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Letter to Editor

Unmonitored exercise or behavioral intervention may not reflect increased muscle mass on MRI in myotonic dystrophy type-1

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Abstract:

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Letter to The Editor

With interest we read the article by Heskamp, L. *et al.*, 2020 about a prospective muscle MRI-study of 27 patients with myotonic dystrophy type-1 (MD1) who underwent either cognitive behavioural therapy (n=18) or graded exercise plus behavioural therapy (n=9). It was concluded that behavioural intervention targeting physical activity increases lower extremity muscle cross-sectional area (Heskamp, L. *et al.*, 2020). We have the following comments and concerns.

A shortcoming of the study is that it is unclear which patients described previously (Heskamp, L. *et al.*, 2019; & van Engelen, B., & OPTIMISTIC Consortium. 2015) were included in the present study. In the article to which the authors refer, 33 MD1 patients were investigated (Heskamp, L. *et al.*, 2019) but the present study included only 27 patients since only these 27 underwent follow-up MRIs. Which were the 6 patients that were excluded and why?

A further shortcoming is the application of the DM1-Activ scale to document graded exercise. Since the scale consists of 25 items describing activities of daily living, which can be assessed at three grades by the patient, the total "exercise" carried out was different in each patient, thus not standardised. We should know if a "graded exercise module" means that the patient filled in the DM1-Activ scale repeatedly. Ii is unclear which cut-offs were applied to define "exercise". Furthermore, we should know how often during the 10 months observational period the form was filled out and how it was controlled that patients filled out the form honestly.

Another shortcoming is that comparisons were carried out only between the standard care and the intervention group but not between the graded exercise and behavioural therapy group. This comparison is crucial to see if exercise truly had a better effect than behavioural therapy alone.

Lastly, MD1 is a multisystem disease, affecting additionally the endocrine organs. Since muscle performance, composition, and morphology may strongly depend on endocrinologic parameters (Horwath, O. *et al.*, 2020), we should know if hormone levels differed between patients or groups and between inclusion and follow-up. Of particular interest are FGF-21 levels, which are increased in MD1 (Lovadi, E. *et al.*, 2017).

Overall, it cannot be excluded that the MRI changes reported reflect the effect of behavioural therapy alone or variable affection of endocrine organs but do not reflect graded exercise at all.

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