# **Original Article**

# Evaluation of Mental Health and Related Factors among Patients with Beta-thalassemia Major in South East of Iran

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**Objective:** Beta-thalassemia major (β-TM) is a c hronic, genetic and hematological disorder. Children and teenagers with chronic physical illnesses exemplified by thalassemia are vulnerable to emotional and behavioral problems. The aim of this study was to evaluate mental health and its related factors among young patients with beta-thalassemia major. **Methods:** In this cross-sectional observational descriptive-analytic study, we studied 164 patients suffering from Beta-thalassemia major with age range of 15-24 years who referred for treatment to Ali Ebn-e Abitaleb (AS) University Hospital in Zahedan, a city in South East of Iran, during 2009-2010. The demographic data and pattern of mental health were collected by standard general health questionnaire (GHQ-28).Data was analyzed using statistical software SPSS (version 17.0); Student t test and Chisquare ( $\chi$ 2) were used.

**Results:** In this study, 96 (58.5%) patients were male; the mean age of all patients was 18.78 ±2.28. Based on data analysis, 83 patients (50.8%) suspected to have psychiatric disorders (58.8% of girls, 44.8% of boys). In addition, frequency of somatic symptoms, depression disorder, anxiety disorder and social dysfunction in all patients were 7.3%, 11.6%, 8.5% and 4.3% respectively. In illiterate patients, 70.4% suspected to have psychiatric disorder. Except for somatic disorder, other mental disorders were more frequent in girls. No significant association was found between mental state and gender, marital and literacy status and occupation.

**Conclusion :** In this study, due to high prevalence of psychological disorders in young patients with Beta-thalassemia major, especially in girls, we suggest implementing further educational psychological programs to decrease the frequency of disorders. Moreover, conducting more quantitative and comprehensive researches is suggested to evaluate specific effective factors in psycho-social health.

Keywords: Beta-thalassemia, Iran, Mental health

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 ${f B}$ eta-thalassemia major disease (eta-TM) is a chronic and genetic disease characterized by hematologic abnormalities (1,2). Patients suffering from this disease are characterized by clinical manifestation of a severe chronic anemia, failure of growth, splenomegaly, bones disorders (specially head and face bones abnormality) (3). World Health Organization (WHO) introduced thalassemia as the most common chronic and genetic disorder in 60 countries, affecting lives of about 10,000 persons annually (4). Also, in Iran the most common genetic disease is thalassemia; as prevalence of β-thalassemia major disease was estimated to be about 22000 patients (4). The number of people with this disease in Sistan-

Balouchistan province in South East of Iran was estimated to be 1167 patients in 2001 (4).

According to other studies, 14 to 24 percent of patients with thalassemia major suffered from psychiatric disorders (3). Even in some studies, up to 80 percent of young patients with beta thalassemia major had serious psychiatric disorders (1, 2); to name a few it can be referred to somatization disorders (SOM), depression especially major depression disorder (MDD), obsessive-compulsive disorder (OCT), tic disorders, oppositional defiant disorders (ODD), psychosis, nocturnal enuresis nocturnal (2,3,5).In addition, somatic complaints, and interpersonal sensitivity are common psychological disorders in these patients (3).

Epidemiological surveys of mental disorders reported varying rates of 11.9% to 32.9% in Iran (6,7).

The difference in personal demographic-characteristics including gender, literacy status, duration of disease and its chronicity, past history of hospitalization due to severe complication of disease, expectance for precocious death due to disease complications, morbidity proceeded from disease, duration of treatment and intense remedies, early treatment, and increasing cost of treatment are among important factors associated with level of general (psycho-social) health, self-care behaviors and life expectancy in young patients with beta-thalassemia (4,8,9).

The patients' underlying condition (such as low serum ferritin), type of treatment (such as Desferrioxamine mesylate or DFO), and its complications have been introduced as affecting factors in general health disorders and psychological disorders in patients with beta thalassemia Major (10).

In addition, it has been shown that social supports from first degree relatives, and from peers, favorable family situation and awareness of own disease have a principal relationship with general health of these patients (10,11).

Based on the mentioned points and significant prevalence of psychiatric disorders in patients with beta-thalassemia major disease, and because a few studies have been done on this subject, the aim of this study was to evaluate the psychological (mental) health and its related factors among 15-24 year old patients with beta-thalassemia major in Sistan-Balouchistan province in South East of Iran during 2009-2010.

### **Materials and Method**

In this cross-sectional observational descriptiveanalytic study, 164 patients with age range of 15 to 24 years suffering from beta thalassemia major disease who were admitted (for therapeutic-supportive interventions) in pediatrics hematology ward of Ali Ebn-e Abitaleb (AS) University hospital in Zahedan (Sistan-Balouchistan province, South East of Iran) were studied during November 2009 to March 2010. Subjects were selected using simple random sampling, and data were collected during 4 months.

After description some information to the subjects about this mental disorder before conducting the interview, demographic information of patients including age, sex, educational level, occupation, parental living situation, marital status, number of children in the family, time elapsed since diagnosis, history of physical activity and smoking and drug abuse were registered in information forms.

To survey the mental health of the patients, standard questionnaire GHQ-28 (28-item General Health Questionnaire) was used (according to WHO version and its Persian translation, which is comprehensible to almost every Iranian). In various studies conducted in Iran (7,11,12), and in an independent study in Tehran/Iran (Noorbala et al. 1999) the sensitivity,

specificity and reliability coefficient of this questionnaire was reported 83-88%, 69-93.8% and 88-93% respectively (7,12).GHQ questionnaire in 1979 by Goldberg and Hillary was developed for screening psychiatric disorders , particularly for screening somatic symptoms, anxiety and insomnia, social dysfunction and severe depression (7,12).

The standard questionnaire (GHQ-28) had four subscales, each of which containing seven items and they are as follows:

- A Somatic symptoms (items 1-7)
- B Anxiety/insomnia (items 8-14)
- C Social dysfunction (items 15-21)
- D Severe depression (items 22-28)

In this questionnaire, all items have a 4 point scoring system that ranges from a 'better/healthier than normal' option, through a 'same as usual' and a 'worse/more than usual' to a 'much worse/more than usual' option. The exact wording will depend upon the particular nature of the item. In all options, low degree indicates well-being and a high degree is indicant of lack health or feeling of discomfort.

After collecting data, the questionnaires were coded. Simple Likert scoring is the best method for scoring (0-1-2-3), and maximum score of all subjects in this method was 84. The cutting point for separating healthy persons from patients based on similar studies in Iran (Noorbala et al. 1999) (7,12) was score of 23, and score 14 was defined as the cutting point in each of the subscales. Therefore, scores more than 23 indicated psychiatric disorders of the studied patients, versus scores less than 23 showing healthier psycho-social status (7,12).

Data analysis was performed using statistical software SPSS (version 17), student's T test and Chi-Square ( $\square 2$ ) test, Fisher Exact test were also used. To determine the correlation between quantitative variables, Pearson correlation coefficient was used, considering the significant level of p<0.05.

#### **Results**

In this study, 164 patients with beta-thalassemia major were evaluated using the General Health Questionnaire GHQ-28. Ninety six patients (58.5%) were male and 68 patients (41.5%) were female. The mean age of the studied patients was 18.7±2.2 years (range 14-24 years); the mean age was 18.6±2.9 years in males and it was 18.4±2.6 years in females. Also, the mean age of patients with mental health disorder was 19±2.8 years and it was 18.4±2.8 years in patients with mental health. In statistical analysis, no significant difference was found between mental health status and age (even considering gender segregation) (p=0.559).

Average time of diagnosis and the onset of betathalassemia major in patients was 17.1±4.2 years (range 1-24 years), it was 17.1±4.1 years in males and 7.1±4.3 years in females.

Further, It should be noted that average time of diagnosis was 17.4±3.7 years in patients with mental health disorders and it was 16.7±4.7 years in patients

with mental health. No significant difference was found between mental health status and time elapsed since diagnosis (with gender segregation) (p=0.989). Neither of the studied patients was addicted to cigarettes or drugs, and most of them even (81%) mentioned having some physical exercise. Distribution of mental health status based on gender of

patients is demonstrated in table 1, and the distribution of demographic data of the patients based on their mental health status is demonstrated in table 2.

Table 1. Distribution of mental health state based on gender of studied patients

mental health state			p-value		
(based on GHQ-20)		Male	Female	All	<del>-</del> ·
Mental health disorder	A <sup>§</sup>	43	40	83	
		(51.8%)	(48.2%)	persons	0.84
	В¶	53	28	81	0.04
	J	(65.4%)	(34.6%)	persons	
Somatic symptoms	+	9	3	12	
		(75%)	(25%)	persons	0.362
	-	87	65	152	0.302
		(57.2%)	(42.8%)	persons	
Severe Depression disorder	+	9	10	19	
		(47.4%)	(52.6%)	persons	0.328
	-	87	58	145	0.020
		(60%)	(40%)	persons	
Anxiety/insomnia disorder	+	6	8	14	
		(42.9%)	(57.1%)	persons	0.261
	-	90	60	150	0.201
		(60%)	(40%)	persons	
Social dysfunction	+	1 (12()	6	7	
		(1%)	(8.8%)	persons	0.021
	-	95	62	157	<u> </u>
		(60.5%)	(39.5%)	persons	

§A: Probable mental health disorder/ psychiatric disorder

¶B: Healthy

Table 2- Distribution of demographic data of studied patients based on mental health state

Demographic data of studied patients		(ba	mental health state (based on GHQ-20)		
		A <sup>§</sup>	в¶	All	p-valu
Literacy state	Illiterate	19	8	27	0.122
		(70.4%)	(29.6%)	persons	
	Elementary school	19	14	33	
	•	(57.6%)	(42.4%)	persons	
	Guide school	` 17 ´	` 21 ´	. 38	
		(44.7%)	(55.3%)	persons	
	High school/Graduate	` 12 ´	` 19 ´	່ 31	
	3	(38.7%)	(61.3%)	persons	
	Up high school/graduate	3	4	7	
	5 T	(42.9%)	(57.1%)	persons	
Occupation	Non practitioner	` 68 ´	` 67 ´	135	0.166
		(50.3%)	(49.7%)	persons	
	practitioner	` 6	` 8 ´	14	
	F	(42.9%)	(57.1%)	persons	
Married state	Married	2	2	4	0.929
		(50%)	(50%)	persons	
	Single	81	76	155	
	g	(52.2%)	(47.8%)	persons	
Life state of patient's mother	Lived	79	75	154	0.865
		(51.3%)	(48.7%)	persons	
	Dead	3	3	6	
		(50%)	(50%)	persons	
Life state of patient's father	Lived	74	71	145	0.950
		(51%)	(49%)	persons	0.000
	Dead	8	7	15	
		(53.3%)	(46.7%)	persons	

§A: Probable mental health disorder/ psychiatric disorder

**¶B**: Healthy

#### Discussion

In our study, the average age of the studied patients with mental health disorders (probable cases of psychiatric disorders) was 19± 2.8 years, and it was 18.4±2.8 years in patients with mental health. No statistical difference was found between age and psychosocial health. However, in a similar study in Tehran/Iran, a significant correlation was found between age and the score of subjects in GHQ-28 questionnaire, and about 78% of thalassemia major patients with undesirable psychosocial health were in adolescence age group (18-21 years-old); this state correlate with more irritability (due life changes such as contrarily facies change and late puberty of these patients) and more responsibility in this age group (against childhood), that can be affect their cooperation in treatment process (including noncompliance in long term remedies of their disease) and develop psychosocial health disorders (9).

Of course, in another similar study in Italy performed using the short form of 36-health survey questionnaire (SF-36) and symptom-check-list-90 revised (SCL-90-R) method, no relationship was found between age and psychiatric disorders in young adults with thalassemia major (2). It should be noted that high prevalence of suspected mental health disorders in the studied patients may be caused by the fact that all the subjects were in their late adolescence years (15 to 24 year).

In our study, based on GHQ-28, 50.6% of the patients had a probable mental disorder. 7.3% of 12 pa tients had somatic symptoms that indicated a possible somatic disorder. Also, 11.6% of the cases (19 patients) had depression, 8.5% (14 patients) anxiety and 4.3% (7 patients) had social dysfunction. Goldbeck and et al. reported that most children with a chronic disease such as thalassemia earn a good compatibility with their disease and live a favorable life (10). However, in a similar study conducted in Turkey in 2003 ,using Child Behavior Check-list (CBCL) and Symptom Distress Checklist 90 (SCL-90) scale), a total of 24% of children with thalassemia major had a psychiatric diagnosis including major depression, anxiety disorder, tic disorder, and enuresis nocturnal (13).

A majority of similar studies have reported a high rate of psychological disorders in children with possible mental health disorders (1,2,3,8).In a similar study conducted in Shahr-e Kord/Iran (Alavi et al. 2004) on 8-18 year-old children with thalassemia major ,using PedSQL questionnaire method, a h igh rate of psychological disorders was found.

Some researchers believe that the high prevalence of psychosocial health disorders, especially mood and anxiety disorders, in thalassemia patients in previous decades has been derived from accommodation of these patients with hard life conditions and expecting death. There was always a background of transient depressive period for these patients. However, nowadays, despite advances in therapeutic methods, these patients are faced with different situations of life

(such as socioeconomic problems) and its uncertainties (10).

According to the results of our study, the most common psychological health disorder was depressive disorder (11.6%),and a nxiety disorder, somatic disorder and social dysfunction were in next ranks respectively. In a similar study in India, the most common psychiatric disorder in children with thalassemia was anxiety disorder (67%) and in the next degrees stood affective disorders, major depressive disorder and conduct disorders (14).

Primarily, some studies reported gender differences in the prevalence of psychosocial disorders, particularly mood disorders, in children with chronic diseases (9). Also, different results have been reported on the prevalence of psychosocial disorders in children with thalassemia major according to gender. (3,9,15).In our study, the possibility of mental health disorders in females were more than males (58.8% of males vs 44.7% of females), and analytic results showed that except for somatic disorder that was more prevalent among males, depressive disorder, anxiety disorder and social dysfunction were more common in females; this can attribute the high prevalence of psychological disorders of females with thalassemia to their vulnerability. In our study and similar other studies in Iran (North and Center provinces) (3,4,9,15) and other countries(6-8) despite the prevalence of general heath disorders which are more common in females, no significant correlation was found between gender and psychosocial health status. In a similar study conducted in Shahr-e Kord/Iran (Alavi et al, 2004) on 8-18 yearold children with thalassemia major using PedSQL questionnaire method, it was found that psychological disorders was significantly more in females (p< 0.05) (4). In this study, in respect to marital status, 52.2% of single persons and 50% of married persons had a possible mental health disorder; and no significant difference was found between the two groups (those with and without possible mental disorder) with respect to marital status. Also, for literacy level, we observed no significant correlation between the two groups. It is noteworthy that among the illiterate patients, 70.4% had a possible mental health disorder. In a similar study conducted in Mazandaran (North of Iran) in 2004, marital status and literacy status in patients with beta-thalassemia major were significantly less than the healthy control group, showing lack of ability for adapting to their disease. In this study, no history of dropping out of school due to illness was reported (3). In this study, no significant association was found between literacy level and health (3). However, in the study conducted in Tehran (centre of Iran)in 2005, 9.6% of patients quitted school due to their illness (9), while some studies in Greece and Italy have shown that the education of children suffering from thalassemia disease was not affected by their disease (5,16). In contrast, another study conducted in Turkey in 2003, demonstrated an adverse impact on the education of children with this disease (17). Cause of unfavorable effect of this disease on literacy status and even quitting school may be due to little knowledge of educational cadre of schools regarding specific condition of these patients and wrong reaction of parents about literacy status of their children (9).

It should be mentioned that neither of the patients in this study was addicted to cigarettes or other drugs; and most persons (81%) reported to have some light physical exercise. Furthermore, in this study, average duration of diagnosis of disease was 17.1±3.7 years in patients with possible mental health disorder, and in patients with mental health it was 16.7±4.7 years. Based on the analytic result, no significant relationship was found between duration of diagnosis of disease and mental health status. Of course in other similar studies these three variables were not surveyed. It should be mentioned that our survey was conducted using the standard GHO-28, which is not a structured clinical interview, so it was unable to assess the prevalence of different psychiatric disorders and definite diagnosis of these disorders. Further, in this study, samples did not include children less than 15 years of age and adults, who constitute a major population of patients with beta thalassemia major. Therefore, conducting more quantitative and comprehensive researches with larger sample sizes which include all age groups are recommended to evaluate the specific effective factors in mental and psycho-social health of these patients.

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