

## ENHANCEMENT OF PARENTS' AWARENESS ABOUT $\beta$ -THALASSEMIA MAJOR DISORDER THROUGH TWO EDUCATIONAL PROGRAMS

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### ABSTRACT

**Objective:**  $\beta$ -thalassemia is one of the most common hereditary diseases in Iran. While many national thalassemia preventive programs have been conducted in Iran, little thought was given to the educational effects of parents of children with thalassemia. This study aimed to investigate how education of parents by means of lecture and/or booklet may lead to reduction of the  $\beta$ -thalassemia major disorder.

**Methodology:** Using three groups of parents (n = 30 each; two cases and one control group) of children with thalassemia and two educational methods (booklet and lecture) the effect of education on parents' awareness about the disorder was assessed.

**Results:** The results show that the educational programs have significant positive effect on increase in knowledge of parents about the disease. No significant differences were found between the three groups tested in terms of the mean age, gender, level of education, job, number of affected children, and age of the child. However young parents were better educated as regards knowledge about  $\beta$ -thalassaemia disorders.

**Conclusion:** Efficient educational programs initiated for the parents can help reduce  $\beta$ -thalassemia major disorder.

**KEYWORDS:**  $\beta$ -thalassemia major, Parents' education, Iran.

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### INTRODUCTION

$\beta$ -thalassemia major, or Cooley's anemia, is a genetic disorder which leads to dyserythropoiesis, resulting in regular blood transfusions.<sup>1</sup> It is most common among people of Mediterranean descent as well as the Arabian Peninsula, Africa, east south Asia and southern China.<sup>2,3</sup>  $\beta$ -thalassemia major is also one of the most common hereditary disorders in Iran.<sup>4</sup> Falling within the so-called Thalassemia-Belt, Iran has a high thalassemia carrier rate. According to Nozari et al.<sup>5</sup> more than two millions carriers of  $\beta$ -thalassemia live in Iran. While 85% of the affected Iranian people by thalassemia are individuals of under the age of 18 years, it is estimated that their annual treatment cost is around \$70 millions.<sup>6</sup>

There is limited knowledge of accurate frequency and distribution of thalassemia

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disorder in the developing country.<sup>7</sup> For prevention of the disease to be effective; the most appropriate strategies are required. Many national thalassemia preventive programs (first one in 1996) have been conducted in Iran<sup>8-13</sup> which usually deals with prenatal diagnosis. Few studies however have been devoted to educational programs. In addition, little thought was given to the effects of education on parents of children with thalassemia on reduction of this disease. Advances in the management of this disease may result in longer life expectancy and improved quality of life.<sup>14</sup>

Since some patients throughout their life need periodically and repeatedly to be confined to bed with nursing care therefore, parents' education can have a significant role in supporting patients who suffer from the disease. Nurses can help to increase knowledge of families' having children with thalassemia disorder. We report that how education of parents by means of lecture and/or booklet may lead to reduction of the  $\beta$ -thalassemia major disorder.

### METHODOLOGY

The study was undertaken at Hajar hospital, Iran in 2006. The subjects were ninety parents who had a child affected by  $\beta$ -thalassemia major. All the parents participated in the study. They were then randomly divided into three groups of 30 parents each: the control group (n = 30) and two cases group (n = 30 each). For the two groups of cases, two methods of education; lecture and booklet were used. No method was considered for the control group. A questionnaire was designed to gather some information about the disease from parents of all three groups. The questions were designed to be simple and consisted of questions such as

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. Scores between 0-10 were classified as "weak awareness", 11-20 as "fair awareness" and 21-30 as "good awareness" about the disease. The questionnaire data were collected, the validity of the questionnaires was tested by comparing. Data were analyzed using descriptive and inference statistical techniques. To determine the statistical relationships, student t-test and Pearson's correlation tests were used. Significance was accepted at  $P < 0.05$ . Table-I compares the specifications of each group.

### RESULTS

No significant differences were found among the three 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 lecture and booklet groups had significant positive effect on increasing knowledge of the parents about the disease (for the booklet group  $P=0.00$  df 29  $t = 6.2$ ; for the lecture group  $P = 0.04$  df 29  $t = 2.16$ ). Nevertheless, no significant relationships were found between the scores of knowledge of lecture and booklet groups after the education ( $P = 0.39$  df 29  $t = - 0.88$ ).

As regards the age of parents of the booklet group and their knowledge of the thalassemia, no significant relationships were observed. However, there was a significant relationship between the age of parents and their knowledge ( $P = 0.04$ ,  $r = 0.38$ ), as parents with lower

Table-I: Parents' specifications of children with thalassemi Figures are in percentages.

Group	Mother	Married	Householder	High-school educated	Family relations
Lecture	83.3	83.3	66.7	53.3	66.7
Booklet	86.7	90	76.7	43.3	26.7
Control	86.7	83.3	66.7	43.3	40

ages had higher knowledge of thalassemia disorder.

In the lecture group there was a significant relation between mean scores of knowledge and level of education ( $P = 0.04$  df 29  $F = 4.79$ ). Also, in both groups of the lecture ( $P = 0.04$ ,  $r = 0.36$ ) and booklet ( $P = 0.03$ ,  $r = 0.39$ ) there were significant relationships between age of children and knowledge of parents. This means that the more age of the affected children, the more knowledge of their parents in relation to thalassemia.

As regards the knowledge before education, mean scores of people who had not previously been educated with those educated. There was no significant statistical difference. After education the results showed that there was an increase in the knowledge score in the lecture and booklet groups with no change in the control group. A test of analysis variance (ANOVA) showed that there were significant differences between mean scores of the three groups ( $F = 20.1$  df 89  $P = 0.00$ ). Finally, level of knowledge in the control group did not increase and most of the groups had "fair awareness" of the disorder.

## DISCUSSION

The lack of significant difference in the three groups of the current study in relation to the mean age, gender, level of education, job, number of affected children, and age of affected individuals are parallel with other studies<sup>15,16</sup> which found that education of parents about the thalassemia could have significant effect in the prevention and reduction of the disorder. In fact, the most efficient way to reduce risks of having affected children with  $\beta$ -thalassemia major is by increase in knowledge of their parents in relation to the disease.

As there appears to be not an absolute treatment for this disease, and the treatment being expensive, other methods including parents' education must be applied for prevention of the disease. Due to the usage of nearly 25% of the annual blood production in Iran, utilisation of a national thalassemia preventive program has become a health care priority in

the country. Besides the medical aids, the patients need to be psychosocially supported by the parents. Having knowledge of disease, parents can help to limit the incidence of this disorder. The results of this study show that our educational strategies to reduce the deleterious effects of  $\beta$ -thalassemia were very effective.

The prominent role of parents' education in the prevention of  $\beta$ -thalassemia is evident from the fact that Sicilian population with poor pre marriage knowledge of the couples about the disease resulted in 62.5% of the affected children. This problem could have been reduced by improvement of the parents' health education.

Both methods of the lecture and booklet increased the level of knowledge in relation to the disease. Similarly, the results of McNaull et al.<sup>17</sup> showed that the method of recombinant education (video, poster, booklet and lecture) is better than education per se. In fact, the effect of lecture on the level of knowledge appears to be more effective than education through poster and/or booklet.<sup>18</sup>

The study shows that in the lecture group, no significant relationships between age of parents and their knowledge about thalassemia were found and the younger parents had higher knowledge. However, in the education group by method of the booklet, a significant relationship between age of parents and their knowledge was evident. This is due to the fact that elderly parents are less keen to learn. This occurred in the lecture group as in this group parents heard the lectures just once. However in the booklet group, parents themselves read the contents and repeated it many times and therefore, the age of parents had no effect on their knowledge.

The results of the booklet group show that there were no significant relationships between level of parents' educations and their knowledge about the disease even though mean scores of knowledge were greater in higher-educated people than the others. This is in contrast with the lecture group in which there was a significant relationship between mans scores

of parents' knowledge and their education. Thus, it appears that there is a direct relationship between education and health.

It is recommended that increase in knowledge levels of health employers and community education can reduce the  $\beta$ -thalassemia disorder. In spite of this, thalassemia disorder has not been considered seriously by health experts. The role of community education and family has also been ignored.<sup>19</sup> Thus the education of parents who have children with  $\beta$ -thalassemia should be done formally. In addition, to increase knowledge of community in relation to thalassemia disorder, efficient programs with cooperation of related organizations including thalassemia society should be initiated. The educational role of health providers must not be ignored either. These groups have more contact with mothers and pregnant women therefore, they have to acquire more information about  $\beta$ -thalassemia major in order to be effective for the patients.<sup>20</sup> To study the effect of educational programs for the whole community including parents of thalassaemic children more studies need to be done.

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