

Awareness and knowledge levels of osteoporosis in patients with neuromuscular diseases: a multicentre study

Banu Dilek¹ , Ebru Şahin¹ , Filiz Meryem Sertpoyraz² , Nihan Erdiç Gündüz² , Aylin Dikici² , Onur Engin¹ , Elif Keskin Pehlivan³ , Uluç Yiş⁴ , İhsan Şükrü Şengün⁵ , Elif Akalın¹ , Minuse Özlen Peker¹ 

¹Department of Physical Medicine and Rehabilitation, Dokuz Eylül University School of Medicine, İzmir, Turkey

²Clinic of Physical Medicine and Rehabilitation, İzmir University of Health Sciences Tepecik Training and Research Hospital, İzmir, Turkey

³Clinic of Physical Medicine and Rehabilitation, Urla State Hospital, İzmir, Turkey

⁴Department of Pediatrics, Division of Child Neurology, Dokuz Eylül University School of Medicine, İzmir, Turkey

⁵Department of Neurology, Dokuz Eylül University School of Medicine, İzmir, Turkey

Abstract

Objective: To evaluate the awareness and knowledge level of osteoporosis in patients with neuromuscular diseases (NMDs) and to investigate the associated factors.

Methods: A total of 48 adult and 60 child patients (74 male, 34 female) were included in the study. The demographic and socio-economic status of all patients were recorded. Functional levels were determined by functional ambulation classification using the Vignos and Brooke scales. The awareness of the participants was questioned and the knowledge level of osteoporosis was assessed using a questionnaire.

Results: The median age of the patients was 15 (range, 1.5-76) years and the duration of illness was 4.5 (range, 0-55) years. Some 30.6% of the patients were Vignos level 4 and above and 89.8% of the patients were Brooke level 3 and below. The percentage of non-ambulatory patients was 18.9% and independent ambulators was 30.6%. Awareness of osteoporosis in parents and adult patients was 93.3% and 97.9%, respectively. However, the osteoporosis knowledge level of the subjects was 13 (range, 0-25) points.

Conclusion: Although there is a high awareness of osteoporosis in patients with NMDs, the knowledge level of osteoporosis is very low in this population.

Keywords: Awareness, knowledge, neuromuscular diseases, osteoporosis

INTRODUCTION

Neuromuscular diseases (NMD) are a large group of diseases that impair muscle function, directly or indirectly. Most NMDs have a progressive clinical course with decreased muscle strength and hypotrophy (1). Patients have problems such as fatigue, and impaired mobility and activities of daily living (2). Bone health is affected by many factors, such as hormones, neurologic factors, glucocorticoid treatment, and lack of calcium, vitamin D, and magnesium intake (3). Poor bone health is often a significant problem for patients with NMD (4). Decreased bone mineral density and increased risk of fracture have been defined in diseases such as Duchenne muscular dystrophy, amyotrophic lateral sclerosis, and spinal muscular atrophy (4-6). The diagnosis of osteoporosis is difficult before a fragility fracture occurs (7). Osteoporosis is a silent disease in most patients admitted to hospital due to fragility fracture. And most of these patients do not know that they have low bone mineral density (8). Osteoporosis may cause serious morbidity and mortality if it is not diagnosed and treated properly. Therefore, awareness of osteoporosis is important in patients with a higher risk of fracture. If the awareness of osteoporosis is determined and information about the disease can be increased, the negative consequences of the disease will also be reduced to that extent (9-11).

When the literature was reviewed, no study was found on the awareness of osteoporosis in patients with NMD and the factors affecting it. The aim of this study was to investigate the awareness and knowledge level of osteoporosis and the factors affecting them in adult patients with NMD and in the parents of pediatric patients.

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Corresponding Author: Banu Dilek **E-mail:** banu.dilek@deu.edu.tr **Submitted:** 02 November 2018 **Accepted:** 10 March 2019



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METHODS

The approval of the local ethics committee at Dokuz Eylül University was obtained before the initiation of the study. Forty-eight adult patients with NMD and the parents of 60 pediatric patients admitted to Dokuz Eylül University and İzmir University of Health Sciences, Tepecik Training and Research Hospital outpatient clinic between May 2016 and May 2018 were included in the study. All of the subjects gave written informed consent before participating in the study. The inclusion criteria were being an adult patient with NMD or a parent of a child with NMD and agreeing to participate voluntarily in the study. The exclusion criteria were the presence of severe cognitive dysfunction and refusal to join the study. The demographic characteristics of the patients were recorded. The duration of NMD diagnosis and type of disease, the presence of additional disease, glucocorticoid medication, menopausal status, previous osteoporosis diagnosis, how the subjects reached information sources (doctor, radio-television, newspaper and magazine, internet, friend, relatives, pharmacy and other) about osteoporosis and a history of osteoporotic fracture were questioned.

Functional levels were assessed through functional ambulation classification using the Vignos and Brooke scales. The Brooke scale was developed to evaluate the functional levels of the upper limbs of patients with NMD in 6 levels, which indicate gradually worsening upper extremity function from Level 1 to Level 6. The Vignos scale was designed to assess lower extremity function. The grades of the Vignos scale range from 1 to 10 (12). If the participants had previously heard of osteoporosis they were considered as being aware of it. The knowledge of osteoporosis was assessed using a 30-item questionnaire that addresses the definition, causes, signs/symptoms, risk factors, diagnosis, treatment, complications, prognosis, and prevention of osteoporosis. Patients responded to the questions as "agree," "disagree," or "unsure." Knowledge scores were created as a result of assigning 1 point to every correct answer and 0 points to every incorrect or 'unsure' answer. The items were summed for a possible range of 0 to 30, with higher scores reflecting greater knowledge (11).

Statistical Analysis

Statistical analyses were performed using the Statistical Package for the Social Sciences (SPSS) Ver. 20 (SPSS IBM Corp.; Armonk, NY, USA) statistical package program. The Kolmogorov-Smirnov test was used to determine the normality of data distribution. Parameters without normal distribution were summarized using median and minimum-maximum. The Mann-Whitney U-test was used to compare the knowledge levels of patients with and without fracture history. Comparisons were made using the Mann-Whitney U-test regarding the association between knowledge levels and education levels. The correlation between the knowledge level of patients and duration of illness was evaluated using Spearman's correlation analysis. For all statistical analysis, a $p < 0.05$ was considered statistically significant.

RESULTS

The median age of the patients was 15 (range, 1.5-76) years, and the median duration of illness was 4.5 (range 0-55) years. Some 30.6% of the patients were Vignos level 4 and above and 89.8% of the patients were Brooke level 3 and below. The percentage of non-ambulators independent ambulators was 18.9% and 30.6%, respectively. The awareness of osteoporosis in the parents and adult patients was 93.3% and 97.9%, respectively. Five (4.6%) subjects were unaware of osteoporosis. The median knowledge score of all subjects was 13 (range, 0-25) (Table 1). Group comparisons could not be made because there was a significant difference between the number of groups with and without awareness of osteoporosis. When the sources of osteoporosis information were questioned in parents, the results were as follows: relatives (30.9%) and radio-television (21.8%) were in the first place, followed by doctors (18.2%), friends (16.4%) newspapers and magazines (5.5%) and others (7.3%). When the sources of information regarding osteoporosis were questioned in adult patients, the responses were as follows: doctors (31.1%) and relatives (31.1%) were first, followed by radio-television (22.2%), friends (6.7%), the internet (4.4%), pharmacy (2.2%) and newspapers (2.2%). The ratios of correct answers among the subjects about the awareness of osteoporosis were 39%

Table 1. Demographic and descriptive data of patients

Age (years)	15 (1.5-76)
Duration of illness (years)	4.5 (0-55)
Type of disease (108)	DMD: 28 BMD: 9 LGMD: 7 FSHD: 3 SMA: 5 ALS: 3 Congenital muscular dystrophy, n=8 Myotonic dystrophy, n=2 Inflammatory myopathy, n=3 Other, n=38
Sex (male/female)	74/34
Education level (primary school / secondary school / high school / university)	43/16/30/19
Osteoporosis (child/adult)	7/9
History of fracture	Child: 5 Adult: 10
Corticosteroid treatment (adult/child)	14/20
Vignos scale (1-9)	Vignos < 3: 64, Vignos ≥ 3: 44
Brooke scale (1-9)	Brooke < 3: 93, Brooke ≥ 3: 15
FAC (0-5)	FAC (0-3): 36, (4-5): 72
FAC: functional ambulation classification; DMD: duchenne muscular dystrophy; BMD: becker muscular dystrophy; LGMD: limb-girdle muscle dystrophy; FSHD: fascioscapulohumeral dystrophy; SMA: spinal muscular atrophy; ALS: amyotrophic lateral sclerosis	

in primary school graduates, 43.8% in secondary school graduates and 46.6% in high school and university graduates. When education levels were divided as secondary education and lower and upper secondary education, no significant relationship was found between educational levels and the level of knowledge of osteoporosis ($p=0.33$). The knowledge scores of osteoporosis in patients with a history of fractures ($n=15$) were 11.73 ± 8.11 . There was no significant difference between the osteoporosis knowledge scores of patients with and without a history of fractures ($p=0.48$). Also, there was no correlation between knowledge scores and the duration of illness ($p=0.26$, Spearman's $\rho=0.10$). Table 2 presents descriptive data for the knowledge items.

DISCUSSION

In this study, we showed that although there was high awareness of osteoporosis in patients with NMDs, the knowledge level of osteoporosis was very low in this population. Osteo-

porosis is an important problem for patients with NMD, and it causes significant morbidity, including increased fracture rates and severe scoliosis. The assessment of risk factors for osteoporosis is essential for the prevention of fractures. Education plays an important role in determining and preventing risk factors (13, 14). Effective protection strategies can be developed by increasing the awareness and knowledge levels of individuals with regard to osteoporosis (15).

In the literature, it has been shown that the awareness of osteoporosis increases with the level of education. In a study by Kutsal et al. with 576 osteoporotic patients and in the study by Gemalmaz and Oge with 768 women living in rural areas, the awareness of osteoporosis was found to be statistically significantly higher in younger and more educated people (10, 16). In the study by Aksu et al. with 464 women and 94 men, it was determined that 44% of participants had an awareness of osteoporosis and there was a positive correlation between the

Table 2. Descriptive data for knowledge items

Domain	(Correct Response: T = True, F = False)	Correct, n (%)
Definition of osteoporosis	1) Osteoporosis is a condition of easy joint dislocation (F)	39 (36.4)
	2) Osteoporosis is a condition of low bone mineral density (T)	49 (45.8)
	3) Osteoporosis is a condition of high bone mineral density (F)	40 (37.4)
Common causes of Osteoporosis	1) Overweight is a common cause of osteoporosis (F)	30 (28.0)
	2) Lack of estrogen is a common cause of osteoporosis (T)	32 (29.9)
	3) High protein diet is a common cause of osteoporosis (T)	40 (37.4)
Common signs / symptoms of osteoporosis	1) A headache is a common sign/symptom of osteoporosis (F)	46 (43)
	2) Frequent fractures is a common sign/symptom of osteoporosis (T)	57 (53.3)
	3) Mood change is a common sign/symptom of osteoporosis (F)	37 (34.6)
Risk factors for osteoporosis	1) Low rice intake is a risk factor for osteoporosis (F)	42 (39.3)
	2) Postmenopause is a risk factor for osteoporosis in women (T)	67 (62.6)
	3) Smoking is a risk factor for osteoporosis (T)	47 (43.9)
	4) Having a neuromuscular disease is a risk factor for osteoporosis (T)	58 (54.2)
Risk of osteoporosis over a	1) Men are at highest risk for osteoporosis during their childhood (F)	32 (29.9)
	2) Women are at highest risk for osteoporosis after menopause (T)	70 (65.4)
Diagnosis of osteoporosis	1) Osteoporosis is diagnosed using X-ray of the bone (T)	48 (44.9)
	2) Osteoporosis is diagnosed with a physical exam (F)	35 (32.7)
	3) Osteoporosis is diagnosed with blood tests (F)	26 (24.3)
Treatment of osteoporosis	1) Osteoporosis can be treated with calcium and vitamin D (T)	72 (67.3)
	2) Osteoporosis can be treated with surgical correction (F)	48 (44.9)
	3) Osteoporosis can be treated with hormone replacement (T)	24 (22.4)
Complications of osteoporosis	1) Diabetes is a complication of osteoporosis (F)	30 (28)
	2) Hypertension is a complication of osteoporosis (F)	34 (31.8)
	3) Hip fracture is a complication of osteoporosis (T)	72 (67.3)
Prognosis	1) Osteoporosis can lead to joint swelling and morning stiffness (F)	12 (11.2)
	2) Osteoporosis can lead to hip fractures and subsequent complications (T)	76 (71)
Prevention of osteoporosis	1) Moderate physical exercise can reduce the risk of osteoporosis (T)	53 (49.5)
	2) Increased rice consumption can reduce the risk of developing osteoporosis (F)	27 (25.2)
	3) A diet rich in calcium and vitamin D can reduce the risk of developing osteoporosis (T)	76 (71)
	4) Cigarette smoking cessation can reduce the risk of developing osteoporosis (T)	55 (51.4)

levels of awareness and education (9). In our study, the awareness of osteoporosis in parents of pediatric patients with NMDs and adult patients was 93.3% and 97.9%, respectively. Sixty-one (59.4%) of those with an awareness of osteoporosis (n=101) had an educational level of secondary education and above. The fact that our patients with NMD were regularly followed up in a particular unit may also have contributed to the high awareness of osteoporosis in these patients. However, no statistical analysis of the relationship between the education level and awareness osteoporosis could be made due to the insufficient number of unaware subjects.

The knowledge level of osteoporosis was found to be quite low in our study. Among the subjects, primary school graduates, secondary school graduates, and high school and university graduates correctly answered the questions at high ratios as 39%, 43.8%, and 46.6%, respectively, and it was concluded that the level of knowledge increased as the level of education increased. Therefore, more information should be given to patients with low levels of education. In a study conducted to measure women's knowledge levels of osteoporosis in our country, it was determined that women with a higher levels of education was better, especially among the young population, and it was indicated that elderly women should be chosen as the target population because their education levels might be low (16). In another study, the level of knowledge of participants about what kind of a disease was osteoporosis and how it was diagnosed was found to be directly proportional to the level of education (11).

Different results were reported in the literature when access to information sources in regard to osteoporosis was examined. In general, radio-television, newspapers, friends-relatives, and doctors were reported as information resources (17). In our study, when the sources of information about osteoporosis were examined, relatives and radio-television ranked first in parents, and physicians and relatives were first in adult patients. The low level of knowledge about osteoporosis in our group may be related to not being informed by a primary care physician. This situation indicates that information should also be given frequently by primary physicians.

Fractures are the most important complications that may lead to morbidity and mortality. Fifteen patients had a history of osteoporosis-related fractures. Only 45.8% of the subjects correctly defined osteoporosis. However, 67.3% predicted that hip fracture might occur as a result of osteoporosis.

Although the definition of osteoporosis was not known well enough, the subjects answered the questions about the complications of osteoporosis at a high rate. This may be related to the difficulty of understanding medical terms, and also because of the emphasized fracture risk of osteoporosis by the information sources. Although there was a high rate of awareness in our study group, this was not accompanied by actual knowledge. The level of knowledge was especially low

in terms of 4 critical aspects of the disease: definition, causes, risk factors, and the diagnosis of osteoporosis. This situation may reflect the actual lack of knowledge in the domains in question; alternatively, lower scores could reflect a poor understanding of the medical terms that appeared in a number of items, including X-ray, estrogen, physical exam, diabetes, blood test, and hypertension.

The strength of our study is that it is the first to evaluate the awareness and knowledge level of osteoporosis in patients with NMD in the literature. However, our study had some limitations. We enrolled patients who were admitted to the outpatient clinic for the first time and who were monitored regularly. We could not standardize and exclude the effect of regular follow-up and current osteoporosis medications on awareness and knowledge levels because our study had a cross-sectional design. Evaluating the parents and adult patients together may have caused a heterogenic group. This may be another limitation. Future studies evaluating the awareness and knowledge level of this population with larger sample size are needed.

In conclusion, in this study, the awareness of osteoporosis in adult patients with neuromuscular disease and the parents of pediatric patients was found to be high; however, their knowledge level of osteoporosis was not adequate. Knowledge about osteoporosis is important for prevention, early treatment, and reducing the risk of complications in this patient population.

Ethics Committee Approval: Ethics committee approval was received for this study from the ethics committee of Dokuz Eylül University (2017/17-01, 22.06.2017).

Informed Consent: Written informed consent was obtained from the parents of the patients who participated in this study.

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