

ORIGINAL ARTICLE

Occupational performance of children with neuromuscular diseases: perspectives of patients and their parents

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Purpose: Neuromuscular disorders consists of a group of various hereditary and acquired diseases. Activity and participation are important issues in children with neuromuscular disorders for social inclusion in community. The study aimed to analyse and compare the occupational performance of children with neuromuscular disorders from the perspectives of children and their parents.

Methods: Fifty-seven children with neuromuscular disorders and their parents were included in the study. Brooke Upper and Lower Extremity Functional Classifications were used to determine the functional levels of children. The occupational performance was analyzed by Canadian Occupational Performance Measurement. Disability was investigated by using Pediatric Evaluation of Disability Inventory and functional independence by Wee Functional Independence Measurement.

Results: Fifteen (26.32%) girls and 42 (73.68%) boys with neuromuscular disorders and their parents were included in the study. The mean ages of the children were 9.66±3.16 years. Functional mobility activities were determined to be the most important occupational area by both the children and parents. The second most important area was their social roles for children and independence-oriented activities for parents. Occupational performance score of the children was 6.69±2.98 from the point of children, while 5.69±2.84 according to their parents (p<0.05). Occupational satisfaction of children with neuromuscular disorders was scored 6.29±3.18 by children, while 4.82±3.21 by their parents (p<0.05).

Conclusion: Except for the concurrence in most important occupational area, no consensus was formed between children and parents in terms of children's occupational performance and satisfaction scores. It was observed that the activity performance and satisfaction expectations of both children and families are different.

Keywords: Neuromuscular diseases, Activities of daily life, Parent, Occupation, Performance

Nöromusküler hastalığa sahip olan çocukların aktivite performansı: hasta ve ebeveynlerinin bakış açıları

Amaç: Nöromusküler hastalıklar çeşitli kalıtsal ve edinsel hastalıklardan oluşan bir grup bozukluktan oluşur. Aktivite ve katılım, nöromusküler hastalığa sahip olan çocuklarda toplumsal katılım için oldukça önemlidir. Bu çalışma, nöromusküler hastalığı olan çocukların aktivite performanslarını çocuk ve ebeveyn gözünden analiz edip karşılaştırmayı amaçlamıştır.

Yöntem: Çalışmaya 57 nöromusküler hastalığa sahip olan çocuk ve ebeveynleri dahil edildi. Çocukların fonksiyonel seviyelerini belirlemek için Brooke Üst ve Alt Ekstremitte Fonksiyonel Sınıflandırmaları kullanıldı. Aktivite performansı Kanada Aktivite Performans Ölçümü ile analiz edildi. Özur seviyesini belirlemek için Pediatrik Özürlülük Değerlendirme Envanteri ve fonksiyonel bağımsızlık için Çocuklar için Fonksiyonel Bağımsızlık Ölçeği kullanıldı.

Bulgular: Çalışmaya nöromusküler hastalığı olan 15 (%26,32) kız, 42 (%73,68) erkek çocuk ve anne babası dahil edildi. Çocukların yaş ortalaması 9,66±3,16 yıl idi. Fonksiyonel mobilite aktiviteleri hem çocuklar hem de ebeveynleri tarafından bildirilen en önemli aktivite alanıdır. İkinci önemli aktivite alanı ise çocuklar tarafından sosyal roller, ebeveynleri tarafından bağımsızlıkla ilişkili aktiviteler olarak belirlendi. Çocukların aktivite performans puanları kendilerine göre 6,69±2,98 olarak belirlenirken ebeveynlerine göre 5,69±2,84 puan idi (p<0,05). Aktivite memnuniyet skoru ise çocuklarda 6,29±3,18 iken ebeveynleri için 4,82±3,21 idi (p<0,05).

Sonuç: En önemli aktivite alanı konusundaki fikir birliği dışında, çocuklar ve ebeveynleri arasında çocukların aktivite performansı ve memnuniyet skorları konularında herhangi bir fikir birliğine varılmadı. Gerek çocukların gerekse de ailelerin aktivite performans ve memnuniyet beklentilerinin farklı olduğu tespit edildi.

Anahtar kelimeler: Nöromusküler hastalıklar, Günlük yaşam aktiviteleri, Ebeveyn, Aktivite, Performans.

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Neuromuscular disorders (NMDs) is a group of various hereditary and acquired diseases localized in the anterior horn cells of the spinal cord, peripheral nerves, neuromuscular junction or muscle itself.^{1,2} Although NMDs include several different types of genetic disorders, symptoms and prognosis are usually similar and require a multidisciplinary approach to treatment.³ Moreover, the disabilities associated with NMDs are reported to be disease-specific depending on their pathogenesis, rate of progression and the range of clinical involvement.⁴ Most of the problems in patients with NMDs occur because of muscle weakness, fatigue and difficulties experienced during exercise that result in limitations to activities of daily living (ADL) and limited participation in daily life.⁵

Although researchers have not yet found an effective cure for many NMDs, efforts have been made by experts in recent years to treat some of these genetic disorders by achieving trial readiness with patient registry, care guidelines, and working networks.⁷ Available treatments, except for the genetic focus, consist of supportive care. These are medical treatments for basic symptoms, such as muscle weakness and pain, surgical approaches for severe joint limitations and scoliosis and physical and occupational therapy and rehabilitation approaches. Rehabilitation offers solutions for problems which may negatively affect daily living, social roles and quality of life.^{5,8}

Pediatric patients with NMDs are exposed to difficulties from their disease at a very early age. Therefore, before planning a therapy program, it is essential to determine the needs and expectations of the child and his or her parents for the rehabilitation. By doing this, a realistic and targeted client and family-centered rehabilitation program may be created by physicians and therapists. Assessment of both needs and expectations are important issues. The Canadian Occupational Performance Measure (COPM) is a client-centered occupational performance analysis tool. The COPM is also used as an outcome measure that examines problems during ADL and self-perception of the patient's performance during these activities. The COPM also measures the client's satisfaction with his or

her performance, participation ability in social life, enjoyment of appropriate activities of his or her own choosing and overall life satisfaction.^{9,10} The COPM is reported to be used in determining targets and measuring outcomes in pediatric rehabilitation.¹⁰⁻¹² In a study performed on parents with disabled children by Verkerk et al., the COPM was reported to identify individualized problems of a child which was not possible to detect with the usual well-known outcome measures in the pediatric area or by asking open-ended questions.¹⁰

Many studies have been conducted in occupational performance research, especially on cerebral palsy, developmental disorders and other diseases that cause disabilities in children.¹³⁻¹⁹ In the present study, the occupational performance of a pediatric population with NMDs was investigated and compared by determining the most important activities, performance and satisfaction from the perspectives of children and their parents in order to form an appropriate therapy program and improve participation in ADL.

METHODS

The study was approved by The Ethics Committee of Hacettepe University, Faculty of Medicine, Ankara, Turkey with the HEK 12/115-11 protocol number and the study was conducted in accordance with the rules of the Declaration of Helsinki. Written and oral information about the study was given to all patients and their parents before the assessment. Informed consent was obtained from all individual participants included in the study.

Participants

The study was performed in Physical Therapy and Occupational Departments of Hacettepe University. A total of 57 patients with the diagnosis of different NMDs who cooperated well with the evaluator, who did not have any mental problems or other chronic disease except for the NMDs, and who were aged from 6 to 18 years were included in the study.

Assessments

After the demographic data was collected as gender and age, functional levels of children

were determined according to the Brooke Classifications and the following assessments were performed on participants.

Brooke Upper and Lower Extremity Functional Classification (BUEFC and BLEFC): The BUEFC and BLEFC were developed by Brooke et al. in 1981 to classify upper and lower extremity functions of patients with Duchenne muscular dystrophy (DMD); they were then used in clinical studies to determine functional levels of patients with different neuromuscular diseases.^{20,21} The BUEFC classifies patients from Grade 1 (starting with arms at the sides, the patient can abduct the arms in a full circle until they touch above the head) to Grade 6 (cannot raise hands to the mouth and has no useful function of hands), while the BLEFC classifies patients from Grade 1 (walks and climbs stairs independently) to Grade 10 (bed-bound). Both classifications were used to determine the upper and lower extremity functional levels of the patients.

Canadian Occupational Performance Measurement (COPM): The COPM was developed as a client-centered tool for therapists to assess children's or adults' self-perceived occupational performance concerns (importance of activity, activity performance and satisfaction) in the areas of self-care, leisure and productivity.^{12,22} The COPM is determined to be a valid and reliable measurement by researchers.²³⁻²⁵ While performing the COPM, the therapist requires the patient to name the activities he or she performs during a routine day. The COPM initially detects the activity that the patient needs and wants to do but which is problematic to perform. After the patient has identified a problematic activity, he or she is asked to rate each activity on a scale divided into 10 units of importance from 'not important at all=1' to 'very important=10'. In this way, the five most important activities are determined. Each activity is also scored in terms of performance and satisfaction from 'not being able to perform at all=1' to 'performing very well=10' and from 'not satisfied=1' to 'very satisfied=10'.¹⁰

Pediatric Evaluation of Disability Inventory (PEDI): The PEDI is a valid and reliable disability assessment tool used for children with physical impairments from six months to 7.5 years of age. It contains three

main domains that examine self-care, mobility and social functions, thus helping to assign the functional performance and functional capacity of disabled children.²⁶ A child's functional ability is determined by the PEDI under the following three scales: i) typical functional skill level, ii) modifications or adaptive equipment used (i.e. braces, motorized wheelchair), and iii) required caregiver physical assistance.²⁷ The PEDI includes 197 functional skill items and 20 items that assess caregiver assistance and modifications. The functional skill items are scored 0 if the child can perform the skill in many situations or 1 if the child is not capable or has limited capability of the skill. Higher scores indicate higher degrees of disability. The assistance items are rated on a 6-point scale, from total assistance (score 0) to independent (score 5). The higher score on assistance items indicates more independence. The above-mentioned three domains of self-care (73 items), mobility (59 items) and social functions (65 items) are the consisted of these items. In this study, a valid and reliable Turkish version of the PEDI was used.²⁸⁻³⁰

Wee Functional Independence Measurement (WeeFIM): The WeeFIM is a valid and reliable functional independence test designed for children, which evaluates the independence level in daily activities. The WeeFIM consists of six domains: self-care (5 items), sphincter control (2 items), transfers (3 items), locomotion (3 items), communication (2 items) and social cognition (3 items). All items are scored between 1 indicates full dependency and 7 indicates full independency. The total possible score is 126, and the higher scores indicate higher degrees of independence.³¹⁻³³

Statistical analysis

The IBM SPSS Statistics 21 (IBM, Armonk, NY, USA) program was used to evaluate assessment results. Descriptive analysis was calculated as minimum, maximum, and mean±standard deviation (X±SD) for the quantitative data, and number (n) and percent (%) values were used for qualitative data. For the data of the study that did not show a normal distribution, the Mann-Whitney *U* test for non-parametric conditions was performed to analysis differences in the assessment results between children and parents. The correlations were calculated by using Spearman's correlation coefficient

(rho=r). The strength of the correlations was determined as r=0.75-1.00 excellent; r=0.70-0.75 very strong; r=0.60-0.70 strong; r=0.40-0.60 moderate; r=0.30-0.40 lower moderate and r=0.05-0.30 weak or insignificant relation. Statistical significance level was accepted as $p<0.05$.

RESULTS

In the present study, a total of 57 children, 15 (26.32%) girls and 42 (73.68%) boys, with NMDs and their parents were included. The mean age of the children was 9.66 ± 3.16 years. The diagnosis distributions of the children were as follows; DMD (45.6%), hereditary motor sensory neuropathy (15.8%), Becker muscular dystrophy (10.5%), spinal muscular atrophy (10.5%), limb girdle muscular dystrophy (8.8%) and other types of muscular dystrophies (8.8%).

The functional levels of the children included in current study were Level 1 according to the BUEFC and Level 2 according to the BLEFC as given in Table 1.

The results related to disability and independence assessments performed using the PEDI and the WeeFIM are given in Table 2. The total score found for the PEDI-Functional Skill Scale was 165.63 ± 41 , and that of the WeeFIM was 105.62 ± 24.64 points.

According to the children and their parents' perspectives, the children's occupational performance and satisfaction scores showed a statistically significant difference. The performance score of the children was 6.69 ± 2.98 , while it was 5.69 ± 2.84 according to their parents ($p<0.05$). The satisfaction score was 6.29 ± 3.18 as reported by the children, while it was 4.82 ± 3.21 as reported by their parents ($p<0.05$). The distribution of the most important activities and their frequencies that children and parents declared according to the COPM areas are shown in Tables 3 and 4. The other ranked activities that children want to do are as follows: 33% ball and/or computer games under play/school activities, 22.8% self-care activities such as eating, brushing teeth, and 1.1% (one child) painting under quiet recreation activities. When the results of the parents were considered, after the mobility activities, self-care activities, such as brushing teeth and

bathing took second place with a ratio of 33.3%, while housework such as preparing meals and folding clothes followed it with 7%, and games and homework followed it with 5.3%. Only one parent reported playing an instrument is important for his child (1.8%).

No statistically significant correlation was found between COPM scores (both children and parent scores) and BUEFC, BLEFC, PEDI-total and WeeFIM-total scores ($p>0.05$) (Table 5).

Table 1. Distribution of functional levels of children according to Brooke Upper and Lower Extremity Functional Classification (N=57).

	n (%)
Brooke	
Upper Extremity Functional Classification (1-6)	
Level 1	47 (82.5)
Level 2	6 (10.5)
Level 3	2 (3.5)
Level 4	1 (1.8)
Level 5	0 (0)
Level 6	1 (1.8)
Brooke	
Lower Extremity Functional Classification (1-9)	
Level 1	18 (31.6)
Level 2	19 (33.3)
Level 3	10 (17.5)
Level 4	0 (0)
Level 5	1 (1.8)
Level 6	3 (5.3)
Level 7	1 (1.8)
Level 8	1 (1.8)
Level 9	4 (7)

DISCUSSION

To the best of our knowledge, the present study was the first to investigate occupational performance from the perspectives of children with NMDs and their parents. The results showed that both children with NMDs and their parents mentioned functional mobility activities under the self-care subheading as the most important activities for their daily life. In this study, no correlation was found between

Table 2. Mean scores of the Pediatric Evaluation of Disability Inventory (PEDI) and Wee Functional Independence Measure (Wee-FIM) of the children (N=57).

Disability and Independency Assessments	X±SD
Pediatric Evaluation of Disability Inventory-Functional Skill Scale	
Self-care (0-73)	63.15±15.13
Mobility (0-59)	42.85±18.16
Social function (0-65)	59.43±12.95
Total (0-197)	165.63±41.00
Pediatric Evaluation of Disability Inventory-Caregiver Assistance Scale (Level of Independence)	
Self-care (0-40)	32.08±10.19
Mobility (0-35)	25.50±12.13
Social function (0-25)	22.84±5.58
Wee-Functional Independence Measure	
Self-care (5-35)	33.48±10.06
Sphincter control (3-21)	13.12±2.64
Mobility (3-21)	16.64±6.12
Locomotion (2-14)	10.64±4.08
Communication (2-14)	13.25±2.37
Social cognition (3-21)	19.22±4.20
Total (18-126)	105.62±24.64

Table 3. The most important activities and their frequencies according to the areas of the Canadian Occupational Performance Measure (COPM) in children (N=57).

Self-care		
Personal care (n=13, 22.8%)	Functional mobility (n=24, 42.1%)	Community management (n=0, 0%)
Brushing teeth (n=4, 7.0%)	Walking (n=9, 15.8%)	
Bathing (n=3, 5.3%)	Ascending/descending stairs (n=7, 12.3%)	
Eating (n=3, 5.3%)	Running (n=4, 7.0%)	
Washing hand/face (n=1, 1.8%)	Turning in the bed (n=2, 3.6%)	
Combing hair (n=1, 1.8%)	Standing from sitting (n=2, 3.6%)	
Independent toilet hygiene (n=1, 1.8%)		
Productivity		
Paid/Unpaid work (n=0, 0%)	House management (n=0, 0%)	Play/School (n=19, 33.3%)
		Computer game (n=5, 8.8%)
		Football (n=4, 7.0%)
		Basketball (n=3, 5.3%)
		Volleyball (n=3, 5.3%)
		Ball (n=1, 1.8%)
		Game (n=2, 3.6%)
		Rope jumping (n=1, 1.8%)
Leisure		
Quiet recreation (n=1, 1.8%)	Active recreation (n=0, 0%)	Socialization (n=0, 0%)
Painting (n=1, 1.8%)		

Table 4. The most important activities and their frequencies for parents according to the areas of the Canadian Occupational Performance Measure (COPM) (N=57).

Self-care (n=48)		
Personal care (n=19, 33.3%)	Functional mobility (n=29, 50.9%)	Community management (n=0, 0%)
Brushing (n=4, 7.0%)	Walking (n=14, 24.6%)	-
Bathing (n=8, 14.0%)	Ascending/descending stairs (n=9, 15.8%)	-
Eating (n=4, 7.0%)	Running (n=2, 3.6%)	-
Dressing (n=1, 1.8%)	Turning in the bed (n=1, 1.8%)	-
Nail cutting (n=1, 1.8%)	Standing from sitting (n=1, 1.8%)	-
Toilet hygiene (n=1, 1.8%)	Standing on one leg (n=1, 1.8%)	-
	Standing independently (n=1, 1.8%)	-
Productivity		
	Preparing the meal (n=3, 5.3%)	Game (n=2, 3.6%)
	Folding clothes (n=1, 1.8%)	Doing homework (n=1, 1.8%)
Leisure		
Quiet recreation (n=1, 1.8%)	Active recreation (n=0, 0%)	Socialization (n=0, 0%)
Playing instrument (n=1, 1.8%)		

Table 5. The relations between the Canadian Occupational Performance Measure (COPM) and the other assessments.

Canadian Occupational Performance Measure	Brooke Lower Extremity Functional Classification r (p)	Brooke Upper Extremity Functional Classification r (p)	Pediatric Evaluation of Disability Inventory-total r (p)	Wee-Functional Independence Measurement-total r (p)
Child				
Performance	-0.011 (0.935)	-0.108 (0.438)	0.063 (0.650)	0.034 (0.810)
Satisfaction	0.034 (0.811)	0.001 (0.993)	0.034 (0.805)	0.034 (0.812)
Parent				
Performance	-0.058 (0.681)	-0.090 (0.524)	0.125 (0.373)	0.085 (0.550)
Satisfaction	0.031 (0.828)	0.070 (0.616)	0.019 (0.892)	-0.013 (0.925)

r: Spearman's correlation coefficient (rho).

the COPM and either the WeeFIM or the PEDI. One interesting finding of current study is that, although the scores related to self-care items and mobility activities as measured by the PEDI and the WeeFIM were higher for both children and their parents, they declared in the COPM that these subjects are the most desired type of activity to perform for their daily life. Thus, need of scales/measures such as WeeFIM, PEDI and the expectation scales such as COPM should be used together to assess activity performance and satisfaction; and rehabilitation programs should also be planned considering expectations and needs of both

children and parents as well as therapists' clinical assessments and experiences.

The study population mostly consisted of patients with DMD (45.6%), which is compatible with studies in the literature, which were performed on heterogenous groups of NMDs.^{34,35} It has been known that children with DMD experience functional loss, including muscular weakness, difficulty in rising from the floor and ascending/descending stairs and the inability to walk independently around 10 years of age.^{36,37} These studies cite 10 as a critical age when functions begin to be limited, so most of the ADL, especially self-care, become

more difficult to perform. In this study, both the activities that children wanted to do most and the activities that parents wanted their children to do most were found to be the activities of functional mobility under the self-care subheadings, such as walking, ascending and descending stairs and turning in bed. It is thought that these activities are expressed as the most important because the mobility skills are affected in children with NMDs. Bendixen et al. showed that children with DMD were less likely to participate in physical activity than their healthy peers because of muscle weakness.³⁷ Similar to Bendixen et al., these children reported their demand to participate in age-appropriate physical activity since they are less able to participate due to muscle weakness. In addition, importance of play/school activities for children was parallel to that proven in the literature;⁶ however, no children in the present study declared that any of the leisure time activities were the most desired which disagree with the literature. This may be since the children with DMD in these studies were assessed with The Children's Assessment of Participation and Enjoyment (CAPE), which assessed their regular activity participation.^{6,37} In this study, children were asked to identify which activities they want to do, need to do, or expect to do in daily life by using the COPM. The difference in measurement methods might be the cause of this different result.

Similar to the studies conducted for families with DMD, in the current study, families expressed ambulation as a problematic activity for their children.^{38,39} Additionally, in contrast to the study of Bendixen et al., children did not mention activities such as housework and participation in social activities, which parents in this study expected their children to do.⁶ This may be because the children's priorities mostly include activities related to social roles, such as mobility and play/school, while the activities that focus on the child's independence, such as personal care and housework, were mostly important for their parents. Also, the children and parents did not the same agree on the activities' performance and satisfaction section in COPM.

It is stated that children with DMD are less likely to participate in social activities, such as visiting friends and going to parties,

which is probably due to diminished motor skills and ambulation from 10 years of age; therefore, there may be fewer opportunities for social participation in society.^{5,40} The researchers also emphasized the important relationship between social participation and physical skills, and stated that these children had difficulty in establishing relationships with their peers due to their poor motor skills. Therefore, they participate less by withdrawing themselves from social environment.⁴¹ However, none of the children with NMDs who participated in this study expressed any of the leisure activities including recreation or socialization in an age-matched group that they would like to participate most. They reported that they wanted to do activities that could be performed by the individual as quiet recreation. This may be due, in part, to the fact that parents of children largely focus on activities that require independency rather than participation or to cultural differences, both materially and spiritually, from other societies.

The present study can be considered as valuable because it is the first and only study to use COPM in a heterogenous group of NMDs and report the results of these children from the perspectives of both children and their parents. The COPM may be considered as a good method to use in this patient group. However, considering the results of the COPM for other patient groups.^{13,42} Although children differ in the activities, they want to perform according to their skills due to their illness, the play/school activities in productivity and self-care activities were found to originate from student roles in terms of their age, a fact that seems to have had more importance for them rather than leisure time activities per se, as seen in this study. From the parent perspective, self-care goals are considered more important than productivity and leisure as also evidenced in present study.⁴³

The better upper and lower limb functions of the children who participated in the study made it possible for them to score higher on the PEDI and the WeeFIM tests. Nevertheless, self-care activities, including mobility, were reported as the most important activities by both children and parents. This may result from the progressive nature of NMDs which limits independency over time, causing

concerns about performance, skills, and success in the ADL.

The results of current study agreed with other studies performed on the community-based participation of children with NMDs indicating reduction of their social isolation, continuity of their interaction with their friends and the importance of maintaining friendships.⁴⁴ In addition, looking at the outcomes of the present study, also agreed with the results of other studies that indicated the children's active participation in physical activity was important as team and game play which supported them to form relationships with their peers.^{41,45}

Even if the study was carried out in units that received the same patient group as a single unit, the socioeconomic and cultural level influences were tried to be reduced, as in every study, it may have influenced the activity preference. Given the scarcity of studies in these areas, the need for new studies is once again seen.⁴⁶

Limitations

The lack of information on the parents' demographic characteristics can be considered as one of the limitations of current study. Since DMD is the most common pediatric neuromuscular disease, the studies related to activity and participation were mostly focused on this population in literature. Thus, in this study, the discussions with literature were mostly made by using studies performed on DMD which can be considered as another limitation of the study.

Conclusion

In COPM, performance and satisfaction points in the activities that children with NMDs want to do due to their age, and the performance and satisfaction points of the activities that families want their children to do are different. However, both told the most important activities is mobility. As a result of this study, it was found that the activity performance and satisfaction expectations of both children and families are not the same.

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