



Mental health status in patients with Thalassemia major in Iran

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ABSTRACT

Thalassemia major is a genetic blood disorder that is detected by the symptoms of chronic and severe anemia, enlarged liver and spleen, failure to thrive and bone deformities in particular deformed face and bulging forehead. Due to changes in physical appearance, the disease can influence on other aspects of the patient's life, so the disease can have a strong impact on the mental health of these patients and their families. Previous studies showed that 80% of patients with thalassemia major have at least one psychiatric disorder. The aim of this paper was to review the mental health status of patients with Beta-thalassemia major in Iran.

Introduction

Thalassemia major is a chronic genetic blood disorder caused by deficiency in one or more globin polypeptide chains synthesis that is passed from one generation to another based on Mendelian laws. The disease is characterized by chronic and severe anemia, growth retardation, hepato-splenomegally and bone deformities like malformed face and bulging forehead.¹ Traditional therapeutic methods such as blood

transfusion and using iron chelating agents have improved the physical health status of the patients with thalassemia major. On the other hand, to prolong the therapeutic period, frequent treatment and change in physical appearance can affect on the quality of life and other aspects of life of the patients and their families.²⁻¹⁰ Some of the previous studies showed that 80% of patients with Thalassemia

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major have at least one psychiatric disorder. The most common psychiatric disorders reported among these patients or their family members included body dimorphic disorders (BDD),^{3,4} anxiety,^{5,6} depression,²⁻⁷ physical impairment,^{3,4-7} and the lack of control of anger.⁸⁻¹⁰ Also, these patients have numerous problems in their social and educational status¹¹⁻¹⁷. So, that the aim of this paper was to review the mental health status in patients with thalassemia major in Iran.

Materials and Methods

In this review, the performed via librarian and the internet approach in 2013, the online database including SID, Google, Magiran, Iranmedx were searched for full text articles in Persian and English related to mental health status of patients with thalassemia major in Iran using the following keywords: mental health, depression, anxiety, mental illness, thalassemia and Iran. Inclusion criteria were all full text articles related to mental health status of thalassemia major patients in Iran in which the General Health Questionnaire (GHQ) and Symptom Checklist-90 questionnaire (SCL90) used as evaluating tools.^{18, 19} The articles lacking the tools above have been excluded.

Results

From the 15 articles related to mental health status of thalassemia major patients in Iran, 7 articles fitted with the inclusion criteria were reviewed. Table 1 shows a summary of findings from the reviewed articles.

Discussion

This review article revealed that the patients with thalassemia major are at risk of psychiatric disorders and have more severe psycho-social problems than the general population.^{20, 21}

Hosseini et al. in 2007 conducted a descriptive analytic study to compare the mental health

status between the patients with beta-thalassemia and normal population using SCL-90 questionnaire. The results showed that thalassemic patients have the higher risk of psychiatric disorders than the general population.²⁰

In addition, in a descriptive study conducted by Messina et al. (2008) on 147 adult patients with thalassemia to evaluate the psycho-social and psychological disorders using a questionnaire SCL_90, they found that thalassemia patients have the most often severe psychosocial problems.²¹

Hasan khani et al. in 2006 performed a cross-sectional study on 687 patients with thalassemia major to assess the mental health status using SCL-90 questionnaire based on age, sex, educational status and severity of symptoms in Mazandaran, Iran. The results showed that 446 (64.9%) of the individuals had the total criteria of the disease more than 7, so they had mental health disorders and 141 (5.20%) were between 4-7 suspected to have mental illnesses and 100 (14.6%) had the index less than 4 and were considered healthy subjects.²²

Naderi et al. in a descriptive analytical study on 147 patients with thalassemia major in South East Iran from 2009 to 2010 evaluated the mental health status and related factors of the patients by GHQ. They found that 83(50.8%) of the patients were suffering from psychiatric disorders.²³

In addition, Khodai et al. (2005) assessed the psycho-social status of 156 young adults with thalassemia major based on a descriptive self-report using GHQ questionnaire. The findings suggested that 80% of the patients had acceptable general health status. On the other hand, 64.1% of the reported cases with psychological problems indicated denying of the disease by the patients.²⁴

Table 1. A summary of findings from the reviewed articles

Author/Date	Title	Type of Study	Population	Intervention	Findings
Hosseini et al. (2007) ²⁰	comparison of mental health status between patients with beta-thalassemia and normal population	Descriptive- analytic	125 thalassemia major patients aged 15-25 years	SCL90	patients with thalassemia major are at risk of psychiatric disorders (87.2%), especially the psychosomatic disorders, difficulty in relationship with others, depression, anxiety and psychosis due to chronic disease, types of treatment, severity and side effects of the disease compared to healthy people (68.4%)
Messina et al. (2008) ²¹	Assessment of psychosocial aspects and psychiatric disorders in adults with thalassemia major	Descriptive	147 thalassemia major patients	WCQ , SF-36, SCL-90-R	The results suggest that thalassemic patients often have severe psychosocial problems
Hasan khani et al. (2006) ²²	Assessment of Mental health status of patients with thalassemia based on age, gender, educational status and clinical symptoms in Mazandaran	Descriptive- cross sectional	687 patients with thalassemia major >15 y/o	SCL90 questionnaire	446 (64.9%) of the participants had overall index greater than 7.0 based on SCL90.R and had mental illness, 141(20.5%) were between 4.0% and 7.0% of the overall index of psychiatric disease and suspected to mental illness and 100 (14.6 %) had overall index less than 4.0% and thus were considered healthy subjects
Naderi et al. (2010) ²³	Study of mental health and related factors in patients with thalassemia major in the South East of Iran	Cross-sectional descriptive- analytic	167 patients aged 15-24 years	GHQ	Among 83 (50.8%) of the patients who suffered from psychiatric disorders; 7.3% had physical health problems, 11.6% had depression, 8.5% had anxiety and physical dysfunction reported in 4.3%.
Khodai et al. (2005) ²⁴	Psychosocial status in adolescents with thalassemia according to self-report	descriptive	101 patients	GHQ	About 80% of the patients had acceptable general health status. On the other hand, 64.1% of the reported cases with psychological problem indicated refusal of the disease by the patients.
Gholami et al. (2009) ²⁵	Effectiveness of Logotherapy on life expectancy, Therapeutic group on general health of thalassemia patients and	Before- after semi experimental study with control group and follow up	110 patients	GHQ and Miller's life expectancy test	Providing a way to Logotherapy regarding average life expectancy and general health of the patients in experimental group following post-test compared to the control group, it caused Increasing life expectancy and general health in experimental groups (P<0.0001)
Ghaffari et al (2004) ²⁶	The relationship between depression and thalassemia	Cohort prospective	110 boys and girls aged 9-16 years	CDS depression scales	The rate of depression among thalassemia major patients was 14%. Nevertheless, the depression scores among the girls in the control group were higher than the girls in experimental group.

Gholami et al. in a study performed on 110 girls with thalassemia major by a pretest-posttest empirical analysis with control group assessed the effectiveness of Logotherapy on the life expectancy and general health of the patients using GHQ and Miller's life expectancy questionnaire. The findings suggested that Logotherapy technique increased an average of posttest score of life expectancy and general health of the patients in experimental group compared with patients in the control group.²⁵

In a cohort study conducted by Ghaffari et al. on 165 male and female patients aged 9-16 years, the association between depression and thalassemia major were assessed using Carroll Depression Scales (CDS). The rate of depression among thalassemia major patients was 14% that was significantly more than the control group (5.5%). Nevertheless, the depression scores among the girls in the control group were higher than the same sex in experimental group.²⁶

In a study conducted by Pouraboli et al., the health status of adolescent patients with thalassemia major referred to Kerman in which specific diseases center was assessed by using GHQ questionnaire analytic. They found that none of the patients had suitable condition. On the other hand, their results revealed that 100% of the patients suffered from mental health problems.²⁷

In another descriptive analytic study performed by Arman and Moallemi on 138 adolescent subjects with thalassemia major in 2003 about depression and self-concept using Beck Depression Inventory and Rogers self-concept questionnaires, the results indicated that approximately 7% of the patients suffered from depression and their self-concept was lower than the general population.²⁸

Ghanizadeh et al. in 2006 studied the prevalence of psychiatric disorders, depression, and suicidal behavior in children and

adolescents with thalassemia major. They performed a face-to-face interview based on the Kiddie-Schedule for Affective Disorders and Schizophrenia (K-SADS) Persian version through an interview. They found that the most common psychiatric disorders were major depressive disorder and separation anxiety disorder. Other psychiatric disorders were oppositional defiant disorder in 3.6%, attention-deficit hyperactivity disorder in 1.8%, and bipolar mood disorder seen in 0.9% of the participants. Depressed mood were seen in 49% and 62.7% suffering from irritability and anger. They also reported recurrent thought of death in more than 43% of cases and 27.3% had suicide attempt the last year. They had concluded that the rate of psychiatric disorders was very low than the previous studies and the most common psychiatric disorders was major depressive disorder. In addition, the rate of suicidal behavior was not different from the general population.²⁹

Shaligram et al. in 2007 performed a study on thirty-nine children aged 8-16 years with transfusion dependent thalassemia who referred to the day care services for blood transfusion. They assessed psychological problems in these patients using the Childhood Psychopathology Measurement Schedule and Quality of Life (QOL) using EuroQOL (EQ-5D). The results showed that 44% of the children had psychological problems and QOL was poor in 74% of cases. The side effects of chelating agents were the independent predictors of psychological problems and impairment of QOL, but the psychological problems were significant predictors of impaired QOL. They concluded that the recognition and management of the psychological problems in thalassemia major patients could improve QOL in the patients.³⁰

In a case-control study by Hashemi et al. in 2012, the prevalence of major depressive and

anxiety disorders in hemophilic and major beta thalassemic patients related to the education of their mothers were assessed. The case group was composed of 34 major beta thalassemic patients and 32 cases of hemophilic patients who referred to special diseases center in Yazd from 2010 to 2012 and the control group was by simple sampling from the students of Yazd's schools that matched with age and sex. Psychological data such as major depressive disorder and anxiety were assessed by Beck and Ketel tests and demographic characteristics included age, sex and mother's educational level were recorded. The results revealed that the prevalence of major depressive disorder and anxiety in thalassemic patients were more than control group and were significantly more in patients with their mother's low educational level. The psychological and demographic data revealed no difference between the hemophilic patients and the control group ($P>0.05$). As a conclusion, they found that patients with major beta-thalassemia had experienced more anxiety and major depressive disorder than healthy persons especially in patients whose mothers had low educational level.¹¹

In 2011, Hamed et al. conducted an observational analytical case-control study to identify the depth of psychological effect of thalassemia, evaluate the presence of psychiatric symptoms such as depressive symptoms, anxiety, phobic anxiety, obsessive symptoms, somatic symptoms, and hysteria among the adolescents with thalassemia and to analyze the QOL of adolescents with thalassemia. The case group was 30 adolescents with a diagnosis of thalassemia, and the control group was composed of 30 adolescents from the gastrointestinal outpatient clinic. A semi-structured interview was performed for all the participants using the Patient Health Questionnaire, the Hospital Anxiety Depression Scale, the Middlesex Hospital Questionnaire, and the McGill Quality of Life Questionnaire.

They found that in thalassemic adolescents, depressive and anxiety symptoms were statistically higher than the adolescents from the gastrointestinal outpatient clinic ($P<0.001$). There was also a highly significant difference in the results of the Middlesex Hospital Questionnaire between the two studied groups ($P<0.001$). Thalassemic adolescents also showed significantly higher levels of anxiety, phobia, obsession, somatization, depression, and hysteria and significant lower levels in different aspects of quality of life with regard to the McGill Quality of Life Questionnaire ($P<0.001$). They concluded that depressive and anxiety symptoms were more prevalent among the adolescents with thalassemia and a higher degree of depression is associated with lower levels of QOL among adolescents with thalassemia.¹²

Hongally et al. in 2012 performed a cross-sectional study on 50 multi-transfused thalassemia children aged 5-10 years to assess the behavioral problems and psychosocial factors affecting them. The inclusion criteria were all the participants who were not suffering from any other major medical illness. Child Behavior Check List (Achenbach) (CBCL) and Parental Attitude Scale (Rangaswamy 1989) were used to collect data from each parent regarding the child's behavior. The obtained CBCL total scores were high in 32% patients, indicating the presence of behavioral problems. Higher CBCL scores were found in children of older age group, those with poor school performance whose mothers' education was more than eighth standard, had history of death of their thalassemic relatives, greater duration of diagnosed illness, poor pre-transfusion hemoglobin level, and who had longer periods of school absence. They concluded that behavioral problems are common in multi-transfused thalassemic children, early diagnosis and periodically assess these children for any psychiatric morbidity and proper intervention

can help them cope with thalassemia and have a better quality of life. Finally, they recommend long-term interventional follow-up studies to prove the hypothesis.³³

Although, most of the studies performed on mental health status in these patients were done by the questionnaires that their validity and reliability have been verified, there are considerable controversies in the findings of different studies. According to the findings of this review, the prevalence of psychiatric problems reported by foreign authors using the questionnaire was 100%, while the results of similar studies performed in Iran based on interviews showed that the prevalence of the psychiatric disorders among thalassemia patients was very low and even the suicide attempts were the same rate with that of the general population.^{21, 29} Thus, using GHQ questionnaires and SCL-90 to assess the prevalence of psychiatric problems in patients with thalassemia is questionable and requires more consideration. Moreover, common physical symptoms of depression and chronic physical illnesses such as thalassemia may be one of the reasons of these different results and HADS questionnaire that evaluates psychological symptoms that may be a better choice of measurement. So that, different significant results could be indicated the weakness of using GHQ questionnaires and SCL-90 to investigate the mental health status of patients with thalassemia major.^{20, 21}

Conclusion

According to the findings of this review, the prevalence of psychiatric disorders in patients with thalassemia major is not clear and different results have been reported by authors. Whether, they are at risk compared to the general population or at increased risk of psychiatric disorders are the problems that need further consideration. Therefore, psychiatric

observations and consultations are needed and a Structured Clinical Interview (SCID) as a diagnostic test to determine Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) Axis I disorders (major mental disorders) is recommended to achieve a deeper and more confident data. In addition, considering the high prevalence of thalassemia disorders in this region, further studies with more samples to generalize the findings are recommended.

Conflict of Interest

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References

1. Kasper LD, S. Fauci AL, Longo D, Braunwald EL, Hauser S, Jameson JL. Harrison's principles of internal medicine, 16th ed. USA; McGraw-Hill; 2005, 599-601.
2. Aydin B, Yapavk I, Akarsu D, Okten N, Ulgen M. Psychosocial aspects and psychiatric disorders in children with thalassemia major. *Acta Pediatrics Japan* 1997; 39: 354-357.
3. Cairns NU, Clark GM, Smith SD, Lansky SB. Adaptation of siblings to childhood malignancy. *J Pediatrics* 1979; 95: 484-487.
4. Hoch C, Gobel U, Janssen G. Psychosocial support of patients with homozygous beta thalassemia. *Klin Pediatrics* 2000; 212(4): 216-9.
5. Noll RB, Gartstein MA, Vnnatta K, Correll J, Bukowski WM, Davies WH. Social, emotional, and behavioral functioning of children with cancer. *Pediatrics* 1999; 103(1): 71-8.
6. Wood B, Boyle JT, Watkins JB, et al. Sibling psychological status and style as related to the disease of their chronically ill brothers and sisters: Implications for methods of biopsychosocial interaction. *J Dev Behav Pediatr* 1988; 9: 66-72.
7. Bennett D. Depression among children with chronic medical problem. *Journal of Pediatric Psychology* 1994; 19: 149-169.
8. Tritt SG, Esses LM. Psychosocial adaptation of siblings of children with chronic medical illnesses. *Am J Orthopsychiatry* 1988; 58: 211-220.

9. Breslau N. Siblings of disable children: Birth order and age-spacing effects. *J Abnorm Child Psychol* 1982; 10: 85-96.
10. Lavigne JV, Ryan M. Psychological adjustment of siblings of children with chronic illnesses. *Pediatrics* 1979; 63: 616-627.
11. Politis C. The psychosocial impact of chronic illness. *Ann N Y Acad Sci* 1998; 850: 349-54.
12. Di Palma A, Vullo C, Zani B, Fscchini A. Psychosocial integration of adolescents and young adults with thalassemia major. *Ann N Y Acad Sci* 1998; 850: 355-60.
13. Bernaudin F, Verlhac S, Freard F, Roudot F, Benkerrou M, Thuret I, et al. Multicenter prospective study of children with sickle cell disease: radiographic and psychometric correlation. *J Child Neurol* 2000; 15(5): 333-43.
14. Goldbeck L, Baving A, Kohne E. Psychosocial aspects of beta thalassemia: distress, coping, and adherence. *Klin Padiatr* 2000; 212(5): 254-9.
15. Monastero R, Monastero G, Ciaccio C, Padovani A, Camarda R. Cognitive deficits in beta thalassemia major. *Acta Neurol Scand* 2000; 102(3): 162-8.
16. Eiser C. Psychological effects of chronic disease. *Journal of Child Psychology & Psychiatry* 1990; 31: 85-98.
17. Bush S, Mandel FS, Giardina PJ. Future orientation and life expectations of adolescents and young adults with thalassemia major. *Ann N Y Acad Sci* 1998; 850: 361-9.
18. General health questionnaie.availbleat. www.nfer.celso.co.uk.last accessed 29 jun 2003).
19. Derogatis LR, Lipman RS, Covi L. SCL-90: an outpatient psychiatric rating scale--preliminary report. *Psychopharmacol Bull* 1973; 9(1):13-28.
20. Hosseini S, Khani H, Khalilian A, Vahidshahi K. Psychological Aspects in Young Adults with Beta-Thalassemia Major, control group. *J Mazandaran Univ Med Sci* 2007; 17 (59) :51-60
21. Messina G, Colombo E, Cassinerio E, Ferri F, Curti R, Altamura C, Psychosocial aspects and psychiatric disorders in young adult with thalassemia major. *Intern Emerg Med*. 2008; 3(4): 339-43.
22. Khani H, Majdi MR, Montazeri A, Hosseini SH, Ghorbani A, Ramezani M et al. Quality of life in Iranian Beta-thalassemia major patients of southern coastwise of the Caspian Sea. *Journal of Behavioral Sciences* 2007; 8(35-36): 325-332.
23. Naderi M, Hormozi MR, Ashrafi M, Emamdadi A. Evaluation of Mental Health and Related Factors among Patients with Beta-thalassemia Major in South East of Iran. *Iranian J Psychiatry* 2012; 7(1):47-51.
24. Khodai S, Karbakhsh M, Asasi N. Psychosocial status in Iranian adolescents with Beta-Thalassaemia Major. *Tehran Univ Med J* 2005; 63 (1):18-23.
25. Gholami M, Pasha GR, Sudani M. The effectiveness of group logo therapy education on life expectancy and general health of female patients with thalassemia. *Knowledge and Research in Psychology* 1388; 0 (42): 25-45.
26. Ghaffari Saravi V, Zarghmi M, Ebrahimi E. The Prevalence of Depression in Thalassemic Patients in the City of Sari. *IJPCP*. 2004; 9 (3):33-40.
27. Pouraboli B. Azizzadeh Forouzi M, Arab M. Assessment of mental health status in patients with thalassemia major referred to Kerman special diseases center. *Nasim Danesh (Scientific Journal of Hamadan Nursing and Midwifery Faculty)* 2013; 21(1): 0-0 [article in press].
28. Arman s, Moallemi Sh. Depression and self-concept in adolescents with Thalassemia major. *Journal of Isfahan Medical School*. 2005; 23(76-77): 6-6.
29. Ghanizadeh A, Khajavian S, Ashkani H. Prevalence of psychiatric disorders, depression, and suicidal behavior in child and adolescent with thalassemia major. *J Padiatr Hematol Oncol*. 2006; 28(12): 781-4.
30. Shaligram D, Girimaji SC, Chaturvedi SK. Psychological problems and quality of life in children with thalassemia. *Indian J Padiatr*. 2007; 74(8): 727-30.
31. 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* 2012; 2(1):11-16.
32. Hamed H, Ezzat O, Hifnawy T. Psychological manifestations in adolescents with thalassemia. *Middle East Current Psychiatry* 2011; 18(4): 237-244.
33. Hongally C, Benakappa D A, Reena S. Study of behavioral problems in multi-transfused thalassemic children. *Indian J Psychiatry [serial online]* 2012 [cited 2013 Jul 16]; 54: 333-6.