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Upper limb rehabilitation in facioscapulohumeral dystrophy patients

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Facioscapulohumeral Dystrophy (FSHD) sufferers live a long life with disability. Symptoms may develop in early childhood and weakness usually noticeable in the teenage years with 95% of affected individuals manifesting disease by age 20 years. The disorder impacts on the upper extremity and torso, impacting negatively on the muscle mass, shoulder mobility and functional tasks. Consequently, chronic disuse of the shoulder negatively impacts independence of sufferers, prospects of employment and staying at work. At present there is no known cure and knowledge regarding the mechanisms underpinning FSHD is not sufficient to halt the progression of the disease via pharmacological interventions or gene therapy. Surgical interventions are used to improve scapular stabilization but long-term effect on disease progression is limited. The aim of this exercise was to understand views of patients for compliance with exercise programs and understand the barriers for regular exercise. This is followed by a pilot of testing arm cycling as potential rehabilitation method. We received 232 responses from the online survey. 92.6% responders are in agreement that upper limb exercise is necessary as upper limb dysfunction impacts daily living in 86.9% patients. Arm cycling was considered to be a feasible exercise by 57.1%. The focus group session echoed the need for home-based exercise program as attending a regular gymnasium was not entertained by patients. In this particular group of patients, pain, fatigue and lack of motivation were additional barriers identified for compliance with exercise programs. Pilot study of arm cycling showed that patients with different level of function were able to perform cycling at cadence and resistance to improve muscle function. There is a need for upper limb rehabilitation and arm cycling offers a potential method to enhance muscle function, but its effectiveness is yet to be shown.

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