

Original Article

Knowledge, attitude, and preventive practice of major thalassemia patients regarding the importance of calcium and Vitamin D

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ABSTRACT

Objectives: Many Iranian studies have reported the high prevalence of osteoporosis and low bone mass in patients with thalassemia. Considering the importance of prevention in lowering the risk of osteoporosis and its complications in patients with thalassemia major (TM), the present study was conducted to assess the knowledge, attitude and preventive practice (KAP) of a group of TM patients regarding the importance of calcium and Vitamin D supplementation and its role in preventing osteoporosis. **Materials and Methods:** The cross-sectional study was conducted on all adult beta-TM patients (200) who visited the Specific Disease Center, in the Iranian Capital, Tehran. A four-section questionnaire on demographic, lifestyle, and socioeconomic information as well as their KAP about the importance of calcium and Vitamin D in preventing osteoporosis in TM patients was filled out for each patient. **Results:** About 63%, 62%, and 33% of those with poor knowledge, attitude and practice towards the importance of calcium and Vitamin D were not physically active, correspondingly. There was no association between age and gender and knowledge or attitude score. **Conclusion:** While a large number of the studied population consumed Ca and Vitamin D supplementation, their poor knowledge about the importance of these supplements points out the need for educating TM patients and their families about the importance of calcium and Vitamin D supplementation in preventing osteoporosis.

Key words: Bone health, Ca-D supplementation, Iran, osteoporosis, thalassemia

INTRODUCTION

Beta Thalassemia is the most common inherited single gene disorder in the world.^[1] It is estimated that there are 270 million carriers of thalassemia worldwide, of which 80 million carry β -thalassemia genes.^[2] The genes are particularly common in Italy and Greece.

Among the eastern Mediterranean region, Iran is one of the major centers for individuals with β -thalassemia.

Considering the high consanguinity among the Iranian population, it is estimated that there are between 2 and 3 million β -thalassemia carriers and 25,000 patients in Iran.^[3]

Nowadays, new treatment modalities have increased longevity in patients with thalassemia major (TM). Several studies, however, have shown that the increased lifespan and long-term treatment duration in these patients is associated with various complications, the most important of which is severe bone deformities which happens early in life.^[4] The etiology of reduced bone mass in this group is not clear. Factors such as hormonal deficiency, especially gonadal failure, bone marrow expansion, increased iron deposition, desferrioxamine toxicity, and calcium/Vitamin D deficiency are considered as the most important causes of bone loss in this group.^[5,6] The

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condition is also considered as the major cause of morbidity in TM patients of both genders, being responsible for up to 20% of vertebral fractures in this group.^[7]

Many studies have therefore reported that addressing bone health in adolescent thalassemic patients would help lower the risk of developing osteoporosis later on in life.^[8,9] This is mainly because several studies have confirmed that thalassemic adolescents who fail to progress normally through puberty also fail to preserve adequate bone mineralization later on.^[10]

Many Iranian studies have also reported the high prevalence of osteoporosis and low bone mass in the patients with thalassemia.^[11] According to a study conducted in the Iranian Capital, Tehran, the prevalence of osteoporosis at the lumbar spine and femoral neck of teenagers with TM was 50.2% and 11.0%, respectively.^[12]

Considering the importance of prevention in lowering the risk of osteoporosis and its complications in TM patients, and the fact that educating the patients and their families and improving their awareness is of great value,^[13] the present study was conducted to assess the knowledge, attitude, and preventive practice of a group of TM patients regarding the importance calcium and Vitamin D supplementation and its role in preventing osteoporosis. It should be asserted that to our knowledge no knowledge, attitude, and practices (KAP) study in this regard has ever been conducted on TM patients.

MATERIALS AND METHODS

The cross-sectional study was conducted on all adult beta-TM patients (n : 200), registered in the Specific Disease Center, established to help patients with maladies such as thalassemia, in the Iranian Capital, Tehran. The study was approved by the Ethical Board Committee of Tehran University of Medical Sciences.

All the individuals signed an informed consent and then a four-section questionnaire was filled out for each patient. The first part of the questionnaire dealt with patients' demographic (age, gender, level of education, occupation, marital status, and menopausal status), lifestyle (physical activity, nutritional habits (Vitamin D and calcium-rich food) and smoking habits), and socioeconomic status (SES) information. The other three parts assessed their KAP about the importance of calcium and Vitamin D supplementation in preventing osteoporosis in TM patients. The questions in each section were selected based on an extensive literature review and expert opinion panel.

Being involved in effective physical activity was defined as exercising for a total of 30 min for least 3 days a week (90 min/week). In order to assess calcium and Vitamin D intake, the patients' habit of eating 19 of the most important calcium and Vitamin D-rich foods during the past month was studied.

To assess the SES of the patients, principle component analysis was performed. In this regard, the family assets including refrigerator, washing machine, dishwasher, personal computer, family car, cellular phone, and access to internet were subjected to varimax rotation and then the three variables with the criterion of eigenvalues exceeding one were considered as the main contributors to the component. The first principal component, which explained 30% of the total variance, was designated as the SES and was used to divide patients into SES tertiles (low, medium, high).

The knowledge section consisted of 15 questions about the risk factors, symptoms, complications, diagnosis and prevention of osteoporosis. There were 17 questions in the Attitude section to assess the individual's favor/disfavor toward interventions to lower osteoporosis risk. The last section (practice) was to assess supplementation use (Ca and Vitamin D supplements) by each patient to prevent osteoporosis.

Total score was obtained by adding the points given for each correct answer in each section. Scores ≤ 10 showed poor knowledge/attitude, whereas those above 10 were considered acceptable.

The content validity of the questionnaire was approved by an expert panel. A reliability coefficient of 0.83 was reported based on a pilot study on 20 patients.

The SPSS version 16 (Chicago, IL) was used for analysis. Normal distribution of the quantitative variables was assessed using Kolmogorov–Smirnov test. Chi-square, ANOVA, and Student's *t*-test were performed. $P < 0.05$ was considered significant. Logistic regression was applied to assess the effect of various factors on the individuals' knowledge, attitude, and practice. Variables with $P < 0.2$ in the univariate analysis entered the multivariate logistic regression (MLR) analysis.

RESULTS

Two hundred patients with the mean age of 29.88 ± 8.41 years, ranging from 18 to 71 years, were recruited. About 54.5% of the studied individuals (109) were female. Table 1 outlines the demographic information of the patients.

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The mean score in the knowledge and attitude section was 10.6 ± 2.22 , ranging from 4 to 14, and 10.49 ± 2.91 , ranging from 0 to 16. About 91% (182 individuals) had heard about osteoporosis, mostly from healthcare providers (52.5%) and media (19%). About 50 (25%) had poor knowledge about the importance of calcium and Vitamin D supplementation in preventing osteoporosis, particularly among TM patients.

Married and employed patients as well as those with an academic degree attained a significantly higher score in the knowledge section [Table 2]. 105 (52.8%) had

acceptable attitude towards the importance of calcium and Vitamin D supplementation. Individuals with an academic degree scored higher in the attitude section. There was no association between age and gender and knowledge and attitude scores [Table 3].

The variables which significantly influenced knowledge, attitude, and practice in the univariate analysis were then entered in MLR analysis [Table 4]. According to the results, the score attained in the knowledge section was positively correlated with that in the attitude part. In other words, each score increase in knowledge score increased odds of having a good attitude in this regard by 67%. Moreover, the odds of having relative good knowledge in subjects with primary education were lower (74%) than those with an academic degree (odd ratio: 0.26, 95% confidence interval: 0.09–0.73).

One hundred and seventeen (58.5%) TM sufferers were not engaged in any type of physical activity. From among this group, 69 (63.3%) were female and 48 (52.7%) were male ($P = 0.13$). There was no significant difference between the number of individuals engaged in physical activity based on the patients' age ($P = 0.07$), marital status ($P = 0.145$), level of education ($P = 0.94$), occupation ($P = 0.197$), and SES ($P = 0.843$). About 63%, 62% and 33% of those with poor knowledge, attitude, and practice toward the importance of calcium and Vitamin D were not physically active, correspondingly.

Table 1: Demographic characteristics of the studied individuals (n=200)

| | Mean±SD |
|------------------------|------------|
| Age (years) | 29.88±8.41 |
| | n (%) |
| Male/female | 91/109 |
| Marital status (%) | |
| Single | 128 (64) |
| Married | 72 (36) |
| Level of education (%) | |
| Primary | 36 (18) |
| Secondary | 81 (40.5) |
| Academic | 83 (41.5) |
| Employment status (%) | |
| Employed | 101 (50.5) |
| Unemployed | 72 (36.0) |
| Students | 27 (13.5) |

SD=Standard deviation

Table 2: Mean scores attained in each section based on the demographic characteristic of the studied population

| | Knowledge | | Attitude | | Practice | |
|----------------------|------------|----------------|------------|----------------|-----------|----------------|
| | Mean | P ^y | Mean | P ^y | Mean | P ^y |
| Gender | | | | | | |
| Female | 10.39±2.15 | 0.456 | 10.81±2.79 | 0.430 | 6.15±1.19 | 0.257 |
| Male | 9.57±2.28 | | 10.09±3.01 | | 5.65±1.12 | |
| Marital status | | | | | | |
| Single | 9.82±2.21 | 0.047* | 10.35±2.79 | 0.953 | 5.91±1.19 | 0.788 |
| Married | 10.43±2.16 | | 10.66±3.10 | | 6.02±1.12 | |
| Level of education | | | | | | |
| Primary | 8.72±2.30 | 0.004* | 10.11±3.06 | 0.008* | 5.94±1.26 | 0.312 |
| Secondary | 10.08±2.16 | | 8.89±3.02 | | 6.09±1.14 | |
| Academic | 10.62±2.02 | | 11.24±2.57 | | 5.81±1.14 | |
| Employment status | | | | | | |
| Employed | 10.44±2.21 | 0.032* | 10.81±3.02 | 0.284 | 5.96±1.18 | 0.671 |
| Unemployed | 9.83±2.10 | | 10.19±2.97 | | 6.01±1.20 | |
| Students | 9.30±2.41 | | 10.07±2.25 | | 5.96±1.17 | |
| Socioeconomic status | | | | | | |
| Low | 10.21±2.44 | 0.747 | 10.68±2.85 | 0.506 | 6.01±1.21 | 0.833 |
| Middle | 9.82±2.19 | | 10.14±2.57 | | 5.89±1.22 | |
| High | 10.14±2.05 | | 10.62±3.25 | | 5.9±1.09 | |

^yChi-square, *p-value less than 0.05 considered significant

Table 3: Univariate analysis of the demographic variable and their effect on the knowledge, attitude of practice categories

| | Knowledge (good/poor) | | | Attitude (good/poor) | | | Practice (good/poor) | | |
|----------------------|-----------------------|-----------|--------|----------------------|------------|--------|----------------------|-----------|------|
| | OR | CI | P | OR | CI | P | OR | CI | P |
| Age | 1.02 | 0.97-1.08 | 0.29 | 0.99 | 0.95-1.04 | 0.917 | 1.04 | 0.96-1.12 | 0.30 |
| Gender | | | | | | | | | |
| Female | 1 | - | - | 1 | - | - | 1 | - | - |
| Male | 0.8 | 0.35-1.82 | 0.59 | 0.93 | 0.415-2.08 | 0.86 | 0.80 | 0.26-2.43 | 0.70 |
| Marital status | | | | | | | | | |
| Single | 1 | - | - | 1 | - | - | 1 | - | - |
| Married | 1.39 | 0.58-3.33 | 0.45 | 0.95 | 0.40-2.24 | 0.90 | 0.53 | 0.14-1.90 | 0.33 |
| Level of education | | | | | | | | | |
| Academic | 1 | - | - | 1 | - | - | 1 | - | - |
| Primary | 0.23 | 0.09-0.56 | 0.01 | 0.694 | 0.32-1.52 | 0.36 | 0.75 | 0.23-2.43 | 0.64 |
| Secondary | 0.73 | 0.39-1.35 | 0.73 | 0.61 | 0.33-1.14 | 0.12 | 1.29 | 0.46-3.63 | 0.64 |
| Employment status | | | | | | | | | |
| Employed | 1 | - | - | 1 | - | - | 1 | - | - |
| Unemployed | 0.58 | 0.32-1.08 | 0.09 | 0.74 | 0.40-1.36 | 0.33 | 1.02 | 0.37-2.82 | 0.97 |
| Students | 0.29 | 0.11-0.74 | 0.01 | 0.51 | 0.22-1.21 | 0.13 | 0.63 | 0.18-2.20 | 0.47 |
| Socioeconomic status | | | | | | | | | |
| Low | 1 | - | - | 1 | - | - | 1 | - | - |
| Middle | 0.77 | 0.39-1.55 | 0.47 | 1.03 | 0.52-2.04 | 0.93 | 0.81 | 0.27-2.39 | 0.71 |
| High | 0.81 | 0.42-1.60 | 0.55 | 1.42 | 0.72-2.80 | 0.30 | 1.23 | 0.39-3.85 | 0.73 |
| Knowledge | - | - | - | 1.70 | 1.40-2.06 | <0.001 | 0.87 | 0.66-1.14 | 0.32 |
| Attitude | 1.58 | 1.34-1.85 | <0.001 | - | - | - | 1.22 | 0.99-1.50 | 0.05 |
| Practice | 0.79 | 0.58-1.07 | 0.14 | 1.65 | 1.21-2.23 | 0.001 | - | - | - |

OR=Odds ratio; CI=Confidence intervals

Table 4: Multivariate regression of the demographic variable and their effect on the knowledge, attitude of practice categories

| | Knowledge (good/poor) | | | Attitude (good/poor) | | | Practice (good/poor) | | |
|--------------------|-----------------------|-----------|--------|----------------------|-----------|--------|----------------------|----|---|
| | OR | CI | P | OR | CI | P | OR | CI | P |
| Level of education | | | | | | | | | |
| Academic | 1 | - | - | - | - | - | - | - | - |
| Primary | 0.26 | 0.09-0.73 | 0.011 | - | - | - | - | - | - |
| Secondary | 1.18 | 0.54-2.55 | 0.678 | - | - | - | - | - | - |
| Knowledge | - | - | - | 1.67 | 1.39-2.01 | <0.001 | - | - | - |
| Attitude | 1.59 | 1.36-1.86 | <0.001 | - | - | - | - | - | - |
| Practice | - | - | - | 1.59 | 1.18-2.12 | 0.002 | - | - | - |

*Only significant items are shown in this table. OR=Odds ratio; CI=Confidence intervals

Regarding the practice section, mean score was about 5.95 ± 1.17 (ranging from 3 to 8). Only 21 (10.5%) of the patients had poor practice in this section. In these patients, hormone replacement treatments (19.5%) followed by levothyroxine (9%), corticosteroids (7%), and anti-seizure medication (2.5%) were the most commonly used drugs. More than 90% of the patients had undergone a bone mineral density (BMD) testing at least once in their life. This is while the laboratory tests to assess bone health were prescribed in only 60% of this group. 170 (85%) and 112 (56%) of them used calcium and Vitamin D supplements regularly in the past 6 months, respectively.

Even though the overall mean knowledge and attitude score was good, their practice in preventing osteoporosis was poor [Table 2]. There was no significant difference in the age, gender, marital status, level of education, occupation and SES of those with acceptable and poor medical practice. An overwhelming majority of those with poor knowledge on osteoporosis (65%) had also a poor attitude towards the disease ($P < 0.001$). This is while from among those with poor osteoporosis practice, about 57% had poor knowledge, and 43% had a poor attitude towards the condition ($P = 0.743$). Moreover, the score attained in the medical practice section was not associated with that of knowledge and attitude parts [Table 4].

DISCUSSION

As new treatment options such as transfusion programs and chelation therapy has significantly prolonged survival rate in TM patients, osteopenia, and osteoporosis, affecting up to 50% of these patients, now represents as a prominent cause of morbidity in young TM adults.^[14]

Several therapeutic approaches are therefore proposed to manage osteoporosis in thalassemic patients but considering the fact that the thalassemia-associated osteoporosis is multifactorial, early diagnosis and the adaptation of simple preventive measures during childhood is of great importance.^[15,16]

Recent studies of bone mineral metabolism in thalassemic patients, therefore, concentrate mainly on the pediatric and adolescent age groups.^[17] According to the results of these studies, annual checking of BMD starting in adolescence is indispensable.^[18,19]

Compared to patients with other thalassemia syndromes, those with beta TM are reported to be at a higher risk of developing multiple endocrinopathies, abnormal calcium metabolism, and hypercalciuria.^[20] Vitamin D abnormalities are also more common among these adolescents, as more than 80% of these patients are Vitamin D deficient.^[21]

Getting engaged in physical activity and following calcium-rich diet must always be encouraged in this group as adequate calcium and Vitamin D intake during skeleton development can increase bone mass in adult life.^[22] Supplementation can also prevent bone loss and fractures.

Several studies have studied the knowledge, attitude, and practice (KAP) of thalassemia patients and their parents towards the disease.^[23,24] According to their results, the majority of the target population have a poor knowledge about thalassemia and thus more education is needed to improve the quality of care in these patients.^[25-27] Some studies, however, have reported an acceptable knowledge, but still poor practice regarding osteoporosis care in thalassemia patients, stressing that more education is needed in this regard.^[28]

This study, similarly, showed high knowledge but poor practice of thalassemia patients regarding supplementation in preventing thalassemia-induced osteoporosis. Our results were in line with other KAP studies which had assessed the awareness about the efficacy of supplementation in preventing osteoporosis in the general population.^[29] Moreover, these results were in line with studies that have shown poor practice for osteoporosis diagnosis and treatment in the general population.^[30]

Level of education was the only factor affecting the knowledge scores; this factor however did not have any effect on the patients' practice and attitude. Age, gender, occupation, and SES were not reported to have any influence on any of these scores. This is while other KAP studies on thalassemia patients had reported level of education, occupation, and age as the major determinant of the patients' knowledge about their disease.^[31-33]

The score attained in the knowledge section was positively correlated with that in the attitude part. The score of the medical practice section, however, was not correlated with knowledge, attitude, physical activity, and nutrition scores. Other KAP studies in this group however had shown a link between knowledge score and practice.^[34]

It could be therefore concluded that improving the knowledge of TM patients and their families about the importance of calcium and Vitamin D in preventing osteoporosis could help improve their attitude and practice and thus lower the risk of osteoporosis-related complications and consequently reduce the burden of the disease in this group of patients.

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