

Assessment of Patients with Beta-thalassemia

Ahmad Hameed Allehaiby¹, Sarah MUSAED Alluheibi², Sarah Mohammed Alnassar³, Mansour Ahmed Bayyidih⁴, Mohammad Mabrook S Almohammadi⁵, Layla Mohammed Alnashry⁶, Abdulrahim Abdullatif Alomair⁷, Mazen Mosfer A Alzahrani⁸, Rawan Ezzi Abufaia⁹, Riyadh Mohammed Alhajji¹⁰, Meshal Fahad M Alshamrani¹¹, Omar Hasan Abdullah Badahman¹¹, Haitham MUSAAD A Aloraini¹²

1- Primary Health Care, Jeddah, 2- Primary Health Care, Mecca, 3- Obhur PHC, 4- Sabya PHC, 5- Elixir Medical Center, 6- University of Tabuk, 7- King Faisal University, 8- Al-Azizyah Maternity & Children Hospital Jeddah, 9- Asfan PHC, 10- Alomran Center, 11- King Abdulaziz University, 12- Almaarefa College

ABSTRACT

Background: Thalassemia major has become a public health problem worldwide, mainly in developing and poor countries, while the role of educating the family and community has not been considered enough in patients' care. **Purpose:** This study was done to examine the impact of partnership care model on mental health of patients with beta-thalassemia major. **Materials and Methods:** This experimental study, with pretest and posttest design, was performed on patients with beta-thalassemia major in Jeddah city. 40 patients with beta-thalassemia major were assigned randomly into two groups of intervention (20 patients) and control (n=20) groups. Mental health of the participants was measured using the standard questionnaire before and after intervention in both groups. The intervention was applied to the intervention group for 6 months, based on the partnership care model. **Results:** There were significant differences between the scores of mental health and its subscales between the two groups after the intervention ($P < 0.05$).

Conclusions: The findings of the study revealed the efficacy and usefulness of partnership care model on mental health of patients with beta-thalassemia major; thus, implementation of this model is suggested for the improvement of mental health of patients with beta-thalassemia major.

Keywords: Beta-thalassemia, mental health, DeferoxamineMesylate.

INTRODUCTION

Thalassemia is a public health problem worldwide, mainly in developing countries^[1].

According to the World Health Organization report, more than 15 million people suffer from thalassemia worldwide^[2] and annually about 56 thousand children are born with it in the world^[3]. This disease is a major problem, not only for patients and their families, but also for public health system in any country, bearing in mind the care and treatment costs; containing regular infusions of DeferoxamineMesylate (desferal), recurrent hospitalization, and other medical procedures^[4, 5]. The aim of the treatment is to preserve hemoglobin levels at at least 10 g/dL in both genders. The blood volume for transfusion was calculated based on the patient's hemoglobin (10–15 mL/kg). Treatment with chelators starts after the first 10–20 blood transfusions or when blood Ferritin level reaches more than 1000 ng/mL [10]. Intravenous chelators are routinely used in chelation therapy. Oral or combined chelator's therapy is used when the patient is unable to tolerate the intravenous chelators or when sufficient intravenous chelators are not obtainable. Deferoxamine is injected subcutaneously using an injection pump at a rate of 20–60 mg/kg of body weight usually over 8- to 12-hour period, and 3 to

5 times a week^[6]. Complex medical care and life long unpleasant clinical self-management regimen have adverse effects on mental function and mood of patients and their families^[7, 8].

Studies have presented that these patients suffer from psychological issues, such as anxiety and depression, and might be easily hurt by these problems^[8]. Another important point is that this disease affects the patients' health and causes physical disorder, growth retardation, and late puberty^[9] which affects their self-conscious and will eventually rise the patient's anxiety and negatively affect their lives^[10].

In developing countries, adults with thalassemia major are not treated due to absence of public consciousness and inaccessibility of drugs and experience mood disorders, including despair, isolation, depression, hostility, sadness, anxiety, fear of death, lack of self-esteem, and anger^[11]. Alternatively, complications of this ailment increment with age and make the patient more tired^[12]. This issue will disrupt the self-care and psychomental status and interrupt the treatment procedure. Nurses are on the front lines of providing care to the patients and witnessing the patients' problems. They need to know about the patient's psychomental status in order to provide the most appropriate care plan. In addition, the

knowledge about these kinds of difficulties can aid nurses to improve the quality of care in ways that enhance quality of life in patients. Endemic care protocols can be an appropriate guide for improvement of care. Therefore, this study aimed to utilize an endemic model, name partnership care model for patients with thalassemia major, and appraise its influence on mental health (depression and anxiety) of these patients. Partnership care model was first developed, implemented, and evaluated^[13]. In this model, the theory of collaboration in the care has been processed. In the care process, the quality and type of communication between the two sides of the relationship are vital. In this regard, knowledge, skill, and special tools for treatment and care are the next important issues. Originality and effectiveness of care depend on the correct and favorable formation of nature and quality of care. Therefore, the partnership care model is a regular process for efficient, interactive, and persistent communication between the patient and the nurse to identify the needs and problems and sensitizing the patients to accept continuous health behaviors and help improve their health. The objectives of this model were : (1) to establish an efficient, interactive, and persistent relationship between team members in the process of care and treatment, (2) to increase the cooperation, team motivation, and accountability in the process of care and treatment, (3) to increase satisfaction and quality of life of patients, and (4) to reduce complications and risk factors. To achieve the purposes of the model, the designed steps have been arranged in a regular structure, which acts as interconnected and dynamic series, through observing the relationship and logical and evolutionary sequence. These steps included : (1) motivation, (2) readiness, (3) involvement, and (4) evaluation, which is predicted for each specific action program^[13, 14]. This study investigated the effect of this model on the mental health of patients with thalassemia major. We hypothesized that the partnership care model could improve both the overall health and quality of life of patients.

METHODS

This experimental study with pre test and post test design was conducted in Jddah City KSA, on patients with beta-thalassemia major. The study population included patients with beta-thalassemia major who referred to King Abdulaziz Hospital, which included 40 patients of the study sample. The samples were allocated randomly into two groups of intervention (20 patients) and control ($n = 20$) groups. Partnership care model (motivation, readiness, involvement, and evaluation) was

conducted for 6 months for the intervention group. Inclusion criteria for this study consisted of patients with thalassemia major, receiving intravenous chelators (Deferoxamine), with the ability to communicate and give information and no history of psychiatric illness.

In the demographic questionnaire, variables such as age, gender, marital status, education level, age at diagnosis, history of other diseases, and family status were evaluated. By the questionnaire, data related to health (including mental health) were collected. The data gathered in this study included demographic questionnaire and the standardized questionnaire GHQ-28. Demographic questionnaire was developed by researchers based on scientific resources and on the objectives of the study. The questionnaire included questions about age, gender, marital status, education, family status, age at diagnosis of thalassemia, and history of other diseases. Content validity was determined using comments of 10 relative nursing faculty members and four blood specialists and psychiatrists. To determine reliability, test-retest was used. GHQ-28 questionnaire was designed in 1979 by Goldberg and Hiller to screen non psychopathic psychological disorders and includes four subscales: physical complaints, symptoms of anxiety, social dysfunction, and depressive symptoms. Each subscale consists of 7 statements and each statement is scored on a Likert scale of 0–3 points and higher scores indicate poorer mental health. In each subscale, scores over 6 and total scores above 22 indicate disease. Goldberg calculated and confirmed Cronbach's alpha coefficient of 0.89 for this tool^[15] and the test-retest, split-half reliability, and Cronbach's alpha coefficients were 0.70, 0.93, and 0.90, respectively, and concurrent validity of the questionnaire was determined at 0.55^[16]. Researchers have introduced the GHQ-28 tool as the best tool in the age group 12–18 years^[17, 18]. Data was analyzed using SPSS 20 software, paired *t*-test, independent *t*-test, and chi-square analysis. $P < 0.05$ was considered as statistically significant.

RESULTS

Mean age of patients in the intervention group was 15.1 ± 4.25 and in the control group was 14.9 ± 3.55 ($P > 0.05$). There was no significant difference between the two groups regarding gender, education, and age at diagnosis (Table 1). After the implementation of partnership care model, there was statistically significant difference between scores of mental health and subscale for symptoms of anxiety, depressive symptoms, social dysfunction, and physical complaints between the two groups ($P < 0.05$) (Table 2).

Table 1: The comparison of the variables between the experimental and control groups

| Variable groups | Intervention group n=20 (%) | Control group n=20 (%) | Statistical test and P value |
|---------------------------|-----------------------------|------------------------|------------------------------|
| Gender | | | |
| Male | 10 (50) | 11 (55) | Fisher |
| Female | 10 (50) | 9 (45) | $P = 0.59$ |
| Education | | | |
| Primary school | 15 (75) | 15 (75) | $\chi^2 = 7.74$ |
| Secondary school | 4 (20) | 3 (15) | df = 4 |
| High school | 1 (5) | 2 (10) | $P = 0.101$ |
| Age at diagnosis | | | |
| <1 year | 15 (75) | 16 (80) | $\chi^2 = 8.94$ |
| 1–3 years | 2 (10) | 1 (5) | df = 6 |
| 3–5 years | 3 (15) | 3 (15) | $P = 0.173$ |
| History of other diseases | | | |
| Negative | 15 (75) | 16 (80) | $\chi^2 = 8.94$ |
| Diabetes | 1 (5) | 1 (5) | df = 6 |
| Kidney disease | 3 (15) | 3 (15) | $P = 0.173$ |
| Liver disease | 1 (5) | 0 (0.0) | |
| Family status | | | $\chi^2 = 2.21$ |
| Living with two parents | 18 (90) | 19 (95) | df = 2 |
| Living with one parent | 2 (10) | 1 (5) | $P = 0.319$ |

Table 2: Comparison of mental health and its subscales in the intervention and control groups before and after intervention

| Variable | Group | Intervention | Control | Independent t-test |
|------------------------------|--------|-----------------------|----------------------|-----------------------|
| | | Mean ± SD | Mean ± SD | |
| Physical complaints | Before | 5.9 ± 0.63 | 5.8 ± 0.70 | $T = 0.64, P = 0.50$ |
| | After | 3.8 ± 0.56 | 5.7 ± 0.65 | $T = 1.19, P = 0.006$ |
| Paired t-test | | $T = 10.5, P = 0.000$ | $T = 1.34, P = 0.17$ | |
| Anxiety | Before | 8.5 ± 1.11 | 8.8 ± 1.20 | $T = 0.42, P = 0.90$ |
| | After | 5.3 ± 1.56 | 9.1 ± 0.71 | $T = 7.2, P = 0.017$ |
| Paired t-test | | $T = 7.7, P = 0.000$ | $T = 1.8, P = 0.108$ | |
| Social dysfunction | Before | 9.7 ± 0.91 | 9.8 ± 0.39 | $T = 0.37, P = 0.77$ |
| | After | 7.1 ± 1.74 | 9.2 ± 0.21 | $T = 2.20, P = 0.072$ |
| Paired t-test | | $T = 5.0, P = 0.007$ | $T = 1.49, P = 0.23$ | |
| Depression | Before | 10.7 ± 1.29 | 11.0 ± 0.69 | $T = 0.29, P = 0.12$ |
| | After | 4.3 ± 1.13 | 11.1 ± 0.43 | $T = 5.19, P = 0.008$ |
| Paired t-test | | $T = 8.4, P = 0.001$ | $T = 1.0, P = 0.36$ | |
| Total score of mental health | Before | 35.1 ± 7.29 | 35.4 ± 7.83 | $T = 0.72, P = 0.41$ |
| | After | 11.3 ± 3.04 | 35.3 ± 6.98 | $T = 7.9, P = 0.004$ |
| Paired t-test | | $T = 48.9, P = 0.000$ | $T = 1.0, P = 0.39$ | |

DISCUSSION

In the current study, mental health scores in thalassemia patients were higher in both groups before intervention than the cut-off point that validated poor mental health status of the patients. **Naderi *et al.*'s study** ^[19] showed that more than half(50.6%) of patients with thalassemia suffer

from mental disorders (19). Other similar studies, along with the high prevalence of mental health, have reported high number of such disorders (such as anxiety and depression) demanding extensive follow-up ^[11, 20]. **Sadowski *et al.*'s** Anther study ^[21] demonstrated that mental health issues in thalassemia patients (47.4%) is not only higher

compared to healthy controls (26.3%), but similarly significantly higher than hemophilia patients (24.6%) (21).

In the present study, the subscales (symptoms of anxiety, social dysfunction, depressive symptoms, and physical complaints) in both groups before the intervention were higher than the specified cut-off point indicating impairment in these subscales. **Salehi et al.'s** study [22] displayed that a high percentage of thalassemia patients were supposed to have or suffering from physical problems as a result of the influence of the disease on their presence, early fatigue, headache, or anemia. Research has shown that thalassemia major can have a devastating impact on social activities of patients [11]; for instance, **Sadowski et al.'s** study [21] indicated severe physical health problems in patients with thalassemia increase over time compared to healthy subjects, leading to social dysfunction and exacerbation of psychiatric disorders such as depression and anxiety (21). The outcomes of multiple studies revealed that the pervasiveness of depression and anxiety is significantly greater in patients with thalassemia than in healthy controls. This anxiety might be as a result of fear of early death, repeated blood transfusions, negative self-thoughts, concern in family formation, and different feelings in these patients [10]. In the present study, amongst the subscales, the highest score was allied to depression. Research has shown relationship between thalassemia major and depression [23]. Depression is confirmed as the most common psychiatric disorders in thalassemia patients in other studies [19]. In the study of **Marvasti et al.'s** [24], the danger of depression was much higher in patients with thalassemia compared to healthy subjects [24]. **Keşkek et al.'s** study [23] displayed It was found that not only is the pervasiveness of depression higher in patients with thalassemia compared to healthy subjects, but the severity of depression is also alarmingly higher in patients with thalassemia which needs urgent measures in these patients [23]. Depression has negative and severe impacts on physical and mental health, which may be as a result of chronic nature of the ailment the changed appearance, long treatment period, early death expectation, sense of deprivation, and social reflections, for example, family, community, and school [25].

Our study showed that the implementation of partnership care model is able to significantly improve the mental health of patients with thalassemia. **Ratanasiripong et al.'s** study [26] showed that application of educational feedback program significantly decreased anxiety, stress, and

depression [26]. **Alijany-Renany et al.'s** [13] demonstrated that the quality of life of children with thalassemia considerably enhanced, compared to control group and before intervention and after implementation of partnership care model [13]. **Ghavidel et al.** [27] showed that the implementation of partnership care model resulted in significant improvement in quality of life of hemodialysis patients in all aspects of physical, mental, and general health and life force and energy [27]. Partnership care model was like wise shown on other patients. A significant and positive outcome of the implementation of this model was approved on improving the quality of life of patients with hypertension, coronary arteries, chronic bronchiolitis, and stroke [28]. This model was implemented by **Mamene et al.**, who concluded that this model will correct the lifestyle in several indexes and diet behavior [29]. **Nayyeri et al.'s** study [30] displayed that the implementation of partnership care model is effective in increasing the quality of sleep in patients with heart failure [30]. The outcomes of all these studies, are similar to our study, which indicate the promising effect of the implementation of this model in different diseases. **Konstam et al.** [31] demonstrated that educating the approaches of controlling anxiety and cognitive treatment interventions can aid special patients recognize the physical and mental reasons of anxiety and depression and the ultimate response of these patients to education of the approaches is reduced anxiety and depression (31).

CONCLUSION

The results of the current study showed that patients with thalassemia major are faced with severe mental health problems, particularly depression, which necessitates planning of the authorities and using experienced consultants to educate life skills and how to face psychological and social problems to avoid and treat psychological disorders in these patients. Similarly, the findings of the current study showed that partnership care model is effective and useful in improving the mental health of patients with thalassemia major; therefore, regarding the efficacy of this model, besides its inexpensiveness and simplicity for families and children, implementation of such program is recommended for improvement of mental health of patients with thalassemia.

REFERENCES

1. **Khani H, Majdi M, Azad M (2012):** Quality of life of Iranian β -thalassaemia major patients living on the southern coast of the Caspian sea. Eastern Mediterranean Health Journal, 18(5): 539–545.

2. Hockenberry M(2011):Wong's Nursing Care of Infants and Children, Mosby Elsevier, 9th edition.
3. **Modell B(2008)**:Global epidemiology of haemoglobin disorders and derived service indicators. Bulletin of the World Health Organization, 86(6): 480–487.
4. **Koutelekos J and Haliasos N(2013)**:Depression and Thalassemia in children, adolescents and adults.Health Science Journal, 7(3): 239–246.
5. **Loukopoulos D(2011)**: Haemoglobinopathies in Greece: prevention program me over the past 35 years. Indian Journal of Medical Research, 134(4):572–576.
6. <https://en.wikipedia.org/wiki/Deferoxamine>
7. Sadock S(2005):Comprehensive Textbook of Psychiatry, Lippincott Williams & Wilkins, Philadelphia, Pa, USA.
8. **Mednick L, Trachtenberg F, Kleinert D et al.(2010)**: Symptoms of depression and anxiety in patients with thalassemia: prevalence and correlates in the thalassemia longitudinal cohort. American Journal of Hematology, 85(10) : 802–805.
9. **Thavorncharoensap M, Nuchprayoon I, Riewpaiboon A et al.(2010)**: Factors affecting health-related quality of life in Thai children with thalassemia. BMC Hematology, 10(10): 20-26.
10. **Yahia S, El-Hadidy M, El-Gilany A et al.(2013)**: Predictors of anxiety and depression in Egyptian thalassaemic patients: a single center study. International Journal of Hematology, 97(5):604–609.
11. Aydinok Y, Bukusoglu N, Yilmaz D and Solak U(2005): “Psychosocial implications of thalassemia major.Pediatrics International, 47(1):84–89.
12. **Kiani J, Ostovar A and Namazi s (2010)**:Effectiveness of cognitive behavioral group therapy (C.B.G.T) in increasing the self-esteem & decreasing the hopelessness of β -thalassaemic adolescents. Iranian South Medical Journal, 13(4):241–252.
13. **Alijany-Renany H, Tamaddoni A, Haghhighy-zadeh M and Pourhosein S(2012)**:The effect of using partnership care model on the quality of life in the school-age children with β -thalassaemia. Journal of Shahrekord University of Medical Sciences, 14(1):41–49.
14. **Khoshab H, Abbaszadeh A, Mohammadie E and Kohan S(2012)**:The effect of partnership care model on depression and anxiety in the patients with heart failure.Evidence Based Care, 2(2):37–45.
15. **Goldberg D(1972)**: The Detection of Psychiatric Illness by Questionnaire, Oxford University Press, London, UK.
16. **Taghv A(2001)**:Assessment of the validity and reliability of the general health questionnaire,” The Journal of Psychology, 5(4): 381–398.
17. **Tait R, French Dand Hulse G(2003)**:Validity and psychometric properties of the general health questionnaire-12 in young Australian adolescents,” Australian and New Zealand Journal of Psychiatry, 37(3):374–381.
18. **Tait R, Hulse G and Robertson S(2002)**:A review of the validity of the general health questionnaire in adolescent populations. Australian and New Zealand Journal of Psychiatry, 36(4): 550–557.
19. **Naderi M, Hormozi M, Ashrafi Mand Emamdadi A(2012)**:Evaluation of mental health and related factors among patients with Beta-thalassemia major in South East of Iran,” Iranian Journal of Psychiatry, 7(1): 47–51.
20. **Messina G, Colombo E, Cassinerio E et al.(2008)**:Psychosocial aspects and psychiatric disorders in young adult with thalassemia major. Internal and Emergency Medicine, 3(4):339–343.
21. **Sadowski H, Kolvin I, Clemente Cet al.(2002)**:Psychopathology in children from families with blood disorders: a cross-national study.European Child and Adolescent Psychiatry, 11(4): 151–161.
22. **Salehi M, Mirbehbahani N, Jahazi A and Aghebati Y(2014)**:General health of beta-thalassemia major patients in Gorgan, Iran,” Journal of Gorgan University of Medical Sciences, 16(1): 120–125.
23. **Keşkek S, Kirim S, Turhan Aand Turhan F(2013)**:Depression in subjects with beta-thalassemia minor. Annals of Hematology, 92(12):1611–1615.
24. **Marvasti V, Dastoori P and Karimi M(2006)**:Is β -thalassaemia trait a risk factor for developing depression in young adults? Annals of Hematology, 85(12):873–874.
25. **Khoury B, Musallam K, Abi-Habib R et al.(2012)**:Prevalence of depression and anxiety in adult patients with β -thalassaemia major and intermedia. International Journal of Psychiatry in Medicine, 44(4): 291–303.
26. **Ratanasiripong P, Kaewboonchoo O, Ratanasiripong N, Hanklang S and Chumchai P(2015)**:Biofeedback intervention for stress, anxiety, and depression among graduate students in public health nursing. Nursing Research and Practice, <https://www.hindawi.com/journals/nrp/2015/160746/>
27. **Ghavidel F, Mohammadzadeh S, Pirasteh H and AlaviMajd H(2009)**:Effect assessment of applyin the partnership care model on quality of life in hemodialysis patients referring to Be'sat Hospital of IRI Air Force. Journal of IRIAF Health Administration, 12(2):22–27.
28. **Mohammadi E, Abedi H, Jalali F, Gofranipour F and Kazemnejad A(2006)**:Evaluation of partnership care model in the control of hypertension.International Journal of Nursing Practice, 12(3): 153–159.
29. **Mamene M, Lakdizaji S, Rahmani A and Behshid M(2014)**:The effect of education based on the collaborative care model on the nutritional behaviors of family members of patients with type II diabetes.Medical - Surgical Nursing Journal, 3(2):99–106.
30. **Nayeri S, Golafrooz M, Sadaghi H, Amini S, Zarrabi L and Rakhshani M(2015)**:The effect of the partnership care model on the quality of sleep among patients with heart failure.Quarterly Journal of Sabzevar University of Medical Sciences, 22(2): 289–299.
31. **Konstam V, Moser D and De JongD M(2005)**:epression and anxiety in heart failure.Journal of Cardiac Failure, 11(6):455–463.