Evaluation of the quality of care and quality of life in patients with thalassemia major that refer to thalassemia clinic of buali hospital in 2012-13

Introduction:

Beta thalassemia major is the most common genetic diseases in humans. According to clinical experience on quality of life in patients with thalassemia major and lack of consistent and reliable research in this field, this study aims to determine the status of various aspects of quality of life in patients with thalassemia major who referred to Thalassemia Clinic of BU Hospital in 2012-2013.

Material and Methods:

The present study is descriptive, analytical and cross sectional. In this study, all patients with thalassemia major who have records in Thalassemia Clinic of Bu-Ali hospital and regularly refer for blood injection and routine examinations and receiving drugs such as deseferral pill or injections were enrolled after explaining the importance of study and also SF-36 questionnaire and check lists were given based on required questions for this study, the questionnaire was composed of eight parts of the patients, questions 1,2,3,34,35,36 on general health, on physical function questions 3, 4,5,6,7,8,9,10,11,12 on physical pain questions 21 and 22, on role limitations due to physical reasons questions 13,14,15,16, social function questions 20,32, on role limitations due to psychological reasons (emotional) questions 17,18,19 and fatigue or vitality questions 23,27,29,31 were evaluated. After completing them with patients information, all data were analyzed by SPSSv16.

Results:

In this study, 40 thalassemic patients with an average age of 20.38 years that 55% were boy were studied. The mean age at diagnosis was 7.5 month and ferritin mean was 2715.75 ng/ml. All patients also underwent echocardiography and 35 patients had undergone audiometry. All of them were negative for hepatitis B and HIV, and 97.5 percent had received hepatitis B vaccine. After reviewing the patients quality of life was observed that the mean score for emotional -mental health was 64.90, general health 61.66, physical function 75.18, physical pain 69.51, role limitations due to physical reasons 77.50, social function 69.68, role limitations due to psychological reasons (emotional) 75 and fatigue or vitality 62.87 were evaluated. It was also observed that 42.5% of life quality was very good. Data analysis showed no significant relationship between age (p=0.246), gender (p=0.753), residance location (p=0.259) with quality of life in patients.

Conclusion:

After reviewing the patients quality of life was observed that there was the highest quality in limitations of physical reasons and lowest quality in general health of patients. about the quality of care datas that gived in study was in good level.

Key word : Thalassemia, major, quality of life, quality of care