IJBC 2014;6(4): 177-181

The Effect of Knowledge, Attitude and Practice on the Function of Thalassemic Patients

Kourorian Z[1], Azarkeivan A[2]*, Hajibeigi B[3], Oshidari A 4, Shirkavnd A[5]

1. Department of Research and Development, Ronak pharmaceuticals, Tehran, Iran.
2. Blood Transfusion Research Center, High Institute for Research and Education in Transfusion Medicine, Thalassemia Clinic, Tehran, Iran.
3. Research Center, Iranian Blood Transfusion Organization (IBTO),
4. Department of research and development, Ronak pharmaceuticals, Tehran, Iran.
5. Department of medical physics, Tehran University of Medical Sciences, Tehran, Iran.

***Corresponding Author:** Azarkeivan A, Email: azazarkeivan@yahoo.com*

Submitted: 14-07-2014 , Accepted: 09-08-2014

Abstract

Background: In thalassemia major as a chronic disease patients need to require information about the disease processes and therapeutic interventions. The aim of the present study was to evaluate the knowledge, attitude, and practice behavior of thalassemic patients.

Patients and Methods: This was a cross-sectional descriptive knowledge, attitude and practice study conducted in Zafar adult thalassemia clinic, Tehran, Iran, with a simple random sampling. The questionnaire was designed by a research team including an expert physician involved in counseling and education of thalassemic patients for many years.

Results: One hundred and ninety thalassemic patients entered the study. Ninety nine patients (52.1%) were female, 91(47.9%) were male, with age range of 14 to 48 years (mean 26.79 ±5.96). Results of the knowledge part of the questionnaire indicated that 39 % of patients had poor information about thalassemia 32.5% had little information and 28.5% had satisfying information. Fifty eight percent of patients had a positive attitude towards their appearance, quality of life and social relations. Positive attitude was significantly correlated with good knowledge (p=0.009). Low knowledge about the disease had caused treatment to be irregular and improper. Based on our questionnaire 144 patients (75.8%) were depressed which was significantly higher among females (P=0.002).

Conclusion: Increasing knowledge, attitude and practice awareness among thalassemic patients considering their disease and treatment methods has a positive influence in their quality of life. This will improve their performance to deal with their lifelong disease and its challenges during the course of treatment.

Keywords: Thalassemia, knowledge, attitude, practice, Iran.

Introduction

Hemoglobinopathies, especially ß-thalassemia, are among important health problems in Iran [1-3]. The high prevalence of ß-thalassemia drains health resources and drastically effects family and personal life of patients [4]. Thalassemia is found in about 60 countries with the highest prevalence in the Mediterranean region, parts of North and West Africa, the Middle East, the Indian subcontinent, southern Far East and southeastern Asia, together composing the so-called thalassemia belt [5]. About 150 million people worldwide carry ß-thalassemia genes. The genes are particularly prevalent in Italy and Greece. Other regions with a high gene frequency are Sardinia (11-34%), Sicily (10%), Greece (5-15%) and Iran (4-10%) [6-8]. In Iran 18,600 cases of major thalassemia were reported in year 2002 [9]. The gene frequency of ß-thalassemia is high and varies considerably from area to area, having its highest rate of more than 10% around the Caspian Sea, and Persian Gulf. The prevalence of the disease in other areas is between 4% and 8%. In Isfahan, the frequency rises again to about 8%. In the Fars province, in southern Iran, the gene frequency is also high and reaches 8-10% [8].

Not long ago, children born with thalassemia seldom survived their first decade of life. Nowadays, the survival of patients with ß-thalassemia major is increasing because of better treatment and supportive measures [10]. Despite the fact that Iran is situated in the thalassemia belt few studies in terms of knowledge and need-assessment of thalassemic patients have been performed. It is essential to investigate the knowledge and educational needs of thalassemic patients to take a positive step toward their health support. Nurses' participation in the education of patients and enhancing their knowledge according to their educational needs is considered as one of the academic and professional responsibilities of nurses.[12]. Pakbaz et al. in their study showed that thalassemic patients are suffering from low quality of life due to excessive problems; which can be overcome with training [11]. Brunner and Suddarth believe that one of the basic needs of human beings is the need for learning, training and data acquisition [13]. Phipps et al. have confirmed that training the individuals based on their health needs is essential and identification and evaluation of potential powers of patients is very important in their education [14].

The aim of the present study was to evaluate the knowledge and attitude of major thalassemic patients towards subjects such as blood transfusion, iron overload, and different brands of deferoxamine.

Patients and Methods

This was a cross-sectional descriptive KAP (knowledge, attitude and practice) study conducted in Zafar adult thalassemia clinic, Tehran, Iran, related to Iranian Blood Transfusion Organization (IBTO). Our inclusion criteria were patients' tendency, type of thalassemia, and age of at least 14 years. We used a simple randomization method to choose the participants from patients who referred to the clinic and had the inclusion criteria.

The study questionnaire for assessing the knowledge and attitude of the patients was designed by a research team including an expert physician involved in counseling and education of thalassemia for many years and a pediatrician with appropriate history of practice in the field of thalassemia. The reliability of the questionnaire was controlled by the test-retest method. The epidemiologic characteristics of the patients were assessed by 26 questions. The knowledge part included 9 questions which were answered by yes, no, or a little. Also, for accessing the attitude 20 questions were asked with a 4 options Likert of absolute agreement, relative agreement, relative disagreement, and absolute disagreement.

Practice part the questionnaire included 20 questions. The study was fully explained to the patients prior to their participation and informed consent was obtained from the participants or their legal guardians. The study was approved by the IBTO ethics committee. Descriptive statistics were used to present the demographic data, and the correlations of variables were studied using Spearman Chi square test. Odds ratios and 95% confidence intervals (CI) were calculated. A p value of <0.05 was interpreted as significant.

Results

One hundred ninety thalassemic patients were asked to complete the questionnaires. There were 99 females and 91 males (52.1% female and 47.9% male). The age of participants was in the range of 14 to 48 years (mean age 26-79 ±5-96). The mean age of thalassemia diagnosis was 17± 20.3 months and in 3.7% of patients the diagnosis was made after 2 years of age. One hundred and seventy two patients (90%) had major thalassemia and the rest of patients had intermediate or alpha thalassemia (Table1). In 47% of cases there was other thalassemic sibling in their family.

Regarding the formal educational level 23 patients (11.5%) did not finish high school, 101 patients (53.2 %) finished high school, and 67 patients (35.3%) had a university degree. Forty eight patients (25.3%) declared themselves as unemployed (Table2).

Thirty females and 22 males were married. Among 52 married patients only 31 patients had genetic counseling for marriage and they ignored it afterwards (Table 3). Because Zafar Clinic is a referral center so patients came from different parts of Iran for treatment (Table 4).

The lack of puberty among females was the most prevalent complication with 21.5 % (95% CI 15.73-27.46) of patients having this problem. Hepatitis was found in 14.7 % (95% CI 9.66-19.73) of patients, diabetes in 11.6 % (95% CI 7.06-16.14), cardiac disease in 10.5 % (95% CI 6.13-14.87), growth disorder in 6.8% (95% CI

3.22-10.38), hypothyroidism in 5.3% (95% CI 2.13-8.47), the lack of puberty among males in 1.6%, hypoparathyroidism in 1.1% and other disorders in 2.1% of patients. Ninety one patients 47.9 % (95% CI 40.79-55.01) did not have any complication. Seventy five patients (39 %) had poor information about thalassemia, 62 patients (32.5 %) had little information and 54 patients (28.5 %) had satisfying information. Out of all patients 48.5% gained their information through health centers (physicians, nurses, etc.).

No statistically significant correlation was detected between the knowledge and gender (p=0.9) or any other demographic parameters, except that the patients with university education had a better knowledge compared to others.

One hundred and ten patients (58%) had a positive attitude towards the appearance, quality of life and social relation. Positive attitude was significantly correlated with good knowledge (p=0.009). However, the majority of the patients indicated that at least sometimes they felt different from others because of their thalassemia. Based on the questionnaire 144 patients (75.8%) were depressed and there was a significant association between depression and the sex (depression was higher among females P=0.002).

Low knowledge about the disease had caused treatment to be irregular and improper. Seventy five patients out of 190 patients had a regular control and management for their disease. One hundred and fifty six used deferoxamine mesylate (130 patients used Desferal® and 26 patients used Desfonak®), and 34 patients used a combination therapy (injection and oral). Sixty four percent of patients used 2.5 ml sterile water for deferoxamine mesylate solvency while 31% of them used 3.5ml and only 5% used 5ml. This finding can explain prevalence of allergic reactions among patients (Table5). The method of Deferoxamine mesylate administration was subcutaneous pump in all patients. The most common problem with this drug was local irritation in 78% of patients. Forty five out of 190 patients used Vitamin C.

Discussion

In this study, our demographic findings such as age, the maximum age at initial diagnosis, age at onset of repeated blood transfusions, iron chelators usage, having someone in the family with major thalassemia were the same as other studies [15-17].

Our patients' emotional state, such as sadness and being bored was better compared to Tabarsi et al. study [18]. The psychological problems such as being tired from the long treatment, disappointment, low self confidence and lack of motivation for continuing the standard treatment were their patients' common emotional problems [18].

In a study conducted in Mazandaran province of Iran by Kousarian et al. [19] despite the lack of patients' knowledge, their attitude was positive but the performance pattern of these patients towards drug usage and treatment compliance was not acceptable. They suggested that the use of various educational methods with emphasis on their patients' believes and practices may be very beneficial to their health state.

Obviously, the problem of low motivation to continue lifelong treatments is particularly exaggerated because of the daily painful infusions of iron chelators. Many of our patients had negative attitude toward the usage of subcutaneous iron chelators especially Desfonak which was related to unfamiliarity with this new brand of drug.

It was also observed that a large number of thalassemic patients had problems with Desferal injection. In a study by Izadyar et al. Subcutaneous injection of Desferal caused many local problems such as local irritation (stiffness, pain, erythema and swelling in injection site), in addition to systemic side effects [20]. In various other studies such local problems have been reported as the most common problems among patients on iron chelation therapy [20-23].

In an analytic case control study 250 thalassemic patients and 51 controls were assessed considering their quality of life using WHOQOL-BREF questionnaire including overall health, physical, psychological, social, and environmental relationship [24]. The results showed that the quality of life in all 6 dimensions was lower in patients compared to the controls (P< 0.05). Also they found that higher education level; lower ferritin level and using oral iron chelators were associated with better quality of life scores. On the other hand, cardiac disease, hepatitis C and history of psychiatric disorders were associated with impaired quality of life. The authors concluded that higher education of the patients may improve their quality of life [24].

Conclusion

Increasing knowledge, attitude and practice awareness among thalassemic patients about their disease and treatment has a positive influence in their quality of life. This will improve their performance to deal with their lifelong disease and its challenges during the course of treatment.

Acknowledgment

We gratefully acknowledge the Ronak pharmaceutical Co. We also would like to appreciate the kind support of Sara Daniyalzadeh and the staff at Zafar adult thalassemia clinic for their arrangements and administrative efforts.

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