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The Energetic study; effectiveness of a self-management group programme to improve social participation in patients with neuromuscular disease and chronic fatigue

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Chronic fatigue is present in more than 60% of the patients with a neuromuscular disease and can be their most disabling symptom. Chronic fatigue often coincides with low levels of physical activity and decreased social participation. We developed a self-management outpatient rehabilitation intervention for patients with a neuromuscular disease and chronic fatigue, called *Energetic*. This multidisciplinary group programme aims to improve social participation and physical endurance and alleviate fatigue. The aim of this study was to evaluate the effectiveness of *Energetic*.

We conducted a multicentre, assessor-blinded, two-armed randomised controlled trial. Assessments were made at inclusion, directly after intervention, and at three and eleven months follow-up. We included 53 patients with a neuromuscular disease and chronic fatigue, and their caregivers. The participants were randomised (1:1) to either an intervention ('Energetic') or control ('usual care') group. *Energetic* covered four months and included four modules: 1) individually tailored aerobic exercise training; 2) education about aerobic exercise; 3) self-management training in applying energy-conservation strategies; and 4) implementation and relapse prevention in daily life. The primary outcome was the perceived performance score of the Canadian Occupational Performance Measure (COPM). Secondary outcomes included the COPM-satisfaction score, and measures of fatigue, physical endurance, activity engagement, mood, self-efficacy and caregiver-burden. There was significantly more improvement directly after the intervention on COPM-performance, COPM-satisfaction, and 6-Minute Walk Test in the intervention group than in the control group, adjusted for baseline COPM scores, gender, work and diagnosis. In May 2017 we expect the results from the final follow-up analyses.

Conflicts of interest: none

Keywords

neuromuscular disease, fatigue, self-management, social participation