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Effect of occupational therapy on activity level and occupational peformance in patients with neuromuscular disease

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Research Article

Purpose: This study was designed to analyze the activities of daily living of patients with neuromuscular disease (NMD) and to investigate the effect of occupational therapy programme on activity level and occupational performance. **Methods:** Sixty adult NMD patients were randomized into two groups. The intervention group was trained with client centred activity adaptation education and the control group received only physiotherapy programme as home exercise. Fatigue Severity Scale (FSS), The Functional Independence Measure (FIM), The Disabilities of the Arm Shoulder and Hand Questionnaire (DASH), and The Canadian Occupational Performance Measurement (COPM) were used. **Results:** According to FIM and COPM the most difficult activities of daily living were "climbing stairs" and according to DASH "doing garden or yard work". Statistically significant difference was found for FSS, FIM (self care, locomotion and motor total), DASH, and COPM scores in the intervention group ($p<0.05$). **Conclusion:** Comprehensive rehabilitation programmes including occupational therapy have positive effects on activity level and occupational performance in patients with NMD.

Key words: Occupational therapy, Neuromuscular disease, Occupational performance.

Nöromusküler hastalarda ergoterapinin aktivite düzeyi ve iş performansına etkisi

Amaç: Bu çalışma nöromüsküler hastalarda günlük yaşam aktivitelerini ayrıntılı olarak analiz ederek hastaların bağımsızlık düzeyini belirlemek ve ergoterapi eğitiminin hastanın aktivite ve toplumsal katılım düzeyine etkisini araştırmak amacıyla planlandı. **Yöntem:** Altmış yetişkin nöromüsküler hastalık tanısı ile izlenmekte olan hasta iki gruba ayrıldı. İlk gruptaki hastalara hasta merkezli olarak oluşturulmuş aktivite adaptasyon eğitimi verildi; kontrol grubu ise sadece fizyoterapi programından oluşan ev programı ile takip edildi. Yorgunluk Şiddet Ölçeği (FSS), Fonksiyonel Bağımsızlık Ölçümü (FIM), Kol omuz ve el sorunları anketi (DASH) ve Kanada Aktivite Performans Ölçümü (COPM) kullanıldı. **Sonuçlar:** FIM ve COPM değerlendirmesine göre hastaların en çok zorlandıkları aktivitenin merdiven inip çıkma aktivitesi, DASH anketine göre ise bahçe işleri yapmak aktivitesi olduğu tespit edildi. FSS, FIM (kendine bakım, lokomosyon alt parametreleri puanları ve FIM toplam puanı), DASH, COPM performans ve tatmin puan farkları gruplar arasında karşılaştırıldığında tedavi grubu lehine istatistiksel olarak anlamlı bir fark bulundu ($p<0.05$). **Tartışma:** Ergoterapi programını da içeren kapsamlı rehabilitasyon programının nöromüsküler hastalarda aktivite ve toplumsal katılım düzeyine olumlu etkisi olduğu görülmüştür.

Anahtar Kelimeler: Ergoterapi, Nöromüsküler hastalık, İş performansı.

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Neuromuscular disorders (NMD) are defined as “a heterogeneous group of acquired or hereditary diseases of the motor unit, including motor neuron diseases, disorders of the peripheral nerves, neuromuscular transmission disorders, and muscle diseases that affects proximal or distal muscle groups”.[1]

People with NMD can experience impairments of body structure and function, activity limitations, and participation restrictions due to physical changes as a result of the disease. While the rate of progression, the clinical features, and the pathophysiology can vary according to the type of NMD or person, muscle weakness and atrophy, muscle shortness, fatigue, decrease in aerobic capacity and pain are the most visible early changes in body structure. The common problem is the decrease of participation in daily living as the disability progressively increases and secondary problems like soft tissue contractures occur Besides physical symptoms, demographic factors such as age of the patient or duration of the illness can also limit activities and participation by causing deficiency in functional activities.[2,3]

Results of previous studies describing experiences and functional abilities of patients with different types of NMD showed that patients have difficulties in performing activities of daily living.[4-6] Uchikawa stated that climbing stairs, chair transfer, toileting, tub transfer, dressing upper and lower body, bladder management are the most commonly affected activities in Duchenne muscular dystrophy.[7] Mobility is the main activity that neuromuscular patients have problems.[8]

NMD can restrict participation in all areas. Morris described participation restriction of people with motor neuron disease in work, leisure, domestic, family and community, social and civic life Therefore rehabilitation of NMD should not only focus on impairments but also consider activity limitations, participation and quality of life.[4]

Occupational therapy (OT) interventions aim to prevent declines in function through use of functional activities and purposeful activities. It helps the client to compensate and adapt as function declines.[9] There are studies showing the multidisciplinary effect of physiotherapy and OT; but the efficacy of OT with NMD has received little attention in research.[10-12] There were two evidence-based studies that mainly focused on the effectiveness of hand training program to improve daily activities in patients with NMD.[13,14]

In order to meet the lack of research, the current study focused on client-centred OT intervention, such as training of activities of daily living, giving advice and instruction in the use of assistive devices, counseling on energy conservation strategies, educating patients, families, and caregivers, or a combination of all in patients with NMD. Therefore, the purpose of this study was to investigate the efficacy of OT intervention on activity level and occupational performance of patients with NMD.

METHODS

Participants

This study included 60 adult patients diagnosed with NMD by a neurologist at the Neurological Department and referred to the Faculty of Health Sciences, Department of Physiotherapy and Rehabilitation, Unit of Occupational Therapy between 2007 and 2009. Written informed consent was obtained from all participating patients. Ethical Committee approved the study.

Inclusion criteria for the patients were (I) not having any other neurological or orthopaedic disease that might affect physical or cognitive function, (II) being able to come to outpatient clinic, (III) not having grade 4 or more for the upper extremity (patients who cannot raise hands to mouth and has no useful function of hands) and not having grade 7 or more for the lower extremity (patients who can stand in long leg braces but unable to walk even with assistance and who uses a wheelchair full time) according to functional grade criteria.[15]

Patients who met the inclusion criteria were randomly assigned to one of two groups as intervention and control groups by means of a random-number generator software on a computer. A physical therapist not involved in the study operated the random number program.

Assessments

Demographic features like age, gender, disease duration of signs, current status of employment, and role in the family were collected from all of the patients. The patients in the intervention group were asked to describe their one week considering their activity limitations and participation restrictions. They were encouraged to define materials difficult to use, environmental barriers, movements difficult for an activity, and need of adaptive equipment.

Both patients in intervention and control groups were analyzed to learn the difficulties in activities of daily living. Considering the whole sample for the assessment of activity limitation, three different instruments were used; The Functional Independence Measure (FIM), Disabilities of Arm, Shoulder and Hand Questionnaire (DASH) and Canadian Occupational Performance Measure (COPM). These questionnaires were used to describe the perceived lower and upper extremity, whole body and person related activity limitation. Patients were also assessed using Fatigue Severity Scale (FSS) to learn more about one of the most problematic symptoms, fatigue, which has a great impact on performing activity.

Functional Independence Measure (FIM): The instrument is an 18-item, 6-level scale that scores independence level [18 (complete dependence) to 126 (full independence)] according to the severity of disability. Six subscales are formed, including self-care, sphincter control, mobility, locomotion, communication, and social communication. The scoring scale includes two independent levels and five helper levels. The need for supervision or assistance of a patient is rated. The highest level (7) indicates total independence; the lowest level (1) indicates total need for the assistance of two helpers to perform the activity. The FIM data may be reported in terms of FIM motor score, by the sum of the first 13 items. FIM motor scores range from 13 to 91.[16] In this study, FIM motor score were used. FIM is potentially a useful instrument for describing disabilities in persons with NMD and it was adapted for the Turkish language and found to be reliable and valid in a spinal cord injury sample.[17]

Disabilities of the Arm Shoulder and Hand Questionnaire (DASH): DASH is a self – administered questionnaire with high validity to measure patients' perception of disabilities and symptoms and symptoms associated with any condition affecting the upper limb. This 30-item questionnaire includes 21 items on physical function, 6 items on symptoms, and 3 items on social or role function. The response to each individual item is scored on a 5-point Likert scale. The DASH assessments were scored ranging from 0 – 100: A score of 0 indicating no impairments and limitations, and a score of 100 indicating maximal impairment and difficulty.[18] DASH is used to get knowledge about the perceived activity limitation of upper extremity. Turkish version of the DASH questionnaire was used in this study.[19]

Canadian Occupational Performance Measure (COPM): COPM is a semi-structured interview that scores nature of clients' reported difficulties in occupational performance and their own satisfaction with their performance. It focuses on activities that the client wants, needs or is expected to perform. It was used to describe and measure activity limitations and participation restrictions as perceived by the individual. During the interview, the patient was encouraged to identify activities within three areas of self care, productivity, and leisure that they would like or need to do but found difficult to complete because of their illness. The importance of each activity, as perceived by the client, is first rated on a 10-point scale ranging from 1 (not important at all) to 10 (extremely important). From the list of activities the clients prioritize five most important activities than they rate their performance and satisfaction on a 10-point scale for performance, ranging from 1 (not at all able) to 10 (able to perform extremely well), and for satisfaction, ranging from 1 (not at all satisfied) to 10 (extremely satisfied).[20]

Fatigue severity scale (FSS): The FSS quantifies the severity, frequency and impact of fatigue in daily living. The average of the items is taken as the FSS score (range 1 – 7) each item's answer alternative is scored from 1 to 7 and the FSS total score is calculated by taking the mean of the nine items. A higher score indicates more severe fatigue.[21] Its validity and reliability has been stated and it has been used in NMD.[22] FSS was adapted for the Turkish language and found to be reliable and valid.[23]

Questionnaires and functional evaluations were applied by the same researcher for all subjects during the study. The self report instruments which were all completed in the unit, took approximately 45 minutes. All patients were assessed initially and after 6 months of treatment.

Treatment Protocol

The same conventional therapeutic home exercise program including breathing exercise, strengthening exercise for upper and lower extremity muscles, abdominal muscle and back extensor muscle, and stretching exercises had been given by a physiotherapist to both intervention and control groups for 6 months.

Intervention Group. Patients in intervention group (N=30) received client centred OT program according to assessments for 6 months in addition to the home exercise programme. The program was adjusted individually according to patient's symptoms, age, wishes, expectations, needs, occupations, emotions and motivation for rehabilitation.

The treatment goals of the occupational therapy program were stated to improve independence in personal and instrumental activities of daily living. As treatment modality, mobility, bathing, feeding and dressing were the mostly used personal care activities. Instrumental activities of daily living included activities such as outdoor mobility, travelling by public transport. Patients were also encouraged to take part in leisure and social activities. Compensatory strategies were used to adapt activities of daily living according to the disabilities of patients, and environmental strategies were used to adapt the patients' environment to patients' disabilities. The possibilities of modifying patients' homes and environment to use compensatory and environmental strategies were used in all patients in the group. Ninety percent of the patients needed adaptive equipment or strategies especially for self-care retraining. Sessions of OT included not only patients but also their relatives or caregivers. They received a standard educational program including the information for management of and coping with the disease. The education programme includes these topics: Knowing what to do, caregiver emotions and stress, acceptance and coping, the meaning of assistance and long-term care.

***Control Group*.** Patients admitted to the control group (N=30) received no input from the OT unit. They received only conventional physiotherapeutic home exercise programme. At the last assessment session they were asked to give information about the continuity of the exercise programme.

Statistical analysis:

Statistical analysis of data was performed using standard statistical software – SPSS 15 (SPSS Inc, Chicago, USA). Continuous variables were described as mean (X) and standard deviation (SD). Categorical data are given as frequency and percentages. The normal distribution was tested using Kolmogorov- Smirnov test. If distribution was normal and sample size was sufficient, means of independent samples were compared using Student's *t* test, if not Mann-Whitney U test was used. Comparison of means for related samples included *t* test (normal distribution) or Wilcoxon (nonparametric distribution) dependent sample t test. The level of significance was set at $p<0.05$.

RESULTS

Of the 60 NMD patients 30 patients (17 females, 13 males) were allocated randomly to intervention group and 30 patients (10 females, 20 males) to the control group. The mean age was 37.53±15.14 years for the intervention group and 38.66±15.41 years for the control group. The mean duration of symptoms were 50.33±68.14 months for the intervention group and 47.76±37.79 months for the control group.

Disease-related demographics and clinical characteristics of patients were summarized in

Table 1. The baseline characteristics of patients were well-matched between the two groups. No significant differences for demographic features and diagnoses of patients were found between the two groups (p>0.05). The patients' diagnoses are presented in Table 1.

Table 1. Demographic features and diagnoses of patients.

	Intervention (N=30) Mean±SD	Control (N=30) Mean±SD
Age (years)	37.5±15.1	38.7±15.4
Duration (months)	50.3±68.1	47.8±37.8
	n (%)	**n (%)**
Gender		
Male	13 (43.3)	20 (66.7)
Female	17 (56.7)	10 (33.3)
Types of disease		
Motor Neuron Disease		
ALS	3 (10)	5
HSMN	3 (10)	1
Muscular Dystrophy		
FSHMD	4 (13.3)	4 (13.3)
BMD	1 (3.3)	2 (6.7)
LGMD	7 (23.3)	9 (30)
Muscular dystrophy	2 (6.7)	3 (10)
Miyotonic dystrophy	2 (6.7)	5 (16.7)
Myopathy	4 (13.3)	5 (16.7)
Neuropathy	3 (10)	1 (3.3)
SMA	1 (3.3)	- (0)

ALS: Amyotrophic lateral sclerosis. HSMN: Hereditary sensory motor neuropathy. FSHMD: Fascioscapulohumeral muscular dystrophy. BMD: Becker muscular dystrophy. LGMD: Limb girdle muscular dystrophy. SMA: Spinal muscular atrophy.

With the COPM, 27 different occupational performance problems were identified. These were subdivided into 20 self-care activities (74.07%), 3 productivity activities (11.1%), and 4 leisure activities (14.81%). The most commonly described problems were "climbing stairs" (72%) and "walking long distance (40%) (Table 2).

The percentages of patients requiring assistance and independence level for each FIM item are shown in Table 2. Need of modifiying activity was highest for climbing stair item, followed in order by dressing lower body, walking, dressing upper body, bathing, grooming, toileting, feeding, chair transfer, tub transfer, toilet transfer. All patients were independent for bowel and bladder management (Table 3).

Table 2. Canadian Occupational Performance Measure (COPM) activity profile.

ACTIVITIES	n (%)
Self care	
Climbing stairs	36 (60)
Walking long distance	20 (33)
Getting on a public transport	18 (30)
Dressing	13 (22)
Toileting	9 (15)
Running	9 (15)
Picking up something from the floor	8 (13)
Squatting	8 (13)
Bathing	7 (12)
Getting up from a chair	7 (12)
Standing	7 (12)
Inclination	5 (8)
Placing an object on a place above your head	5 (8)
Buttoning	5 (8)
Cutting nail	4 (7)
Carrying a heavy object	4 (7)
Drinking water	3 (5)
Using two hands together	2 (3)
Turning a key	2 (3)
Speaking	1 (2)
Productivity	
Going to work	5 (8)
Laundry hanging	1 (2)
Writing	3 (5)
Leisure	
Visiting neighbours	8 (13)
Reading	4 (7)
Praying	2 (3)
Dancing	1 (2)

The first 21 items which question the difficulty in doing activities in the DASH questionnaire were used to describe the perceived upper extremity related activity limitation. The activity of "doing garden or yard work" is reported as the most difficult upper extremity related activity. Forty four point six percent of the patients answered this activity as "inability to do". On the other hand, activities like "put on a pullover sweater", "recreational activities which require little effort (e.g., card playing, knitting

Table 3. The percentages of patients requiring assistance according to the Functional Independence Measure (FIM).

Subscales	ToA %	MaA %	MoA %	MCA %	SSU %	MI %	CI %
Eating	0	0	0	2	0	2	96
Grooming	0	0	2	6	0	2	90
Bathing	0	2	0	8	0	10	80
Dressing upper	0	2	2	10	0	10	76
Dressing lower	0	2	4	12	0	8	74
Toileting	0	0	0	6	0	18	76
Bowel	0	0	0	0	0	0	100
Bladder	0	0	0	0	0	0	100
Chair transfer	0	0	0	0	2	0	98
Toilet transfer	0	0	0	2	0	4	94
Tub transfer	0	0	2	2	0	8	88
Walking	0	0	0	4	0	14	82
Stairs	0	6	0	6	0	50	38

ToA: Total assistance, MaA: Maximal assistance, MoA: Moderate assistance,MCA: Minimal contact assistance, SSU: Supervision of set up, MI: Modified independence, CI: Complete independence.

Table 4. The perceived activity limitation in the upper extremity related activities according to the Disabilities of the Arm Shoulder and Hand Questionnaire (DASH).

Items	No difficulty %	Mild difficulty %	Moderate difficulty %	Severe difficulty %	Unable %
1	26,7	15	33,3	15	10
2	55	11,7	25	5	3,3
3	55	18,3	18,3	6,7	1,7
4	43,3	23,3	16,7	10	6,7
5	31,7	25	28,3	8,3	6,7
6	28,3	20	18,3	28,3	5
7	6,8	30,5	10,2	27,1	25,4
8	5,4	12,5	28,6	8,9	44,6
9	30	26,7	13,3	15	15
10	20	26,7	25	18,3	10
11	11,7	13,3	21,7	26,7	26,7
12	19,3	21,1	15,8	21,1	22,8
13	50	23,3	10	13,3	3,3
14	35	28,3	16,7	13,3	6,7
15	60	23,3	11,7	3,3	1,7
16	53,3	21,7	16,7	5	3,3
17	58,6	10,3	20,7	5,2	5,2
18	35,1	12,3	21,1	14	17,5
19	33,3	28,3	10	13,3	15
20	37,3	23,7	18,6	10,2	10,2
21	57,5	17,5	12,5	7,5	5

Table 5. Fatigue severity scale (FSS), Functional Independence Measure (FIM), Disabilities of the Arm Shoulder and Hand Questionnaire (DASH) and Canadian Occupational Performance Measure (COPM) results in two groups.

	Intervention Group			Control Group			
	Baseline Mean±SD	Follow up Mean±SD		Baseline Mean±SD	Follow up Mean±SD		
FSS	42.7±12.5	40.4±12.6	*	47.1±13.3	43.6±14.7	**	^{a,b}
FIM							
Self care	39.7±3.2	40.8±1.8	**	39.7±5.8	39.7±5.6	*	^{a,b}
Mobility	20.7±1.0	20.9±0.7	*	20.6±1.2	20.6±1.2	*	^{a,c}
Locomotion	12.4±2.0	12.7±1.8	**	12.5±2.5	12.6±2.5	**	^{a,b}
Motor total	85.9±6.4	88.3±3.6	**	85.5±13.1	85.6±12.9	*	^{a,b}
DASH	30.0±21.5	28.3±21.2	*	38.7±21.2	36.6±21.8	**	^{a,b}
COPM							
Performance	4.7±1.5	5.4±1.9	**	5.0±2.1	5.5±2.0	**	^{a,b}
Satisfaction	4.5±2.3	4.9±2.2	*	4.7±3.2	5.4±3.0	*	^{a,b}

* $p>0.05$ between baseline and follow-up. ** $p<0.05$ between baseline and follow-up.
a: $p>0.05$ at baseline, between intervention and control groups. b: $p<0.05$ at follow-up, between intervention and control groups. c: $p>0.05$ at follow-up, between intervention and control groups.

etc.)" and "sexual activities" were described as "no difficulty at all" (Table 4).

The FIM self care, mobility, locomotion and total motor scores for intervention group and control group are given in Table 5. After the intervention, the mean FIM motor total score increased in the intervention group as compared to the control group. This change over time was significantly different for self care, locomotion and motor total scores ($p<0.05$). Differences between the intervention and control groups were statistically significant for self care, locomotion, and motor total score ($p<0.05$). For other items, a higher rate of recovery was also reported for the intervention group but the difference gained did not reach statistical significance (Table 5).

All patient groups experienced high levels of fatigue. The mean FSS score at follow-up was decreased in the intervention group ($p>0.05$). For the control group it was significantly increased ($p<0.05$). The difference between two groups for baseline and follow-up scores reached a statistical significance ($p<0.05$) (Table 5).

The mean DASH score decreased in the intervention group but it was not statistically significant. However in the control group, DASH scores significantly increased, and there was a significant difference between two groups ($p<0.05$) (Table 5).

After the intervention, COPM performance score improved significantly in the intervention group. On contrary, in the control group, performance score decreased significantly ($p<0.05$). The average COPM performance score was also significantly different between two groups ($p<0.05$). In the intervention group, COPM satisfaction score improved and in the control group this score decreased. There was a significant difference in the satisfaction score between the two groups ($p<0.05$) (Table 5).

DISCUSSION

Our results showed that patients with NMD, who were treated with OT intervention over a period of four weeks, experienced statistically significant improvements in fatigue, independence level of ADL, occupational performance, and disability level compared to patients who did not.

Studies have shown that NMD patients have difficulty in climbing stairs followed in order by dressing lower body and walking.[6,8] Our results conformed previous study findings as climbing stairs, walking, and dressing lower body required highest assistance according to FIM instrument. While doing COPM interview, a wide range of activities was listed as important activities. However, the most of the listed activities were self-care and mobility activities like climbing stairs, walking long distance, getting on public transport and dressing. Activities related to productivity and leisure were reported as less important activities. This result may reflect the effect of cultural and environmental factors on activities. Turkish people find self-care activities more important than productivity and leisure activities. Most of the patients marked doing garden or yard work, carrying a heavy object as “unable to do” in DASH questionnaire. Analysis of activities in NMD patients revealed that abilities that need lower extremity proximal muscle strength were mostly impaired. Lower limb muscle strength is one of the most important factors influencing functional ambulation.[8]

According to COPM results, performance parameters increased significantly in the intervention group. On the other hand, the result was not statistically significant for the satisfaction results. This can be a result of increased expectations and demands of the patients. After the interventions, patients realized that they can be more active with adaptations. Bodiam also showed a statistically significant increase in client ratings of performance and satisfaction with the use of COPM.[24]

Our study shows that patients both in the intervention group and in the control group experienced high levels of fatigue. This means that the experience of severe fatigue is a major complaint in patients with NMD. Most patients believe that rest and reduced activity is helpful in controlling fatigue, so they begin to limit all their activities. This is also a reason of loss of life roles and social participation. We believe that the positive effect of OT on patients’ outcomes can be best explained by compensation of the lack of knowledge about fatigue and balance between the activity and rest in their lives.[25] The OT interventions, including energy conservation techniques and improving knowledge could be an important coping strategy with fatigue.

In our study, patients were treated individually; OT interventions were tailored to the patient’s individual needs. We recognized that the interventions differed according to the patient and the resources that the patient had. However there were some limitations while adapting OT techniques to daily life. The result of our study shows that financial status act as a main barrier for the interventions like housing adaptations and prescribing for assistive devices. The other big obstacle was acquirement of the device. Third party payers such as state insurance or private insurance companies pay some type of durable medical equipment but often deny coverage for assistive technology devices that are not perceived medically necessary. On the other hand, medical eligibility for assistive technology varies from time to time. It is important for the occupational therapist, patients and family members to be aware of the laws and policies to use this process when necessary. Production and sale of assistive devices are not common in Turkey so patients are not aware where to get these instruments. This study also supported the fact that production and use of technology for the disabled are not at desired levels in our country. Suitable tools to make it easier of everyday life must be designed and serviced for the different disability groups.

A limitation of the study is that our study group was not a homogenous group. Further research is needed to carry out within the same homogenous subgroups to show the scientific evidence for OT in patients with NMD. As NMD is a rapidly progressive disease and the requirements and demands of daily living activities are changing quickly, future studies should include severely disabled patients rather than mild disabled ones.

According to our knowledge, this is one of the first studies demonstrating the efficacy of an OT program in NMD patients. In conclusion, our clinical trial showed a beneficial post-treatment effect of OT interventions on activity level and occupational performance and also on the ability of managing daily life in patients with NMD.

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