

Activity balance: An important outcome measure for fatigue management in neuromuscular diseases.

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Introduction: About 60% of persons with neuromuscular diseases (NMD) experience chronic fatigue. Fatigue management programs support persons to balance important life activities. Although the aim of most patients is to obtain 'life balance', the challenge is to define the construct of life balance and to find and validate measures for this construct. Activity balance is an important key to obtain life balance for people who experience fatigue problems. In the Netherlands, the Activity Calculator has been developed as a promising tool to register daily activity balance using time units of activities, and weighing of the energy costs related to activities varying from -1 (activity gives energy) to 3 (activity costs much energy). Recently, the Life balance research group added a score for the meaning of activities, ranging from 0 (minimally meaningful) to 10 (maximally meaningful).

Objective: To understand patient perceptions of the weight and meaning scores allocated to daily activities in the Activity Calculator.

Method: Qualitative study with cognitive interviewing in 15 persons with facioscapulohumeral dystrophy and 15 persons with mitochondrial myopathy. The Three-Step Test-Interview (TSTI): An observational instrument for pretesting self-completion questionnaires will be used.

Results: Full results will be available in the winter of 2017-2018. The results will reveal the decision-making process behind the weighing of energy costs and meaning of activities from a patient perspective.

Conclusion: This study will give insight into themes and topics that influence decisions regarding energy costs and meaning of activities.