

Factors influencing outcome and implementation of Energetic, a fatigue self-management programme for patients with a neuromuscular disease

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Introduction: Energetic is a self-management outpatient rehabilitation intervention for patients with a neuromuscular disease to improve social participation, physical endurance and alleviate chronic fatigue. Energetic includes four modules: 1) individually tailored aerobic exercise training; 2) education on aerobic exercise; 3) training of energy-conservation strategies; and 4) implementation in daily routines and relapse prevention. A randomised controlled trial (RCT) showed improved participation, assessed with the Canadian Occupational Performance Measure (COPM).

Objectives: Identifying factors influencing the outcome and implementation of Energetic.

Method: A process evaluation was carried out using a mixed method approach including a quantitative analysis of patient satisfaction and a qualitative analysis of semi-structured interviews and focus groups with patients and professionals.

Results: Patients scored 8.7 (SD 1.1) on a scale from 1-10 with regard to satisfaction with Energetic. Patients reported increased knowledge, insight and acceptance of the disease and better physical endurance, which helped them to self-manage fatigue and undertake more activities. Finding a suitable sport in their own living environment remained a challenge. Regarding the delivery of the programme, some patients felt that Energetic was very intensive. Patients and professionals appreciated the group interaction with peers and attention for implementation in daily routines. For the implementation in the settings the professionals mentioned the combination of theory and learning by practice as an important factor.

Conclusion: This process evaluation showed that patients and professionals are positive about the results and content of Energetic. But dealing with the intensity of Energetic and finding a suitable sport are points to be considered for improvement.