Student	16	16.0
		Employees	7	7.0
		Retired	1	1.0
		Freelancers	24	24.0
		Housewife	36	36.0
		Unemployed	16	16.0
7	**Economic**	Low income	2	2.0
		Median income	74	74.0
		Good income	24	24.0

F = Frequency, % = Percentage, SD = Standard deviation.

The demographic characteristic of 100 thalassemic adult patient indicated that the majority of them (45%) were 18-22 years old, (52%) were male, most of them (91%) were single, (16%) were students, (27%) of those student primary graduate and only (14%) were College graduate, (36%) were housewife, and (74%) were the medium level of economic status .

Table (2) Distribution of adult thalassaemic patients according to clinical characteristic.

	Clinical characteristic		F	%
1	**Times of blood transfusion**	1-2 times monthly	78	78.0
		More than a month	22	22.0
2	**Age at blood transfusion.**	> 1-3 years	100	100
3	**Hemoglobin test**	< 9.5 g/dl	95	95.0
	Minimum Hb3.6	9.5-10.5 g/dl	5	5.0
	Maximum Hb10.0	**Mean ± SD 7.707 ± 1.2884**		
4	**S. Ferritin.**	< 1000 µ g/l	11	11.0
	Minimum 200	1000-2500 µ g/l	31	31.0
	Maximum 14000	> 2500 µ g/l	58	58.0
		Mean ± SD 3505.10 ± 2647.1		
5	**S .bilirubin**	< 5 µmol/L	1	1.0
	Minimum 2.6	5-17 µmol/L	8	8.0
	Maximum 165.9	> 17 µmol/L	91	91.0
		Mean ± SD 48.012 ± 30.2547		
6	**Splenectomy**	Yes	34	34.0
		No	66	66.0
7	**Age at splenectomy**	6 months-1 year	1	2.9
		2 years-5 years	3	8.8
		6 years-12 years	10	29.4
		13 years-and above	20	58.8
8	**Chelation Therapy**	DFO	49	51.0
		DFX	51	49.0

F = Frequency, % = Percentage, β = Beta, DFO = Deferoxamin, DFX =Deferasirox.

The clinical characteristic of 100 thalassemia adult patient, (78%) was taken blood transfusion 1-2 times monthly, most of them (95%) the hemoglobin test less than 9.5 g/dl. Concerning the level of S.ferritin , (58%) of those patients was more than 2500 µ g/l, (91%) were S.bilirobin test more than 17 µmol/L, (34%) of those patients have Splenectomy (51%) take DFX drug.

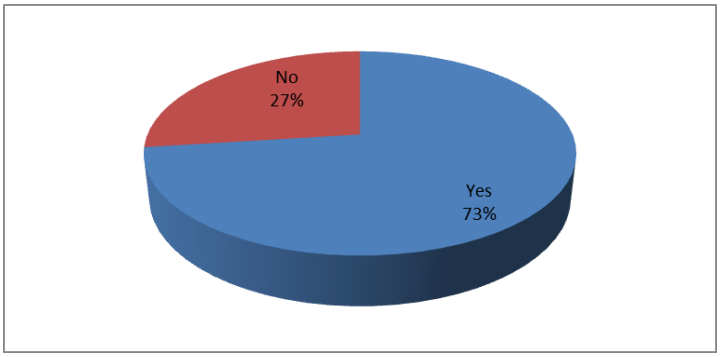

Figure 1. Effect of the disease on continuing study

The findings revealed that the majority (73%) of the sample were the disease effect on the continuing study. The result shows that there are highly significant differences between Adverse effect of disease on continuing education (P=<0.001).

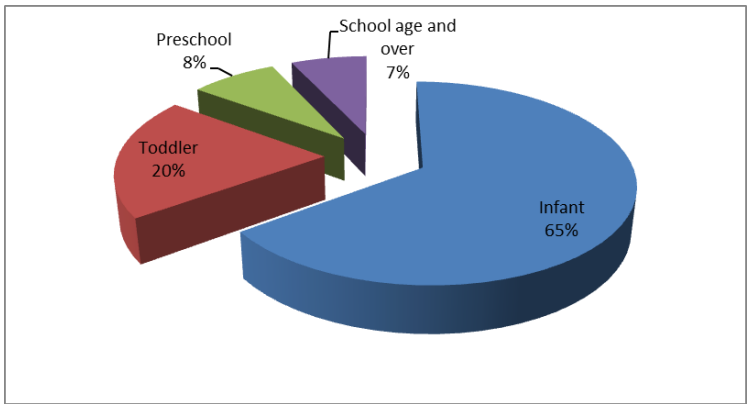

Figure (3) Age at Diagnosis

The result shows that the (65%) of the sample were infant at the age of diagnosis of thalassemia.

Table (3) means of scores and relative sufficiency of Self-Efficacy Scale for Thalassemia patients (adults).

DOMAIN OF SELF-EFFICACY SCALS		Routine exercise	Get Help from family and friends	Communicate With Physician	Manage Disease	Do Chores	Social/Recreational Activities	Manage the Symptoms	Control/Manage Depression
TOTAL	M.S	2.72	3.7	3.84	3.27	3.11	3.33	2.92	3.05
	R.S	54.5	74	76.8	65.4	62.2	66.6	58.4	61
	Score Level (Grade)	Very low	Moderate	Moderate	Low	Low	Low	Very low	Low

M.S = mean of the score, R.S = relative sufficiency, very low of self-efficacy = less than 60, Low = 60-68, moderate 69-.76.9-, high = 77-84, very high from 85 and more.

The results of this table revealed that the grade level of self-efficacy for 100 thalassemic adult patients was very low, low and moderate. The very low self- efficacy was in exercise and manages symptom domains, lower self- efficacy was in managing disease, do Chores, social / recreational activities, and control/Manage depression, while moderate self-efficacy was in getting help from family and friends, communicate with physician domains**.**

Table (4) Association of Self-Efficacy with type of chelation therapy for the thalassaemic patients (adult)

Self-Efficacy domains	DFO n = 49 (Mean ± SD)	DFX n = 51 (Mean ± SD)	t- test	Sig.
Routine exercise	10.7±3.5	11.0±3.1	-.480	.632
Get Help from family and friends	14.7±2.6	14.9±2.4	-.411	.682
Communicate With Physician	7.4±1.4	7.9±1.2	-1.382	.170
Manage Disease	16.2±3.0	16.4±4.0	-.259	.796
Do Chores	8.3±2.2	10.2±2.6	-3.774	.000
Social/Recreational Activities	6.4±2.0	6.8±2.2	-.781	.436
Manage the Symptoms	5.4±1.6	6.2±1.6	-2.639	.010
Control Manage Depression	8.6±2.8	9.6± 2.5	-1.857	.066
Total	81.8±9.8	78.9±8.7	-2,322	0.02

n= number of samples, DFO = dereroxamine drug, DFX = deferasiroxe drug, SD = standard deviation, sig = significant.

This table indicates that no statistical differences are between the DFO and the DFX and self-efficacy in routine exercise, get help from family and friends, communicate with physician, manage disease, social recreation and activities, and control manages depression. While there is a high statistical difference in do chores ($p< 0.000$), and manage symptoms ($p< 0.02$). Of the total of the patients' self-efficacy, a statistical difference was noted among the two groups, the DFO and the DFX ($p< 0.02$)

Table (5) Association of Self-Efficacy with demographic characteristic of thalassemia patients (Adults)

Variable	Test	P ≤ 0.05
Age	**F =.646**	**.665**
Sex	**t = -.888-**	**.377**
Marital status	**t = .331**	**.741**
Level of Education	**F = 7.089**	**.000**
Occupation status	**F = 2.811**	**.021**
Level of Economic	**F = 5.514**	**.005**

F = One way ANOVA, t = Independent T test.

The result of this table revealed that there are highly statistically significant differences between the self-efficacy and level of education p. Value = 0.00, and a statistical significant difference with the occupation status p value = 0.021 = and levels of economic p value = 0.005 while there are no statistically significant differences of self-efficacy with the age, sex, marital status and occupational status.

Table (6) Association of Self-Efficacy with Clinical Characteristic of Thalassemic Patients (Adults)

Variable	Test	P value
Age at Diagnosis	**F =0.073**	**.974**
Effect of the disease on their study	**t = -5.365**	**.000**
Age at blood transfusion	**t =0.169**	**.866**
Hemoglobin test	**t =0.193**	**.848**
Ferritin test	**F =0.394**	**.675**
S.bilirobin test	**F =0.396**	**.674**
Splenectomy	**t =0.595**	**.553**
Age at Splenectomy	**F =0.269**	**.897**
Chelation Therapy	**t = -2,322**	**.02**

F = One way ANOVA, t = Independent T test.

The finding revealed that a highly statistical significant between self-efficacy and the effect of disease on education p value =0.000, and a statistical significant difference with the type of chelation therapy at P value =0.02. Other clinical characteristic has no statistical significant differences relative to patient self-efficacy.

IV. Discussion

Demographic and clinical characteristics of Thalassemic patients.

Through the course of the data analysis of the present study show that the majority (78%) of thalassemic adult patients age is the range between 18-27 years old Most of the sample (52%) was male, (91 %) were single (table 1) these results agreed with study found that (46.9%) of thalassemia major patients, the age range between (20-30) years old and the marital state was (92.2%) were single [(13)]. Fifty four percent of the present sample is primarily graduate illiterate) and read and write (table 1) this finding disagreed with the study found that (69.3%) of patients with beta-thalassemia major, the educational level were high School (22.8%). Bachelor of Science (13.9 %,), master of science (26.7%), and doctorate (5.9%). And they indicate that the adult thalassemia patients who were regularly transfused were more likely to have attained higher education [(14)]. Seventy four percent of the present study are moderate level income (table 1) These results agreed with the evidence is available in the study that found (44.6%) patients with beta-thalassemia major, evident moderate level of economic [(14).]

The present study revealed that (78%) of the patient takes blood transfusion one time per month, ninety-five percent of adult thalassemia patients suffering from severe anemia with hemoglobin level were (< 9.5 g/dl) (table 2) these results agree with another study that found the interval between blood transfusions were (18-30) day [(15)]. and the mean of the hemoglobin level was to be low in patients of β thalassemia (5.4 gm/dl) [(16)]. For beta thalassemia major should need a regular blood transfusion program that keeps the minimum hemoglobin concentration from 9.5 up to 10.5 g / dl [(17)]. As a result of frequent blood transfusion of adult thalassemic patients, (85%) of patients have high levels (>2500 µg/l) of ferritin and the mean ±SD was (3505.10 ± 2647.1) Ninety-one percent of the patients have high (>17µmol/L) of S. bilirubin level More than half percent of the patients, the splenectomy were done at age of thirteen years and above (table 2) these result earliest to study found that the mean of serum ferritin level were (1266.5 ng/ml), and the total means of serum bilirubin was to be high among β Thalassemia patients (3.4mg/dl) [(16] The splenectomy were at age (11 to 15) years old and also they indicated that the main reasons for splenectomy were, increasing demand for blood transfusion, Thrombocytopenia and frequent left upper quadrant pain due to splenomegaly [(18)].

Seventy-three of the percent study, the transfusion and chelation therapy appear to be obstacles to achieve of education and it was long associated with education. The main reason for not completing their

education was the deteriorating health situation (Figure 1) this result is not consistent with studies that indicated (60%) of adults with thalassemia had a college degree and 14% of thalassemic patient had achieved some post college education [(19)]. Majority of sample (65%) were Infant during diagnosis (Figure 2) this result agreed to study that reported that the β Thalassemia was diagnosed (68%) at infancy[(20)].

Discussion of the Self-Efficacy for patient with β Thalassemia

The results of the our study showed that the self-efficacy was very low related to routine exercise domain, this may be reflected in a large proportion of patients had hemoglobin less than 9.5 g/dl. Anemia has an important role in exercise performance [(21)]. Other domains of self-efficacy that the thalassemic patients' response very low self-efficacy was managing symptoms domain, patients can't reduce the physical pain or comfort and control any symptoms or health problems they had. This result agrees with study reported that the participants manage their symptoms were more likely to call their doctor or nurse for guidance [(22)]. Also the domains of the our study rated low self-efficacy was manage disease, do chores and social/recreational activity domains. On the other hand the domain that rated moderate grade was get help from family and friends and communicate with physician that the patient had confidence and satisfaction of family, friend and communication with doctors (table 3) These results are earliest to study indicate that the social support and cognitive restructuring was used by majority (98%) of children with thalassemia major [(23)], and the social function values were considerably lower in adult young thalassemic patients [(26)]. The finding disagrees with study found that the proportion of patients who perceived communication difficulties with their physicians (ie, their cardiologists or surgeons) ' and, the physical activities and energy of the adolescent patients affected by the disease [(24)] [(25)].. According to the present study, seventy present of adult thalassemic patient has depression, Previous studies reported that the patient's major depressive disorder and anxiety in patients with major beta-thalassemia is more than the healthy patients [(27, 28)].

The present results indicated that there are no statistical significant differences between the Deferoxamine (DFO) and the Deferasirox (DFX) at ($p< 0.05$) and self-efficacy in routine exercise, get help from family and friends, communicate with physician, manage disease, social recreation and activities, and control manages Depression while there are high statistical differences in do chores, and manage symptoms. This result disagrees with the result obtained from a study which found the effect of iron chelating therapy on the ability of the beta-thalassemia patients to perform their daily tasks, and they indicated a statistically significant difference was noted among the three groups ($p = 0.006$). Patients receiving DFO were more limited [(34)].

Association of Self-Efficacy with demographic characteristic of patients.

The outcome of present study displays a statically significant difference between self-efficacy and some aspect of demographic characteristic such as high significant with educational status and significant with occupational status and level of income ($p = \leq 0.001$)& ($p \leq 0.05$). Educated patients, employed patients and high level of income associate with high self-efficacy. Another aspect of demographic characteristics revealed no statically significant differences with self-efficacy, such as age, sex, and marital status (table 5) The earliest study which indicated that the patients with higher incomes had significantly higher scores for physical health, mental health and total scores, in comparison with the patients with lower incomes ($P < 0.001$) [(14)]. And another study reported there are no significant differences in health related quality of life with regard to gender [(29)].

Association of Self-Efficacy with clinical characteristic of patients.

The analysis of present data display a statically significant differences between self-efficacy and some aspect of clinical characteristic such as, high significant with effect of disease on educational status and significant with type of chelating therapy, other aspect of clinical characteristics revealed no statically significant differences with self-efficacy such as age at diagnosis, age at blood transfusion, hemoglobin test, Ferritin test, S.bilirobin test, age at splenectomy and type of β. Thalassemia (table 6) This finding disagrees with study which reported a significant Correlation of childhood psychopathology with age at diagnosis of β-thalassaemic children, their mean IQ, QOL [(23)]. These results are consistent with studies which highlight the education status of the patients showing that (39.4%) they "never went to school", and an equal number responding that they left the school during the primary education) [(31)]. The level of hemoglobin has an effect on quality of life in patients with thalassemia [(32)], the quality of life has no significant association with the ferritin level test, age at diagnosis and age at first transfusion and no statistically significant relationships between the scores and splenectomy [(14, 33))]. The presence of comorbidities, poor compliance with iron-chelating therapy and lower income were inversely correlated with the score for the physical health dimension (β-coefficients = -0.197, -0.285 and -0.332; and $P = 0.027$, 0.002 and < 0.001, respectively) [(14)].

V. Conclusion

The majority (91%) of thalassemic patient were single, they did not complete the educational level because the deteriorating health situation, the majority of patients age is the range between 18-27 years old**.** The Hemoglobin test was < 9.5 g/dl, (58%) of sample the ferritin level was > 2500 µ g/l, treatment by the Chelation Therapy (49%) DFO, (51%) DFX, the most patients were major thalassemia

Self-Efficacy in adult thalassemic patients was ranging between very low, low and moderate level. Present statistical significant between self-efficacy and some aspects of characteristic such as level of education, economic status, occupation, effect disease on educational level and type of iron chelating therapy. A high statistical differences are between the DFO and the DFX ($p< 0.05$) and self-efficacy, patients who treated with DFX demonstrated higher levels of self-efficacy than the patient who treated with DFO in related to do chores, and manage symptoms.

VI. Recommendation

- Continuous programs of health education of patients about early detection any abnormal clinical manifestation and how to be managed
- A setting of nursing educator should be established in thalassemia wards, to provide training and education for thalasemic patients.

References

[1]. Rund D, Rachmilewitz E: Beta-thalassemia, New Eng. J. Med, 353 (11); 2005: 1135-46.
[2]. Karimi M, Bagheri MH, Tahmtan M, Shakibafard A, Rashid M: Prevalence of hepatosplenomegaly in beta thalassemia minor subjects in Iran, Eur J Radiol, 69(1); 2009: 120-2.
[3]. Derakhshandeh-Peykar P, Akhavan-Niaki H, Tamaddoni A, Ghawidel-Parsa S, Naieni KH, Rahmani M, et al: Distribution of beta-thalassemia mutations in the northern provinces of Iran. Hemoglobin, 31(3); 2007: 351-6.
[4]. Goljan E. Pathology, 2nd ed. Mosby Elsevier, Rapid Review Series 2009. Available from: www.ask.com. [Accessed on 1/4/2010].
[5]. Wood J, Origa R, Agus A, Matta G, Coates T, Galanello R: Onset of cardiac iron loading in pediatric patients with thalassemia major, Haematologica, (93); 2008: 917–920.
[6]. Taher A, Isma'eel H, Cappellini MD: Thalassemia intermedia: revisited, Blood cells, Molecules and Diseases, 37(1); 2006: 12-20.
[7]. Schulz M: Light Microscopic Analysis in Skeletal Paleopathology: a new approach to the study of ancient diseases", in Ortner D.J. 2003, "Identification of Pathological conditions in Human Skeletal Remains", Academic Press
[8]. Zago MA, Talassemias. In: Zago MA, Falcão RP, Pasquini R: editores. Hematologia: fundamentos e prática. 2ª.ed. São Paulo: Atheneu; 2005. p. 309-28.
[9]. Tabassum U, Rehman G: The relationship between self-efficacy and depression in physically handicapped children, Journal of Pakistan Psychiatry Society, 2(1); 2005: 37.
[10]. Adegbola M: The relationship among spirituality, self-efficacy, and quality of life in adults with sickle cell disease, Doctoral Dissertation, The University of Texas at Arlington; 2007 ProQuest Digital Dissertation, AAT 3289109
[11]. Lorig K, Sobel D, Ritter P, Laurent D, Hobbs M: Effect of a self-management program for patients with chronic disease, Effective Clinical Practice, (4); 2001: 256–262
[12]. Lorig K, Stewart A, Ritter P, González V, Laurent D, Lynch J: Outcome Measures for Health Education and other Health Care Interventions. Thousand Oaks CA: Sage Publications, 1996, pp.24-25,41-45.
[13]. Khamoushi F, Ahmadi S M, Karami-Matin B, Ahmadi-Jouybari T, Mirzaei-Alavijeh M, et al: Prevalence and Socio-Demographic Characteristics Related to Stress, Anxiety, and Depression among Patients with Major Thalassemia in the Kermanshah County, J Boil Today's World, Mar; 4 (3), 2015 :79-84.
[14]. Haghpanah S, Nasirabadi S, Ghaffarpasand F, et al: Quality of life among Iranian patients with beta-thalassemia major using the SF-36 questionnaire, Sao Paulo Med J, 131(3), 2013:166-72.
[15]. Shamsian B, Arzanian M, Shamshiri A, Alavi S, Khojasteh O: Frequency of Red Cell Alloimmunization in Patients with β-Major Thalassemia in an Iranian Referral Hospital, Iran J pediatr, Jun; Vol 18(2), 2008; 149-153.
[16]. Chattopadhyay K, Biswas, R, Bhattacherjee S, Bandyopadhyay, R: An epidemiological study on the clenico-hematological profile of patients with congenital hemolytic anemia in a tertiary care hospital of Kolkata, Indian J. Prev. Soc. Med. Vol. 43 No.4, 2012.
[17]. Thalassemia International Federation: Guidelines for the clinical management of thalassemia 2nd edition. 2008. [http:// www.thalassemia.org.cy.
[18]. Karimi M, Emadmarvasti V, acob Hoseini J, and Shoja L,: Major Causes of Hospital Admission in Beta Thalassemia Major Patients in Southern Iran. Iran J Pediatr, Vol 21 (No 4), Dec 2011:509-513
[19]. Pakbaz Z, Treadwell M, Kim HY, Trachtenberg F, Parmar N, et al,: Education and Employment Status of Children and Adults with Thalassemia in North America, Pediatr Blood Cancer, 55(4) 2010 October :678–683.
[20]. Sattari M, Sheykhi D, Nikanfar A, et al: The Adverse Effects of Thalassemia Treatments Including Blood Transfusion and Main Pharmacological Therapies. Pharmaceutical sciences, January; 18(4), 2013: 199-204
[21]. Benedetto D, Rao CM, Cefalù C, Aguglia DO, Cattadori G, D'Ascola DG, et al: Effects of Blood Transfusion on Exercise Capacity in Thalassemia Major Patients. PLoS ONE 10(5): 2015, 1-8 piergiuseppe.agostoni@unimi.it
[22]. Jody A, Britz D, Karen S, Dunn P: Self-care and quality of life among patients with heart failure, Journal of the American Academy of Nurse Practitioners, (22) 2009: 480–487.
[23]. Khairkar P, Malhotra S, Marwaha R: Growing up with the families of β-thalassaemia major using an accelerated longitudinal design, Indian J Med Res, October; 132, 2010: pp 428-437.
[24]. Quan H, Galbraith P, Norris C, et al: Opinions on chelation therapy in patients undergoing coronary angiography: Cross-sectional survey, Can J Cardiol, Jun; 23(8), 2007: 635–640.
[25]. Cheuk D, Lee A, Chiang A, Lau Y, Chan G: Quality of life in patients with transfusion-dependent thalassemia after hematopoietic SCT, University of Hong Kong, Published online 16 June; 2008: 321-324.
[26]. Messina G, Colombo E, Cassinerio E, Ferri F, Curti R, Altamura C, Cappllini M: Psychosocial aspects and psychiatric disorders in young adult with thalassemia major. Intern Emerg Med, Dec; 3(4), 2008: 339-43.

[27]. Hashemi A, Banaei-Boroujeni Sh, Kokab N: Prevalence of Major Depressive and Anxiety Disorders in Hemophilic and Major Beta Thalassemic Patients. Iranian Journal of Pediatric Hematology Oncology, January; Vol2. No1, 2012: 11-16.
[28]. Pur movahed Z, Dehghani Kh, Yasini-ardakani S M. Evaluation of Hopelessness and Anxiety in Young Patients with Thalassemia Major. Journal of Medical Research, 2003; 1:45-52.
[29]. Stahl E, Lindberg A, Jansson S: Health-related quality of life is related to COPD disease severity. Health and Quality of life Outcomes. vol 3, 2005: P 56.
[30]. Day S, Chismark E. The Cognitive and Academic Impact of Sickle cell disease. The Journal of School Nursing. December, 2006; 22(6): 330-335.
[31]. Riaz H, Riaz T, Khan M, et al: Serum ferritin levels, socio-demographic factors and desferrioxamine therapy in multi-transfused thalassemia major patients at a government tertiary care hospital of Karachi, Pakistan, licensee BioMed Central Ltd, 4:287, 2011: 1-5
[32]. Thavorncharoensap M ,Torcharus K, Nuchprayoon I, Riewpaiboon A, Indaratna K: Factors affecting health-related quality of life in Thai children with thalassemia. BMC Blood Disorders, Vol; 10:1, 2010. http://www.biomedcentral.com/1471-2326/10/1
[33]. Caocci G, Efficace F, Ciotti F, et al: Health related quality of life in Middle Eastern children with beta-thalassemia. BMC Blood Disorders, Vol; 12:6, 2012. http://www.biomedcentral.com/1471-2326/12/6.a
[34]. Goulas V, Kourakli-Symeonidis A, Camoutsis C: Comparative Effects of Three Iron Chelation Therapies on the Quality of Life of Greek Patients with Homozygous Transfusion-Dependent Beta-Thalassemia. ISRN Hematology, Vol; 2012: Article ID 139862, http://dx.doi.org/10.5402/2012/139862.