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KNOWLEDGE AND EXPECTATIONS ON THE MANAGEMENT OF NEUROMUSCULAR DISEASE AMONG TURKISH PHYSICAL MEDICINE AND REHABILITATION SPECIALISTS

TÜRK FİZİKSEL TIP VE REHABİLİTASYON HEKİMLERİ ARASINDA NÖROMÜSKÜLER HASTALIKLARIN YÖNETİMİNE İLİŞKİN BİLGİ VE BEKLENTİLER

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ABSTRACT

Introduction: Neuromuscular diseases (NMDs) have a substantial burden on patients, their caregivers, and healthcare systems. The level of knowledge of Physical Medicine and Rehabilitation (PMR) specialists about NMD is of great importance for these patient groups. This study aimed to measure the level of knowledge and expectation of PMR specialists about NMD.

Methods: We conducted a national, population-based, cross-sectional survey of PMR specialists caring for persons with NMD. An experience-based survey had three themes: clinician facing NMD, clinician's NMD knowledge, and clinician's expectations.

Results: Of the 198 PMR specialists included in the study. Among the NMD subgroup diseases, Duchenne Muscular dystrophy was the most well-known disease (n=179, 90.4%), followed by Myasthenia Gravis (n=174, 87.9%) and Amyotrophic Lateral Sclerosis (ALS) (n=162, 81.8%). The subgroup with the least awareness was diabetic polyneuropathy (n=61, 30.8%). While most of the participants (n=192, 97%) thought that rehabilitation programs could be effective in NMD, almost half of them (n=83, 41.9%) thought that stretching and strengthening exercises were harmful.

Conclusion: Despite the high potential and thousands of patients who might benefit, NMD rehabilitation awareness is inadequate among PMR specialists. Improving PMR specialists' knowledge of NMD may contribute to patient outcomes. We recommend future studies investigating patient outcomes based on increased PMR knowledge following educational interventions.

Keywords: Neuromuscular diseases, quality of life, rehabilitation

ÖZET

Giriş: Nöromüsküler hastalıklar (NMH), hastalar, bakıcıları ve sağlık sistemleri üzerinde önemli bir yüke sahiptir. Fiziksel Tıp ve Rehabilitasyon (FTR) uzmanlarının NMH hakkındaki bilgi düzeyi, bu hasta grupları için büyük önem taşımaktadır. Bu çalışma, FTR uzmanlarının NMH'ler hakkındaki bilgi ve beklenti düzeyini ölçmeyi amaçlamaktadır.

Yöntemler: NMH'li kişileri tedavi edan FTR uzmanlarına yönelik ulusal, nüfusa dayalı, kesitsel bir anket çalışması yaptık. Deneyime dayalı bu anketin NMH ile karşı karşıya kalan klinisyen, klinisyenin NMH bilgisi ve klinisyenin beklentileri şeklinde üç teması vardı.

Bulgular: Çalışmaya 198 FTR uzman hekimi dahil edildi. NMH alt grup hastalıkları arasında Duchenne Musküler Distrofi en iyi bilinen hastalıktı (n=179, %90,4), bunu Myastenia Gravis (n=174, %87,9) ve Amyotrofik Lateral Skleroz (ALS) (n=162, %81,8) izledi. En az farkındalığa sahip alt grup diyabetik polinöropatiydi (n=61, %30,8). Katılımcıların çoğu (n=192, %97) rehabilitasyon programlarının NMH'de etkili olabileceğini düşünürken, neredeyse yarısı (n=83, %41,9) germe ve güçlendirme egzersizlerinin zararlı olduğunu düşünüyordu.

Sonuç: Yüksek potansiyele ve fayda sağlayabilecek binlerce hastaya rağmen, NMH rehabilitasyon farkındalığı FTR uzmanları arasında yetersizdir. FTR uzmanlarının NMH hakkındaki bilgilerinin geliştirilmesi hastaların sonuçlarına katkıda bulunabilir. Eğitim müdahaleleri sonrasında FTR bilgisinin artmasına dayalı olarak hasta sonuçlarını araştıran çalışmalar yapılmasını öneriyoruz.

Anahtar kelimeler: Nöromüsküler hastalıklar, yaşam kalitesi, rehabilitasyon

INTRODUCTION

Neuromuscular diseases (NMDs) are a heterogeneous group of diseases caused by an abnormality in hereditary or acquired anterior horn motor cells, peripheral nerves, neuromuscular junction, or muscle (1,2).

International standards have been developed for the diagnosis and treatment of various NMDs. Evaluation is the first step to achieve treatment goals in international standards. NNDs are associated with disability in body structure and function, leading to issues with activity and participation, as per the World Health Organization's (WHO) International Classification of Health, Function, and Disability (ICF) (3). This is important in determining the patient's problems and treatment goals in NMD.Primary and secondary approaches can be used to treat these issues in muscle diseases. Muscle pain, atrophy, pseudohypertrophy, myotonia, and loss of postural control are primary diseases; exercise intolerance, exhaustion, problems with mobility and transfer, contractures, respiration, and psychological issues are secondary diseases. The pathophysiology, course, and

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nature of the patient's difficulties are all connected to the type of disease (4).

Today, there is no cure for these diseases, however; preventive and supportive approaches have an important place in the treatment of diseases. The purpose of rehabilitation applications among supportive treatments is to preserve maximum function by preventing complications as long as possible and increasing the quality of life. Rehabilitation is planned and implemented individually according to the needs of the patient and should be addressed in a multidisciplinary manner due to the multisystem interactions and psychosocial problems caused by the disease. Maintaining patient health and improving treatment globally also depend on thoroughly and regularly addressing the myriad NMD problems. This will provide NMD patients the best chance to take part in clinical trials that could further slow down the progression of their illness. Advocates, government agencies, physicians, scientists, academicians, volunteer health agencies, and scientists have all prioritized the creation and application of standardized care recommendations. Specialists in physiatry and neuromuscular medicine are well-suited to collaborate in order to deliver this kind of interdisciplinary treatment, and can significantly enhance patient care (5,6).

NMDs which are largely genetic, degenerative, and life-threatening or life-altering, have a substantial burden on patients, their caregivers, and healthcare systems. Therefore, we consider that it is very important for physical medicine and rehabilitation (PMR) specialists to know about NMD, to follow innovations, and to work multidisciplinary. This study was conducted to measure the level of knowledge and expectation of PMR specialists about NMD.

MATERIALS AND METHODS

Study Design

The current study is a cross-sectional survey designed to measure PMR specialists' expectations and level of knowledge regarding NMD.

During the PMR congress, a table was set up for survey work for 1 day. Before participation, the volunteers were verbally informed about the purpose of the study, and both verbal and written consent was obtained. Lists were created from the names of the participants. Afterward, a questionnaire was given to the participant. To avoid repetitive data, the names were checked from the participant list while conducting the survey. The study was approved by the local institutional ethics committee (dated 26-07-2021; Protocol No. 116/22).

Survey

Questions included in the survey were created by 3 experts with at least 5 years of experience in this field. The questions were first tested on a small group of 10 people and the difficulty level was evaluated in terms of expression and meaning. As a result of the feedback received, the questionnaire was finalized.

A total of 10 questions were prepared, including 1 question about the field of study, 8 questions about encountering NMD and characteristics of NMD, and 1 question about expectations in this regard. The entire questionnaire consisted of multiple-choice questions, and 5 of them also had an open-ended and commentable section. Multiple-choice answers were allowed to be marked more than once.

Study protocol

The responses to the questionnaire form given to the participants were collected within one day and the data were recorded in the analysis program by an independent expert who was not involved in the preparation of the questions.

Statistical Analysis

All statistical analyzes were performed using the SPSS 22.0 statistical package (SPSS, Chicago, IL, USA) used in the analysis of the data. Descriptive statistics were presented as frequencies and percentages (%) for nominal variables.

RESULTS

Of the 198 PMR specialists included in the study, 39 (19.7%) were working in a university hospital, 97 (49%) in a training and research hospital, 32 (16.2%) in a public hospital, and 30 (15.2%) in a private hospital. Questions and answers regarding the encounter with patients with NMD are presented in Table 1.

Table 1. PMR specialists' encounters with patients with NMD (N=198)

Questions and Answers	Participants n (%)
Which clinic do patients with neuromuscular disease come from?	
Direct	71 (35.9)
Neurology	144 (72.7)
Medical practitioner	6 (3.0)
Other	0
Are neuromuscular patients referred to you for rehabilitation in your institution?	
Yes	112 (56.6)
No (coming directly to the PMR clinic)	86 (43.4)
If yes, where please specify	
Neurology	62 (55.4)
Pediatry	50 (44.6)
Approximate number of patients you admit in one year	
0-10 patients	87 (43.9)
11-30 patients	45 (22.7)
Over 31 patients	66 (33.4)

Abb. PMR, Physical Medicine and Rehabilitation; NMD, Neuromuscular disease

Table 2. Distribution of questions and answers including general knowledge of the participants (N=198)

Questions and Answers	Participants n (%)
Which of the following is in the NMD disease group?	
Guillain barre syndrome	150 (75.8)
Amyotrophic lateral sclerosis	162 (81.8)
Duchenne Muscular dystrophy	179 (90.4)
Cerebral palsy	58 (29.3)
Poliomyelitis	121 (61.1)
Diyabetic polyneuropathy	61 (30.8)
Multiple sclerosis	68 (34.3)
Myastenia gravis	174 (87.9)
Do you think NMD is just a childhood disease?	
Yes	13 (6.6)
No	185 (93.4)
What are the problems in the diagnosis of NMD disease in your opinion?	
Inadequate education	71 (35.9)
Lack of multidisciplinary work	156 (78.8)
NMD being only a childhood disease	10 (5.1)
Other	9 (4.5)
Difficulties in reaching the correct hospital	9 (100)
Do you think rehabilitation will work in patients with NMD?	
Yes	192 (97)
No	6 (3)
Do you think exercises such as Passive / Active / Stretching / Strengthening may be harmful in this group of patients?	
Yes	83 (41.9)
No	115 (58.1)
If yes, specify which disease subgroup and which exercise	
Diseases	
Myastenia Gravis	
Myopathies	
Muscular dystrophies	
Poliomyelitis	
Multipl Sclerosis	
Cerebral palsy	
Exercise types	
Active/pasif strengthening	
Active/pasif stretching	

Abb. NMD, Neuromuscular disease

Distribution of the questions and answers on the general information about NMD is presented in Table 2. Patients mostly (n=144, 72.7%) from the neurology clinic applied to the participants. Mostly, patients were referred from neurology and pediatrics clinics to the PMR clinic in their center (n=112, 56.6%). The number of patients most participants looked at 1 year ranged from 0 to 10 (n=87, 43.9%).

Among the NMD subgroup diseases, Duchenne Muscular dystrophy was the most known disease (n=179, 90.4%), followed by Myasthenia Gravis (n=174, 87.9%) and Amyotrophic Lateral Sclerosis (ALS) (n=162, 81.8%). The subgroup with the least awareness was diabetic polyneuropathy (n=61, 30.8%).

Most of the participants knew that it was not just a childhood disease (n=185, 93.4%) and the majority thought that the reason for the delay in diagnosis in adulthood was the lack of multidisciplinary studies (n=156, 78.8%).

While the majority of the participants (n=192, 97%) thought that rehabilitation programs could be effective in NMD, almost half of them (n=83, 41.9%) thought that stretching and strengthening exercises were harmful especially in Myasthenia Gravis, Myopathies, Muscular dystrophies, Poliomyelitis, Multiple Sclerosis, and Cerebral palsy.

The distribution of the answers, including the expectations of the participants to better understand the disease, is shown in Table 3. Accordingly, most PMR experts thought that multidisciplinary meetings (n=96, 48.5%) would be beneficial.

Table 3. Distribution of the answers including the expectations of the participants (N=198)

Which activities do you think will contribute to understanding the disease? Please indicate your priority as a single answer.	**Participants n (%)**
Symposium	49 (24.7)
Difficult case meetings	14 (7.1)
Multidisciplinary meetings	96 (48.5)
Course	39 (19.7)

DISCUSSION

This study was conducted to evaluate the knowledge and expectation levels of physical therapy specialists on NMD, and as a result, it was determined that specialists need more knowledge and experience on this subject.

Anterior horn cells, peripheral nerves, neuromuscular junctions, muscles, and other problems affecting the peripheral neuromuscular system are all included in the diverse category of disoeases known as NMDs (6,7). The most prevalent NMDs are thought to affect 500,000 people nationwide in the United States (7-13). A variety of conditions, including autoimmune, viral, metabolic, toxic, or paraneoplastic causes (such as ALS, myasthenia gravis, Lambert-Eaton syndrome, botulism, Guillain-Barre syndrome, or diabetic peripheral neuropathy), can result in the acquisition of NMDs that are not related to genetics. There are currently over 500 different NMDs known to exist, and these diseases have been causally related to specific genes. (11,13). In this study, among the NMD subgroup diseases, Duchenne Muscular dystrophy was the most known disease (n=179, 90.4%), followed by Myasthenia Gravis (n=174, 87.9%) and ALS (n=162, 81.8%). The subgroup with the least awareness was diabetic polyneuropathy (n=61, 30.8%).

It can be confused with other disease groups that are not included in the NMD group, as there are similarities in the basic symptoms. A majority of 88% of the participants in the study have the idea that multiple sclerosis (MS) is in this group of diseases. The persistent demyelinating disease of the central nervous system (CNS) is known as MS. (14). There are significant differences in how the diseases progress. Deficits can include, in different combinations, autonomic dysfunction, pain, fatigue, muscle weakness, and sensory loss. These deficiencies compound to produce limitations in activity, constraints in participation, and impairments in musculoskeletal and sensory functions (15).

In the current study, while most of the participants (n=192, 97%) think that rehabilitation programs can be effective in NMD, almost half of them (n=83, 41.9%) think that stretching and strengthening exercises are harmful especially in Myasthenia Gravis, Myopathies, Muscular dystrophies, Poliomyelitis, Multiple Sclerosis. There are nearly 600 distinct NMDs, and there is a wide range in which they can be referred to physical therapy (PT) (16). Regarding the sort and level of PT, opinions differ (17). Exercise therapy is frequently used in physical therapy (PT) to preserve or improve muscle function (strength, endurance), as well as aerobic capacity to prevent or lessen secondary issues such contractures, pain, or fatigue (15-18). So far, three Cochrane systematic reviews have been limited to randomized clinical trials (RCTs) or controlled clinical trials (CCTs), and have concentrated on one kind of NMD or a particular kind of exercise therapy. Van der Kooi et al. stated that moderate-intensity strength training in myotonic dystrophy and facioscapulohumeral muscular dystrophy appeared unlikely to be harmful in their Cochrane assessment on muscle strength training and aerobic exercise training for individuals with muscle diseases (19).

Resistance exercises can be used in strength training. One of the best methods for improving the neuromuscular system's functioning ability is resistance exercise training. Nonetheless, there is ongoing debate in the literature on the possible advantages and disadvantages of strength training for NMDs. To improve muscle strength in NMD, progressive strengthening activities are also frequently employed (20). Exercises for progressive strengthening increase muscle mass, contractile strength, strength, and physical function in addition to lean body mass. The rate at which the disease

progresses determines the degree to which improvements one can get. The benefits of mild to moderate intensity strength exercise (25–40% of maximal weight) on muscle strength are well acknowledged in recent years, and it has no negative effects, particularly for slow-progressing NMD (21).

The American College of Sports Medicine states that when an ideal frequency of 70–85% of maximum heart rate and 60–80% of maximum oxygen consumption is combined with an optimal frequency of 3–5 days per week, it is sufficient to improve cardiorespiratory fitness for the majority of aerobic training (22). For NMD patients with a decent functional level, anaerobic training at this intensity may be advised, according to a systematic study by Cup et al. The majority of the research included in the study advised using an estimated maximal heart rate or utilizing 70% of the heart rate reserve when performing cycling or treadmill workouts at least three times per week. It is reported that the entire program, which includes both aerobic and muscle-strengthening activities, lasts at least 10 weeks. Regular physical therapy supervision is added to the program to maximize its efficacy, safety, and adaptability (23).

CONCLUSION

Due to treatment problems and knowledge gaps, NMD management poses a huge global issue to health policymakers, healthcare providers, patients, and society at large. All stakeholders in the health care system must work together to effectively solve these problems. According to July 2021 data, there are nearly 3000 PMR specialists (experts and assistants) in our country. This study includes approximately 7% of PMR specialists in our country. We consider that it is a good number compared to a similar study. Among the first significant obstacles is the level of awareness among experts. Our survey reveals that the knowledge of PMR specialists about NMD is not sufficient. The participants of this survey consider that multidisciplinary meetings and NMD-specific symposia would be beneficial. We also believe that incorporating NMD training into PMR residency programs and developing national guidelines for NMD rehabilitation would be beneficial.

This study contributes to the difficult and challenging issue of NMD from the perspective of Turkish physicians and raises awareness about the effects of NMD on Turkish society. We recommend future studies investigating patient outcomes based on improved PMR knowledge following educational interventions.

Ethics Committee Approval: The study was approved by the local institutional ethics committee (dated 26-07-2021; Protocol No. 116/22) of University of Health Sciences, Diskapi Yildirim Beyazit Training and Research Hospital, Ankara, Turkey.

Informed Consent: Informed consent was obtained from all patients who participated in this study.

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