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Specific hand training in patients with myotonic dystrophy type 1.

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Introduction: Myotonic dystrophy type 1 (DM1; Steinert´s disease) is the commonest form of muscular dystrophy in adults with a prevalence of 1/8000 in most populations and is associated with muscle weakness, wasting and myotonia as the main symptoms. In the limbs, weakness is initially distal and the finger and wrist flexors are particularly affected, causing substantial disability and major problems to perform Activities of Daily Living (ADL).

Objectives: The aim was to study effects of hand training in patients with myotonic dystrophy type 1 (DM1).

Methods: The study was a single-blind randomized controlled trial with crossover design. Thirty-five patients were divided into two groups stratified for grip force. One group received 12 weeks of hand training such as muscle strength training three times per week with individually customized resistance putties; the other served as control. After a wash-out period of 12 weeks the control group received hand training for 12 weeks and the previous hand-trained group became control. All patients were tested four times during one year. Outcome measures were Grippit®, Grip Ability Test, hand-held Myometer (Microfet2^{TM}), Purdue Pegboard, AMPS and COPM. Data were analysed for the intention-to-treat population. A second analysis population was evaluated with the complete cases approach.

Results: Significant group level changes comparing treatment periods with control periods were shown. Analyses on an individual level showed that several patients improved hand function and ADL ability.

Conclusion: Twelve weeks of hand training in DM1 patients is safe, with minor but significant improvements.

Contribution/EBM: Persons affected by a disease likeDM1, for which there is no cure, have a desire for interventions that may delay the progression of the disease. There is a need to maintain physical capacity and independence in ADL as long as possible. This is the first RCT on this patient group.