Short Communication

Quality of Life in Patients Suffering from Beta-Thalassemia Major in Amirkola, Iran

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Abstract

Introduction: Thalassemia is regarded as a genetic hematologic disease that affects various aspects of patients' life. Measuring the health-related quality of life is a multidimensional concept that focuses on the disease as well as its treatment.

Materials and methods: This cross-sectional study consisted of 50 adolescents aged 12-18 years suffering from Thalassemia major, out of which 30 were females and 20 were males with the mean (±SD) age of 15.38(±2) years old. The present study was carried out applying the Kidscreen-27 health-related questionnaire.

Results: There was no statistically significant difference between urban and rural patients' scores (P-value=0.22). Comparison of quality of life amongst female and male patients indicated male patients' better scores in regard with physical well-being, psychosocial well-being and the total score of quality of life compared to the females (P-value<0.05). The total score of quality of life within adolescents with higher educated fathers was reported to be slightly higher than that of the other groups.

Conclusion: The study findings revealed that there was neither a significant difference between urban and rural patients with thalassemia major, nor a relation between adolescent patients' quality of life and their fathers' education level. Nonetheless, male patients were demonstrated to have better quality of life than females.

Keywords: Adolescents; Kidscreen-27; Quality of life; Thalassemia major,

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Introduction

Thalassemia is a genetic hematologic disease, which can be fatal if not treated properly [1]. Through the modern medical treatments, morbidity and mortality of thalassemia major has significantly decreased, however it still affects various aspects of patients' life. Stability and dynamism of the family can be affected by diagnosis and treatment of thalassemia major. Moreover, bone deformities and short stature can cause poor self-image. Frequent hospitalization for blood transfusion, subcutaneous infusion of Iron chelator, delay or absence of sexual development and reproductive impairment, as well as such complications as heart disease, bone disease, diabetes, infections and uncertainty about the future and long-term planning difficulties can be mentioned as the results of thalassemia major [2]. World Health Organization (WHO) explains quality of life as individuals' perception of their position in life in context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by an individual's physical health, psychological state, independence level, social relationships, personal beliefs and an individual 's relationship to salient features of their environment [3]. Measuring quality of life is considered as a tool to identify patients' ideas concerning the disease as well as its applicable therapies. Furthermore, it allows the patients to understand their health and preference needs for their treatment [4] Therefore, this study aimed at measuring the quality of life amongst adolescents suffering from thalassemia major in Amirkola Thalassemia Center.

Materials and Methods

This cross-sectional study consisted of50 adolescents aged 12-18 years suffering from Thalassemia major. The present study was carried out using Kidscreen-27 health-related questionnaire in March 2015. The questionnaire has five dimensions including: Physical Well-being (5items), Psychosocial Well-being (7 items), Parent Relation and Autonomy (7 items), Peers and Social Support (4items), and School Environment (4 items) [6].

Results

Our primary demographic results are as follows: There were 30 females and 20 males with the mean age of 15.38 years old, among which 50% were urban residents. Most of patients' fathers were illiterate and most of their mothers had middle school education.

Table 1 demonstrates scores for different dimensions of kidscreen-27 questionnaire completed by urban and rural thalassemia patients, according to which No statistically significant difference was observed within the patients.

Table 1: Scores of Kidscreen-27 related to Urban and Rural patients

Dimension	Patients' Mean score (SD)		P-value
	Urban	Rural	
Physical well-being	14.76 (3.52)	16.40 (2.66)	0.07
Psychosocial well-being	23.60 (5.73)	24.72 (4.42)	0.44
Parent relation and autonomy	25.48 (4.48)	26.52 (5.40)	0.46
Peers and social support	13.84 (2.87)	14.80 (3.22)	0.27
School environment	15.35 (1.87)	15.28 (3.54)	0.92
Total	93.04 (14.28)	97.72 (12.24)	0.22

Conclusion

No aspect of the questionnaire revealed a significant difference while comparing the quality of life of rural and urban patients, which is contrary to Alavi et al' s findings [7] in Shahrekurd city where the quality of life of rural children was lower than urban children. This difference can be explained by proximity of villages to cities in the northern part of Iran, access ease of people to health centers, and little difference of life standard in this area.

As Table 2 reports, comparing quality of life between female and male patients indicated that male patients had better scores in regard with physical well-being, psychosocial well-being and the total score of quality of life compared to the females

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Table 2: Kidscreen-27 scores of male and female patients

Dimension	Patients' Mean score (SD)		P-value
	Female	Male	
Physical well-being	14.80 (3.15)	16.75 (2.97)	0.03
Psychosocial well-being	22.80 (4.23)	26.20 (5.69)	0.02
Parent relation and autonomy	24.97 (4.13)	27.55 (5.72)	0.70
Peers and Social support	13.90 (3.29)	14.95 (2.61)	0.24
School environment	14.83 (2.91)	16.05 (2.52)	0.13
Total	91.30 (10.89)	101.50 (14.65)	0.007

The present study findings are in line with those of Alavi et al.' s study[8], where female patients had lower quality of life than males in regard with the physical dimension. In the same manner, Haghpanah et al. [9] in their study in Shiraz found that, females demonstrated significantly lower scores concerning body pains and emotional role

scales than males. However, it is contrary to Ansari et al's study in Tehran[2] which showed female patients had a significantly better quality of life than males. These differences can be due to female patients' better psychological quality of life in a big city like Tehran in terms of social support and healthy interactions with family and society. In addition, since boys are going through the puberty process at this age, their muscle strength are higher than girls, which aids them to do physical activities better than girls.

Comparing the quality of life of patients and their parents' education levels, the total score of the quality of life was reported to be slightly higher amongst adolescents having high-educated fathers compared to the other groups, though, this difference was not proved to be statistically significant. These findings were consistent with those of Khaledi et al. 's [10] study, in which a significant correlation was detected between the quality of life and patients' father education. This correlation can be attributed to the higher family income as a result of higher education, which could the family lead to better understand the patient's situation.

The current study revealed no significant difference between urban and rural patients with thalassemia major. Moreover, no relationship was reported between the quality of life amongst adolescent patients and their fathers' education level. Nonetheless, male patients were demonstrated to have better quality of life than females.

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