

Impact of Education on Awareness Towards Reproductive Health in Women With Beta-Thalassemia Major

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Abstract

Objectives: This study aimed to investigate the effect of nursing educational programs on the awareness of females with β -thalassemia major (β -TM) regarding their disease and reproductive health.

Methods: Thirty-nine consecutive female patients with β -TM (age range between 20 and 32 years) participated in this interventional pre-post study. All patients attended the Thalassemia Clinic of Dastgheib hospital, a referral governmental center in Shiraz, Southern Iran. Awareness of patients regarding reproductive health was evaluated by a designed questionnaire. The intervention consisted of nursing educational program regarding important issues related to reproductive health of female patients with beta-TM. Knowledge of patients was reevaluated and compared with their knowledge before education. Data were analyzed using SPSS software v.21 using Paired t-test, Pearson correlation test and Mann-Whitney test.

Results: Total awareness score significantly increased after education (mean \pm standard deviation (SD): 16.12 ± 1.67 vs. 13.69 ± 2.35 , $P < 0.001$). Increased knowledge of patients after the intervention was not significantly associated with educational level or with age of the patients ($P = 0.058$ and $P = 0.395$, respectively).

Conclusions: An educational program can be helpful in increasing awareness of females with β -TM regarding their disease and reproductive health issues resulting in increased life expectancy and quality of life.

Keywords: Awareness, Beta-Thalassemia, Reproductive Health

1. Background

The homozygous form of β -thalassemia, β -thalassemia major (β -TM), is one of the most common forms of congenital hemolytic anemia. Although regular blood transfusions and advanced therapeutic regimen of iron chelators have improved the survival and life expectancy of patients with β -TM, these patients are faced with several complications of iron-overload. It is still one of the main contributors of morbidity and mortality in this population (1, 2). Hypogonadotropic hypogonadism is amongst well documented complications, which leads to growth failure, impaired sexual development, infertility and osteoporosis in female patients with β -TM. Therefore, these patients deal with several difficulties in their reproductive and sexual health resulting in physical and psychological stress (3, 4). Obviously increased knowledge of patients towards their disease could be helpful in increasing adherence to treatment (5) as well as better coping with possible difficulties and improvement in quality of life (QOL).

2. Objectives

This study aimed to investigate the effect of educational programs on the awareness of females with β -TM regarding their disease and reproductive health.

3. Methods

Thirty-nine consecutive female patients with beta-TM aged 20 years old and above participated in this interventional pre-post study. All patients attended the Thalassemia clinic of Dastgheib hospital, a referral governmental center in Shiraz, Southern Iran. Diagnosis of the patients was based on complete blood count and hemoglobin electrophoresis. Patients that had menopause as well as patients who had no desire to participate, had some difficulties to take part in the educational program, or had severe mental disease that was diagnosed by psychiatrists, were excluded from the study. In the first step, awareness of patients regarding reproductive health was evaluated by a designed questionnaire that consisted of 20 related questions on a total scale ranging from 0 to 20. Each item was scored 0 or 1 (0: incorrect and 1: correct answer). A higher score represented higher knowl-

edge. Three hematologists evaluated the appropriateness and relevance of the questions. They reported that the instrument was an appropriate measure with good content and construct validity. Also, pilot testing was done with five patients and they reported that it was easy to understand. Reliability (internal consistency) of the questionnaire was determined and it was acceptable (Cronbach's alpha = 0.86). The protocol of the study was approved by the ethics committee of Shiraz University of Medical Sciences (grant number = 5548), and informed written consent was obtained from all patients. The intervention consisted of an educational program regarding important issues related to reproductive health in female patients with beta-TM. All of these programs were conducted by expert nurses in three sections. After one month, knowledge of patients was reevaluated. Data were analyzed by the SPSS software v.21. Descriptive data were presented as mean \pm standard deviation (SD) or median and Inter-quartile range (IQR) as well as percentages. Paired t-test was used to compare the total score before and after the educational program. The correlation of difference of total score before and after education with age was determined by Pearson's Correlation test and association of this difference with educational levels of patients was determined by the Mann-Whitney test. P values less than 0.05 were considered statistically significant. Sample size calculation was done based on the results of the pilot study using the Med-Calc software. Considering increase in mean of total scores as two (SD: 1.5), 90% power and $\alpha = 0.05$, minimum sample size was calculated as 12 patients. For higher accuracy we increased the sample size to 39 patients.

4. Results

Thirty-nine women with beta-TM, and mean age of 24.9 ± 3 years (range: 20 to 32 years), were evaluated. Regarding educational level of patients, nine patients (23.1%) were under diploma level, 23 patients (59%) had diploma and others were students or had bachelor of science (BS) degrees.

After education, total awareness score increased significantly in comparison with pre-test evaluation (mean \pm SD: 16.12 ± 1.67 vs. 13.69 ± 2.35 , $P < 0.001$).

Patients were categorized to two groups regarding educational level: group 1, diploma and under diploma and group 2, students and BS. Increased awareness of patients after the teaching program was compared between the two groups of patients. Increased knowledge of patients after the intervention was significantly higher in patients with diploma and under diploma compared with patients who were students or had a BS degree. However, it was not statistically significant (median and IQR: 3, 1 vs. 2, 2, $P = 0.058$). Also, increased awareness showed no statistically

significant correlation with age of the patients ($r = 0.140$, $P = 0.395$).

5. Discussion

In this study, 39 females with β -TM in the reproductive age range were investigated. Knowledge of the patients regarding their disease and reproductive health issues before and after the educational program was evaluated on a scale ranging from 0 to 20. Our study revealed that their awareness significantly increased regardless of their age and education level. Increased knowledge of patients with thalassemia towards their disease can be helpful in improving patient adherence to treatment (5). Psihogios et al. (3) evaluated knowledge, attitude and behavior towards reproductive health in 104 patients with β -TM. Hypogonadotropic hypogonadism was present in 52.8% of patients. Ten females reported pregnancy, from whom six patients were hypogonadal at the time of conception and they needed medical assistance to become pregnant. It was interesting that fewer than 50% of them could properly explain the risk of having a child with β -TM in a couple affected by β -TM.

Due to complexity and chronicity of the disease, patients with β -TM are influenced by considerable psychological impact resulting in emotional problems, hopelessness, and difficulty in social integration (6). Also, they suffer from decreased self-esteem, feelings of difference from others, poor self-image, need to be dependent, and anxiety problems (7). In the study by Messina et al. (8), severe psychological problems in young adults with thalassemia major were reported. In that study, based on the results of the short form, 36-health survey on 147 patients with β -TM, emotional role and social function scores were considerably lower than all other domains. They suggested that medical treatment in this population should be accompanied by psychological support. Psychological aid can be helpful not only in increased QOL of these patients but also it plays a critical role in the improvement of adherence in medical treatment. Also, Shaligram et al. (9) showed psychological problem in 44% and poor QOL in 74% of patients with β -TM. The most frequent findings were anxiety-related symptoms, and emotional problems especially depression and conduct problem.

Our study was limited due to low sample size and the lack of control group. Also our study would become more powerful if it included patients with β -thalassemia intermedia. Then the results could be compared between the two groups.

In conclusion, based on our results, educational program can be helpful in increasing awareness of females with β -TM regarding their disease and reproductive health

issues. On the other hand, due to the chronic feature and complexity of the disease, these patients faced several physical and psychological difficulties. Therefore, educational programs in different aspects of the disease, and psychological support for the patients and their families will be helpful for increasing life expectancy and quality of life of these patients.

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Footnotes

Authors' Contribution: Sezaneh Haghpanah wrote the manuscript and performed the statistical analysis; Mehran Karimi edited the manuscript. All other coauthors participated in data gathering and educational program.

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