

Describing Perceived Limitations in Activities of Daily Living in Patients with Neuromuscular Disease

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Introduction: Neuromuscular disease (NMD) is a term used for various types of hereditary and progressive neuromuscular diseases. The increasing muscular weakness presents the individual with a great many problems in daily life. As the disease progresses, patients become more and more dependent in activities of daily living (ADL).

Objectives: To describe perceived limitations in ADL of Turkish patients with NMD.

Methods: This study included 60 adult patients with a diagnosis of neuromuscular disease by the neurological department of Hacettepe University Hospital. Written informed consent was obtained from all participating subjects. ADL were questioned with three different instruments. Difficulties in activities of daily living were asked with Functional Independence Measurement and perceived limitations of mostly involved upper extremity functions were asked with Disabilities of Arm Shoulder and Hand Questionnaire. Individualized perception of occupational performance was investigated with Canadian Occupational Performance Measure.

Results: We tried to describe the difficulty pattern by calculating the percentage of patients requiring assistance/problems. According to FIM results the percentage requiring assistance was the highest for stair item, followed in order by dressing lower body, walking, dressing upper body, bathing, grooming, toileting, feeding, chair transfer, tub transfer, toilet transfer, All patient was independent for bowel and bladder management. According to DASH results clients clarified that they have problems in activities like garden or do yard works, carry a heavy objects. According to COPM results they have most difficulties in activities like climbing stairs and walking.

Conclusion: The perception of difficulty is a personal experience behind the main symptoms like muscle weakness, local and general fatigue socio- cultural and environmental factors might play a role for perceived difficulties. To provide comprehensive rehabilitative management to maximize their function and quality of life (QOL) it is essential to assess patient's disability objectively, and to determine the factors related to it.

Reference list:

1- Natterlund, B., Ahlström, G., (2001).Activities of daily living and quality of life in persons with muscular dystrophy. J Rehab Med, 33: 206–211.