

of children with β -thalassemia major disorder

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Abstract

Objective: To assess the effects of booklet and combining methods (lecture, video, etc.) on parents' awareness of children with β -thalassemia major disorder.

Methods: Two groups of parents ($n=30$ each) of children with thalassemia were selected randomly. Among educational programmes, in one group booklet and in the other group combined method were used. A questionnaire was designed to gather information about the disease from parents of the two groups. The data were analysed using student's t-test and Pearson's correlation, significance was considered at $p < 0.05$.

Results: There was no significant difference between the two groups in terms of the mean age, gender, level of education, job, number of affected children, and age of the child. However, in both methods of education (lecture and combined), knowledge of parents about the disease significantly increased ($p < 0.001$).

Conclusion: The education whether through booklet or combined method has a significant positive effect on increasing knowledge of the investigated groups. It is recommended that increased knowledge levels of parents can decrease the burden of β -thalassemia (JPMA 58:485;2008).

Introduction

Thalassemia is an autosomal recessive disorder resulting from mutations in genes synthesizing the α - and β -globin chains of the haemoglobin molecule. Thalassemia has a high incidence in the geographical area extending across the Mediterranean and parts of Africa, through the Middle East, India, and Southeast Asia, and into the Pacific Islands. In these areas, the carrier frequency for β -thalassemia varies from 1 to 20 percent. This disease is also one of the most common hereditary disorders in Iran.¹ According to Nozari et al.², more than two million carriers of β -thalassemia live in Iran. The prevalence of this disease in the Iranian population has been reported to be around 5-10%.³ While 85% of the affected Iranian people by thalassemia are individuals of under the age of 18 years. It is estimated that approximately 70 millions dollars annually are spent for the treatment of this disease.⁴

Chronic disorders including β -thalassemia major have a great influence on patient performance and family as a whole, causing psychosocial imbalance.⁵ The extremely stressful consequence of thalassemia causes patients face a variety of physical, psychological, and social problems.⁶ In fact, rate of psychiatric disorders such as depression and anxiety in children with β -thalassemia is higher than children with other chronic diseases.⁶ A patient with thalassemia needs to be supervised continuously to ameliorate consequences of the disease in order that he/she is able to have an active and suitable life. With proper prevention and treatment, many diseases can be controlled

before leading to the dangerous and irretrievable difficulties.⁷

Many national thalassemia preventive programmes (first one in 1996) have been conducted in Iran⁸⁻¹² that usually deal with prenatal diagnosis. Few studies however have been devoted to educational programmes. In addition, little thought was given to concern about the educational effects of parents of children with thalassemia on the reduction rate of this disease. Advances in the management of this disease may result in longer life expectancy and improved quality of life.¹³

The aim of this study was to assess the effect of booklet and combined method (lecture, video, etc.) on the awareness of parents bearing children with β -thalassemia major disorder.

Subjects and Methods

The study was undertaken at Hajar hospital, Iran in 2006. The subjects were sixty parents who had a child affected with β -thalassemia major and referred to this hospital. All the parents participated in the study. They were then randomly divided to two groups of 30 parents each: the booklet group ($n=30$) and combined group ($n=30$ each). A questionnaire was designed to gather information about the disease from parents of both the groups. The questions were simple and inquired about age, level of education, any relation with their spouse, genetic education and knowledge, how they behave with their child and some other general questions. The questionnaire comprised of 30

multiple choice questions with equal values. Score +1 for a correct answer, zero for an incorrect answer was considered. Data were analysed using student's t-test and Pearson's correlation, significance was considered at $p < 0.05$.

Results

Age of the patients in the both groups was between 1-11 years and that of their parents ranged from 20-55 years. The average age of the parents in the two educational groups of booklet and combined were 26 ± 4 years.

In the booklet group, 86.7 % were mothers, 90% married, 76.7% householders, 53.3% high-school educated, and 73.3% of the parents had family relationships. Among the affected children, 36.7% were male, 52% had an age range 5-10 years, 40% were diagnosed at twelve months, 53.3% were the first baby of the family, 36.7% were taking blood transfusion every four weeks and 56.7% were also injected desferal pump.

In the combined group, 58.6 % were mothers, 86.7% married, 60% householders, 10% high-school educated, and 52.4% of the parents had family relationships. Among the affected children, 50% were male, 73.3% had an age range 5-10 years, 59% were diagnosed at six months, 45% were the second baby of the family, 49% were taking blood transfusion every four weeks and 80% were also injected desferal pump.

In both groups of the booklet and combined, no significant relation between mean scores of knowledge and level of education was found. Also, in both groups of booklet ($p = 0.03$, $r = 0.39$) and combined ($p = 0.01$, $r = 0.42$), there were significant relationship between age of children and knowledge of parents. This means that the higher the age of the affected child, the more the knowledge of the parents on thalassemia.

No significant differences were found among the two groups tested in terms of the mean age, gender, level of education, job, number of affected children, and age of the child. However, education in each of the booklet and combined groups had significant positive effect on increasing their knowledge about the disease (for the booklet group $p < 0.01$; for the combined group $p < 0.001$).

Regarding the age of parents of the booklet and their knowledge of thalassemia, no significant relations were observed. However, there was a significant relation between the age of parents and their knowledge ($P = 0.04$, $r = -0.38$), so that those parents with lower ages had higher knowledge of thalassemia disorder.

Comparing the mean scores of parents who were not previously educated with those educated showed that there was no significant statistical relationship. A test of

analysis variance (ANOVA) showed that there were significant differences between mean scores of the both groups ($p < 0.01$).

Discussion

This study showed that in both groups of booklet and combined educational programmes, no significant difference in relation to the mean age, gender, level of education, job, number of affected children, and age of affected individuals was observed. This agrees with other studies^{14,16} which found that education of parents about thalassemia could have a significant effect in the prevention and consequences of the disorder. In fact, the most efficient way to reduce risks of having affected children with β -thalassemia major is by increasing knowledge of their parents in relation to the disease. The results of this study showed that our educational strategies to reduce the deleterious consequence of β -thalassemia were very effective.

Thalassemia is the most common genetic disease worldwide. About 150 million people (3% of the world population) are carriers of β -thalassemia.¹⁷ Thalassemia major requires long life specialty care and an expensive supportive system.¹⁸ While thalassemia is a major health problem, the Iranian thalassemia programme is far from complete or perfect.¹⁹ A national preventive thalassemia programme has been developed by Iranian scientists about 14 years ago.

Living and coping with this disease is complex and a dynamic process which requires social support in particular for parents of the patients.²⁰ It has been found that the social support for the β -thalassemia major is positively correlated with self-care behaviour. Young people affected with β -thalassemia major have lots of worries and difficulties concerning their disease. In fact, besides the medical aids, the patients need to be psychosocially supported by the parents. The affected young children have to cope with resources and strategies in order to live a "normal life". Except other health providers, i.e. physicians and nurses, parents are the major source of support to the patients. Having knowledge of the disease, parents can struggle to limit the consequences of the disorder.

The education whether through the booklet or combined has a significant positive effect on increasing knowledge of the investigated groups. In the current study both methods caused the level of knowledge to be increased. The same results were found by Arab and Abbaszadeh,²¹ where education of β -thalassemia increased knowledge among the students.

It is recommended that increased knowledge levels of health employers and community education can reduce the

β -thalassemia consequences. In spite of this, thalassemia disorder has not been taken seriously by health experts. The role of community education and family has also been ignored.²² The education of parents who have children with β -thalassemia should be done formally. In addition, to increase knowledge of community in relation to thalassemia disorder, efficient programmes with cooperation of related organizations including thalassemia society should be provided. The educational role of health providers must not be ignored. These groups have more contact with mothers and pregnant women therefore, they have to acquire more information about β -thalassemia major in order to be effective for the patients.²³

Conclusion

There is limited knowledge of accurate frequency and distribution of thalassemia disorder in the developing countries including Iran. For making prevention and treatment of the disease effective, the most proper strategies are required. As there is no absolute treatment for this disease, and the treatment being expensive, other methods including parents' education must be replaced. This study showed that both booklet and combined methods have positive significant effect due to parents' awareness on β -thalassemia disease.

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