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A Comparison of Quality of Life between Adolescences with Beta Thalassemia Major and their Healthy Peers

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Abstract

Background

The chronic genetic blood disorder, thalassemia, affects Quality of life (QOL) negatively. Regarding this, if adolescences with thalassemia are treated well, they will grow into an adult who will have a good potential for participating in society. Objectives: to determine the strongest predictor of QOL, compare QOL between the adolescents with beta-type major and their peers in Abadan city.

Materials and Methods

This was a cross-sectional study; the population consisted of 65 beta thalassemia major patients and 65 healthy peers with the same ages as the witness group. The data collection tools included SF-36 questionnaire and a questionnaire for demographic information. Data analysis was performed using independent t-test, correlation and linear regression by SPSS-16.

Results

The results of the study revealed that there is a significant difference ($P < 0.05$) in the average quality of life between the two groups of the study. On the other hand, the results showed that there was a meaningful relation between different aspects of life quality and family history of thalassemia ($P< 0.05$). Also, there was a negative correlation between quality of life and the frequency of blood transfusion per year ($P< 0.05$).

Conclusion

Adolescences with beta thalassemia major do not have a desirable quality of life, therefore, this fact shows the necessity of serious reforming in various fields of health care, treatment, family, social and financial support, and rehabilitation that need more attention from health care policymakers.

***Key Word*:** Adolescence, Quality of life, SF-36, Thalassemia major.

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1-INTRODUCTION

Thalassemia major is a chronic genetic blood disorder caused by deficient synthesis of one or more hemoglobin polypeptide chains, which is passed down from generation to generation (1, 2). Beta thalassemia is the most severe form of thalassemia (3). The World Health Organization (WHO) has introduced thalassemia as the most common chronic genetic disorder in 60 global countries. Thalassemia is also the most common genetic disorder in Iran (4, 5). There are 25,000 patients with thalassemia and 3 million thalassemia carriers in Iran where beta thalassemia is uncommonly prevalent (6). Thalassemia is mostly prevalent in Mazandaran, Fars and Khuzestan provinces-Iran (7). Nowadays, life expectancy in patients with thalassemia has increased and mortality rate has significantly dropped with the help of available therapies and numerous reports around the world. Currently, the concept of quality of life (QoL) significantly determines health care delivery for these patients (8, 9). In the past, it was thought that a practitioner could provide favorable conditions for a patient with respect to using effective therapies and controlling the disease symptoms. However, evidence currently shows that improved quality of life is considerably important in treatment of a chronic disease such as thalassemia in addition to controlling the disease symptoms (10).

Duration of disease and treatment period, hospitalization and increased medical expenses, psychological state and social harm effectively cause stress in the patients with a chronic disease (such as thalassemia) and their families (11). Thalassemia has different effects on different age groups. The adolescents with thalassemia not only suffer from disease-related symptoms and treatment side effects at school age, but also the disease affects different aspects of their lives such as physical, social and psychological. They also should deal with such problems as absenteeism from school, decreased academic achievement, reduced self-esteem and inadequacy in undertaking normal tasks, feeling anxious about uncertain and unknown situations, restrictions in social communication and playing, isolation and depression. All these issues negatively affect quality of life of the patient (5, 12, 13). In addition, adolescents with thalassemia major cannot experience adulthood as their healthy peers (14). WHO has also addressed improved quality of life. Health-Related Quality of Life (HRQOL) is a broad multidimensional concept that usually includes self-reported measures of physical and mental health (15).

Baraz *et al.* in Ahvaz (2009) and Ismail *et al.* in Malaysia (2006) showed that the patients with thalassemia experience less quality of life compared to their healthy peers and families (9, 12). Proper plans could be made to resolve the patients' problems and improve their quality of life with regard to through knowledge on states of the difference dimensions of patients' QoL (16).On the other hand, it should be noted that a well-treated adolescent with thalassemia will be an adult with proper potential for social participation in the future. Therefore, no proper decision could be made as long as the information about life status of the patients is unavailable. Appropriate decisions should be made with regard to clinical findings.

Given the importance of the concept of quality of life in patients with thalassemia, high prevalence of the disease in Khouzestan province and Abadan City and lack of adequate studies in this field in recent years, the authors attempted to examine quality of life of the patients in Abadan-Iran, in order to identify various problems of the patients and effectively endeavor to improve plans and develop health and social policies to improve

quality of life and increase social participation and reduce negative effects of the disease on various aspects of quality of life of the patients by examining effects of the disease on various aspects of lives of these patients.

1-1.Objectives

The present study primarily aimed to compare quality of life between the adolescents with beta-thalassemia major and their peers. The secondary objective of the study lied in investigating the relationship of quality of life with gender, familial history of thalassemia and annual frequency of blood transfusion. Finally, the strongest predictor of quality of life was also determined.

2-MATERIALS AND METHODS

2-1. Study Design and Population

This was an observational cross-sectional study for comparison of quality of life of two groups of patients with beta-thalassemia major and their healthy peers in Abadan, Central west of Iran, in 2013-2014 (Figure.1). The first group as a case study consisted of the patients with beta thalassemia major who were hospitalized in the thalassemia ward in Shahid Beheshti Hospital in Abadan. In total, 305 thalassemia cases were documented in this ward among which 98 patients had the inclusion criteria (were eligible for the study). Finally, 65 patients consented to participate in the study. The participants were selected using an available sampling method.

Inclusion criteria were as follows: 1. between 14 to 18 years old, 2. suffering from beta thalassemia major, 3. dependent on blood transfusions and regularly visiting the hospital for blood transfusions, 4. absence of debilitating health problems, 5. had to be able to speak and read Persian. The second group consisted of 65 healthy adolescents with no history of the disease, who were selected using an available sampling method through visits to residency of the case-study group. The selected individuals were classified as the control group after consenting to participate in the study. Both groups were matched in terms of gender, age and place of residence.

Fig.1: Abadan locational, Iran

2-2. Measuring tools

The SF-36 Questionnaire for assessment of quality of life and a demographic questionnaire were used as data collections tools. Demographic information covered age, gender, education, familial history of thalassemia and frequency of blood transfusion. The SF-36 Questionnaire is designed to evaluate health of public people and specific populations, determine health policies and evaluate efficacy of the treatment. The questionnaire was used in case of many chronic diseases. This questionnaire encompassed eight dimensions and 36 items for assessment of physical, psychological and social health. The dimensions were as follows: physical functioning, role limitations due to physical functioning, bodily pain, general health, vitality, mental health, role limitations due to emotional functioning and social functioning. The SF-36 form is

a quantity Questionnaire. Score of each dimension was determined based on sum of scores of the items. The scoring method is as follows: scores 0, 20, 40, 60, 80, and 100 for 6-option multiple-choice questions, scores 0, 25, 50, 75, 100 for 5-option multiple-choice questions, and scores 0, 50, and 100 for 3-option multiple-choice questions. The scores were converted to a scale from 0 (the worst case scenario) to 100 (the best case scenario). Higher scores show better status. Validity and reliability of Persian version of the questionnaire were confirmed in Iranian population. Baraz reported reliability of the tool as 85% using Cronbach's alpha (17-20).

2-3. Methods

The scholar frequently visited thalassemia ward to meet the patients. The research objectives were explained to the patients who were ensured of confidentiality of their information. Witten consents of the patients were obtained. The questionnaire procedures were explained to them. Then, the questionnaires were distributed among the patients who filled out the questionnaires in presence of the scholar. The scholar completed the questionnaire with respect to ethical principles for those patients who were illiterate or were unwilling to fill out the questionnaire. Some information was extracted from patient records. Then, the scholar visited residency of the patients and selected appropriate and matched healthy adolescents. The questionnaire was completed by the selected individuals too.

2-4. Data analyses

SPSS version 16 was used in this study. The collected data was analyzed using descriptive-analytic statistics (independent t-test, correlation and linear regression). The independent t-test was used to compare QoL dimensions between the two groups and also, it was used for assess of relationship between QoL dimensions with gender and family history of thalassemia. Pearson correlation was used to assess correlation between QoL dimensions and annual frequency of blood transfusion. Liner regression was used to determine predictors of QoL. The significance level was 95%.

2-5. Ethical considerations

The researcher considered moral ethics through the study and, after explaining the goals of the study and optional participation. Finally, we asked the participants to read and sign the informed consent form. This study was approved in Ethics Committee of Abadan School of University Medical Science (ID number: 91.ST.006).

3-RESULTS

The results showed that the mean age was equal to 15.96 ± 1.41 years old in the case-study group and equal to 16.27 ± 1.39 years old in the control group. 50.8% of the individual were males.

In the patients group, in terms of education, 3.1% were illiterate, 10.8% were at primary schools, 24.6% were at secondary schools, 61.5% were at high schools and 17 patients (26.2%) were mentally retarded. The results also showed that 43.1% patients had a positive familial history of thalassemia. Mean annual frequency of blood transfusion was equal to 15.77 ± 2.61 times.

The results showed a significant difference in mean quality of life between the two groups. Mean quality of life was higher in the control group. In the patient group, the lowest mean was obtained in mental health (48.46 ± 25.63) and the highest mean was obtained in social function (71.77 ± 18.67). In the control group, the lowest mean was obtained in physical function (93.00 ± 9.91) and the highest mean was obtained in social function and bodily pain (100 ± 0) (Table.1).

The results showed the significant relationship of dimensions of quality of life with familial history of thalassemia (P<0.001). The quality of life was lower among the patients with familial history of thalassemia. On the other hand, the results showed that mean of all dimensions of quality of life were lower among females except bodily pain, which was equal in two genders. Sum of mean of dimensions of quality of life in females was lower than in males but the difference was not statistically significant (P >0.05) (Table.2). In addition, a negative correlation was found between dimensions of quality of life and frequency of blood transfusions. Increased frequency of blood transfusion caused decrease quality of life (Table. 3).

Results showed frequency of blood transfusions strongly predicted quality of life in adolescents with beta- thalassemia (β = -0.908 and P = 0.001) (Table.4).

Table 1: Comparison of mean score and standard deviation (SD) of dimensions of quality of life between case and control groups

Quality of life dimensions	Patients' group (n=65)	Witness group (n=65)	P value
Physical function	61.46±24.15	93.00±9.91	<0.001*
Physical role	56.15±22.84	97.15±7.17	<0.001*
Bodily pain	70.31±16.95	100.00±0.00	<0.001*
General health	51.92±22.99	98.69±5.17	<0.001*
Social function	71.77±18.67	100.0±0.00	<0.001*
Emotional role	64.46±15.69	96.92±7.79	<0.001*
Mental health	48.46±25.63	96.62±8.05	<0.001*
Vitality	49.08±24.70	95.15±9.39	<0.001*
QOL: total of means	473.62±146.93	777.54±30.05	<0.001*

Abbreviation: QoL: Quality of life; Data are presented as mean ± SD; Independent t-test was used; * Correlation is significant at the 0.05 level.

Table 2: The relationship between quality of life dimensions with gender and family history of thalassemia

Demographic variable	P value	
Quality of life dimensions	Family history of thalassemia	Gender
Physical function	<0.001*	0.324
Physical role	<0.001*	0.773
Bodily pain	<0.001*	0.883
General health	<0.001*	0.658
Social function	<0.001*	0.540
Emotional role	<0.001*	0.167
Mental health	<0.001*	0.930
Vitality	<0.001*	0.800
QOL: total of means	<0.001*	0.586

Table 3: The correlation between quality of lfe dimentions with frequency of blood transfusion (year)

Quality of life dimensions	Frequency of blood transfusion (year) (Pearson correlation)
Physical function	_ 0.779 **
Physical role	_ 0.873 **
Bodily pain	_ 0.780 **
General health	_ 0.911 **
Social function	_ 0.824 **
Emotional role	_ 0.848 **
Mental health	_ 0.886 **
Vitality	_ 0.877 **
QOL: total of means	_ 0.915 **

** Correlation is significant at the 0.01 level.

Table 4: Predictor of quality of life, with 95% confidence interval in the patients

Variables	Standardized coefficient (Beta)	P value
Age	_ 0.069	0.248
Gender	0.022	0.694
Education	0.017	0.771
Frequency of blood transfusion per year	_ 0.908	0.001 *
Family history of thalassemia	_ 0.003	0.966

Data are presented as Standardized coefficient (Beta) and P-value; Liner regression was used. * Correlation is significant at the 0.05 level.

4-DISCUSSION

The results showed that the adolescents with beta thalassemia had lower quality of life compared to their peers. The lowest mean was obtained in mental health and the highest mean was obtained in social functioning in the patient group. The results showed that quality of life had a significant relationship with familial history of thalassemia while no significant relationship was found between quality of life and gender. A negative correlation was found between dimensions of quality of life and annual frequency of blood transfusion, which strongly predicted quality of life. In this study, 26.2% of the patients were educationally retarded. Khani *et al.* showed that 36.7% of the participants were educationally retarded in Mazandaran province-Iran (2008) (2). Pakbaz *et al.* in the U.S. (2005) and Ayoub *et al.* in Saudi Arabia (2013) showed that thalassemia patients dealt with great deficiencies in terms of academic achievement (21, 22), which was due to absenteeism from school for the purpose of visiting health centers and practitioners for blood transfusion. They also suffered from decreased academic achievement, reduced self-confidence, hospitalization as well as physical and mental problems (12, 23).

At current study, the results showed that mean of dimensions of quality of life were significantly lower in the patients group

compared with the control group. These results were consistent with those obtained by Ismail *et al.* in Malaysia (2006), Ansari *et al.* in Tehran-Iran (2014), Baraz *et al.* in Ahvaz-Irann (2009), Khaledi in Kurdistan-Iran(2012) (9, 12, 24, 25).

In this study, a significant difference was found in all dimensions of quality of life between patients and the control group. However, Hadi *et al.* found no significant difference in dimensions of mental health (happiness and vitality, social functioning, role limitations due to emotional problems and mental health) between the case-study and control groups (2009) (7). The difference may be due to different methods used in the two studies. In our study, patients had no communication with the control group. Therefore, an actual difference in quality of life between the patients and healthy individual was found. The participants in the control group were selected from visitors due to similarities between the patients and the control group. This is because the visitors may experience such psychological disorders as sadness, depression and anxiety due to unfavorable situation of the patient. Moreover, various studies have shown that a family member with the disease cause a psychological crisis for all family members. Families of the patients with thalassemia suffer from emotional and psychological concerns due to frequent visits to the hospital (12).

The results also showed that the lowest mean was obtained in dimension of mental health in patients. Khani and Ansari achieved the same results too (2, 24), but confounding results were obtained in other studies (9, 12, 24, 25). The difference in different regions may be due to different scales used to assess quality of life, sample size, age group, geographical regions, race, culture, familial and societal support and health care quality.

Psychological problems are common in patients with thalassemia major. Some studies have shown that 80% of the patients with thalassemia major suffer at least from one psychiatric disorder (26, 27). Khani *et al.* showed that 46.1% of the patients were unsatisfied with their lives, which represented unfavorable psychological state of the patients with thalassemia (2). Medical care and concerns about premature death in the patients with chronic diseases greatly cause such mental disorders as anger, despair, isolation and stress (9). Shaligeram *et al.* conducted a study on 8 to 16 years old patients with thalassemia in 2007 and showed that 44% of the patients suffered from mental disorders, 67% from anxiety-related symptoms, 62% from emotional problems and depression and 49% from behavioral disorders. Mental disorders affect quality of life of the patients (28). The results of our study as well as the above-mentioned studies show that psychological disorders of the patients were less paid attention to. It is essential to develop appropriate strategies in this field due to importance of mental dimension, which can be the root of other disorders.

The results showed that although mean quality of life was lower in females than in males, no significant relationship was found between quality of life and gender. Hadi *et al.*, Ismail *et al.* and Kahani *et al.* showed no significant relationship between gender and quality of life (7, 9, 29). However, Shaligeram *et al.* and Ansari *et al.* achieved confounding results (24, 28). The difference may be due to different measurement tools, race, age groups, etc. In each region, this issue should be considered specifically according to which clinical decisions should be made.

The results showed a negative correlation between quality of life and frequency of blood transfusion. Hadi *et al.* showed that mean of dimensions of quality of life is lower in patients with more than 18-time blood transfusion compared to those with less than 18-time blood transfusion, but the difference was not statistically significant

(7). Frequent visits to health centers for blood transfusion led to absenteeism from work and school. On the other hand, the patients with frequent blood transfusion were more severely affected by the disease, which reduced the quality of life (9). Blood transfusion in the evening and at night and on weekends reduce absenteeism and improve the quality of life (30). On the other hand, annual frequency of blood transfusion strongly predicted quality of life. Therefore, patients with frequent blood transfusion should be more addressed. Furthermore, frequency of blood transfusion could be used as a predictor of quality of life. Proper strategies should be adopted for comfort-ability of the patients.

5-CONCLUSION

The findings showed that quality of life was unfavorable in terms of all dimensions in adolescents with beta-thalassemia in Abadan-Iran. Therefore, the authorities should develop serious measures and plans to improve quality of lives of these patients. Reduced quality of life in the patients may be due to health care team, familial and societal support, education and financial support. It should also be noted that adolescence is a critical period when an individual should be prepared for adulthood. If appropriate measures were not adopted in adolescence, the patients would face numerous problems in adulthood. However, proper planning for the patients in adolescent could promise a bright future for them in adulthood. Unavailable information on the patients could also restrict appropriate therapies. The study attempted to identify problems of the patients to develop proper planning. Nurses are mostly in contact with the patients and can be significantly influential in the patients' quality of life. The nurses can use the results of this study to enhance their clinical performance and training. On the other, psychological counseling for the patients and their families should be an important part of an effective therapy. Unfortunately, no counselling was given to the patients in the study. In addition, the patients incurred heavy financial costs, which could affect the treatment process. Thus, the patients should be financially supported more than ever. The results could be fundamentally used for better planning on the basis of clinical evidence for the patients in the adolescence in order to improve the quality of their lives and prepare them for adulthood.

Finally, it is recommended to conduct a similar study with a larger sample size and different age groups and other types of thalassemia in order to better clarify the problems of these patients. In addition, other disorders such as sleep disorders, mental disorders and other issues that affect quality of life should be widely examined.

6- AUTHORS' CONTRIBUTIONS

Study concept and design Mojtaba Miladinia. Acquisition of data: Elham Mousavi Nouri. Analysis and interpretation of data: Mojtaba Miladinia. Drafting of the manuscript: Mojtaba Miladinia, Elham Mousavi Nouri and Shahram Baraz. Critical revision of the manuscript for important intellectual content: Mojtaba Miladinia and Shahram Baraz. Statistical analysis: Mojtaba Miladinia. Administrative, technical, and material support: Shahram Baraz. Study supervision: Mojtaba Miladinia.

7-CONFLICT OF INTEREST: None.

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