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The Importance of Upper Limb Function in Patients with Duchenne Muscular Dystrophy

Duchenne Musküler Distrofi Hastalarında Üst Ekstremite Fonksiyonunun Önemi

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Abstract: In this study, the importance of upper limb function in patients with Duchenne Muscular Dystrophy was highlighted. The loss of upper limb skills in patients with Duchenne Muscular Dystrophy and the negative effects of this condition on patients were stated. The importance of upper limb skills in activities of daily living was discussed. Attention was drawn to upper limb-oriented evaluation and intervention approaches in the early period of the disease and in the later stages of the disease when ambulation is lost.

Keywords: Duchenne, Muscular dystrophy, Upper limb

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Öz: Bu çalışmada Duchenne Musküler Distrofi (DMD) hastalarında üst ekstremite fonksiyonunun önemi vurgulandı. Duchenne Musküler Distrofi hastalarında üst ekstremite beceri kayıpları ve bu durumun hastalar üzerindeki olumsuz etkileri belirtildi. Üst ekstremite becerilerinin günlük yaşam aktiviteleri içerisindeki önemi tartışıldı. Hastalığın erken dönem ve ambulasyonun kaybedildiği ilerleyen süreçlerinde üst ekstremite odaklı değerlendirme ve müdahale yaklaşımlarına dikkat çekildi.

Anahtar Kelimeler: Duchenne, Musküler Distrofi, Üst ekstremite

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Dear Editor,

The most common neuromuscular disease in childhood is Duchenne Muscular Dystrophy (DMD), which is X-linked recessive and affects only males. This disease causes many functional disabilities due to progressive muscle weakness (skeletal, respiratory, cardiac) (1). From an early age, boys with DMD have difficulty in walking, running and climbing stairs, and over time they lose their ability to walk. Proximal lower limb muscle weakness, one of the main features of the disease, progresses with upper limb muscle weakness and hand/arm limitations in the later stages of the disease. (2). Accordingly, there are deficits in various functions related to the use of the upper limb. Loss of upper limb function leads to negative factors such as reduced participation in activities of daily living and reduced independence (3).

Patients with DMD begin to experience weakness in their upper extremities while they can still be able to walk, with difficulty in the proximal muscles gradually increasing and a 'proximal-to-distal' progression occurring (4). Although attempts are made to slow the loss of function with various applications, the patient becomes dependent on a wheelchair as the muscle weakness progresses. Once walking is lost, DMD patients spend most of their time in a wheelchair and are dependent on the use of their arms. In the advanced stages of the disease, when walking is lost, the importance of functional use of the upper limb activities of daily living increases (5).

Professionals working with patients with DMD have generally focused on lower limb, trunk and respiratory exercises. In recent years, the importance of upper limb weakness has attracted attention and the need to properly assess upper limb function and determine the optimal treatment method has emerged (6,7).

Despite the paucity of studies on DMD in older age groups after loss of ambulation and on the upper limb, recent review emphasizes the importance of assessing and focusing on upper limb function (6). The few researches in DMD include outcome measures of upper limb functionality, exercise advice and protocol for maintaining arm strength and the increase of endurance. This research highlights the positive effects of the upper limb on functionality. Similarly, the meaning of maintaining upper limb joint range of motion and muscle strength in DMD rehabilitation in terms of functionality is also noted (3, 7). It can be emphasized that studies on upper limb assessment and rehabilitation are very few, but the studies conducted by Demir and Alemdaroğlu pioneered this in our country (5, 7).

As a result, upper limb abilities are important for ensuring independence in activities of daily living, such as self-care, leisure activities, social communication, and feeding/dressing/playing/self-care (8). In patients with DMD, loss of upper limb function in the early and progressive stages of the disease is an important marker of patient functionality. In this context, it should be noted that assessment and intervention programs should be included in the rehabilitation processes of patients from the early stages in a continuous manner, with a focus on the upper limb.

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