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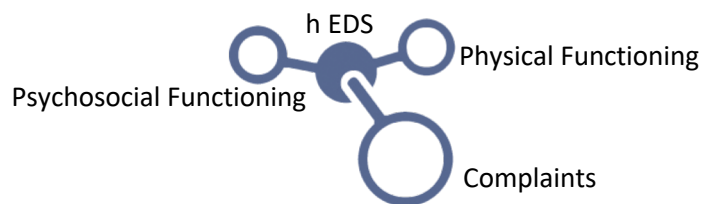
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Psychosocial- and physical functioning in hypermobile Ehlers-Danlos Syndrome: a 5-year follow-up study

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Introduction



There are various hypotheses regarding the development of complaints in patients with hypermobile Ehlers-Danlos syndrome (hEDS). These complaints are multidimensional and affect both the physical- and psychosocial functioning.

Numerous studies investigate the physical- and psychosocial functioning of hEDS patients cross-sectionally, whereas longitudinal studies are lacking.

Aim

To investigate physical- and psychosocial functioning in female adults with hEDS during a five – year follow-up study.

Method

T₀ (2012) → T₁ (2017)

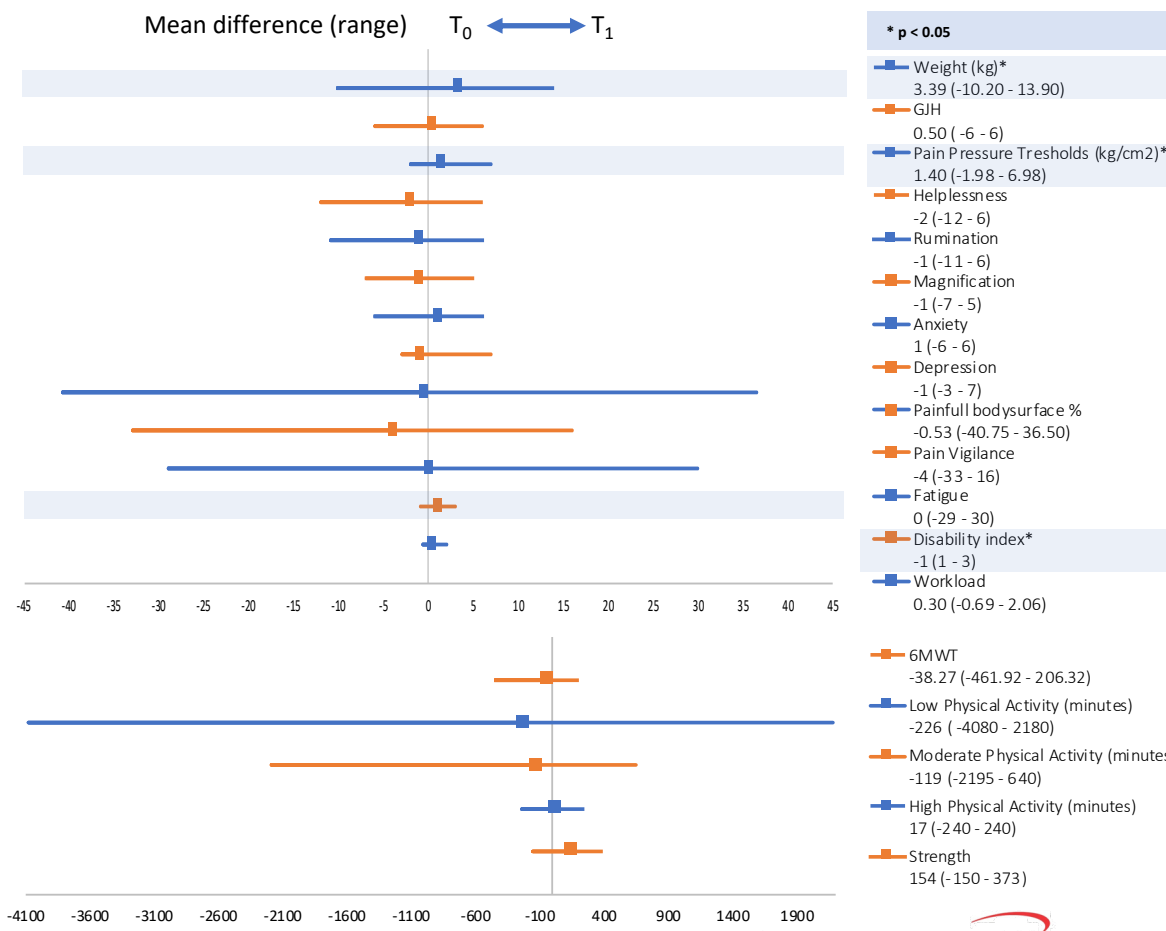
height, weight, joint (hyper)mobility
Physical functioning: muscle strength, pain pressure thresholds, workload, 6MWT, pain disability, physical activity level, fatigue

Psychosocial functioning: anxiety, depression, pain, catastrophizing, pain vigilance
 Paired Sample T-Test or Wilcoxon Signed Rank Test based on distribution of the data.

Results

N = 22 hEDS patients

Mean(SD) 42 ± 9 years



Preliminary Conclusion

Weight and pain pressure thresholds significantly increased between T₀ and T₁.

Functional disability significantly decreased between T₀ and T₁.

No significant changes between T₀ and T₁ were found within daily activity level, fatigue, pain coping and presence of anxiety disorders and depression.

Muscle strength increased significantly. Increased strength was seen in three of the five measurements; hip flexors, ankle dorsal flexors and grip strength. scored within normal range.

Future Directions

First longitudinal cohort study in adult EDS patients.

Analysis of results, follow up regarding:

- Relabeling of patients using 2017 diagnostic criteria hEDS at T₁.
- Comparing hEDS and HSD
- Pain sensitivity, type of pain, and pain distribution.
- Physical and psychosocial functioning.