

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

Author(s)

de Vries, Janneke; Rombaut, Lies; De Wandele, Inge; Scheper, Mark; Malfait, Franciska; Engelbert, Raoul; Calders, Patrick

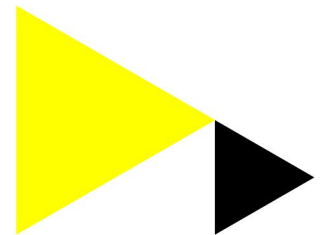
Publication date

2018

[Link to publication](#)

Citation for published version (APA):

de Vries, J., Rombaut, L., De Wandele, I., Scheper, M., Malfait, F., Engelbert, R., & Calders, P. (2018). *Psychosocial- and physical functioning in hypermobile Ehlers-Danlos Syndrome: a 5-year follow-up study*. Poster session presented at International Symposium on the Ehlers-Danlos Syndromes, Ghent, Belgium.



General rights

It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

Disclaimer/Complaints regulations

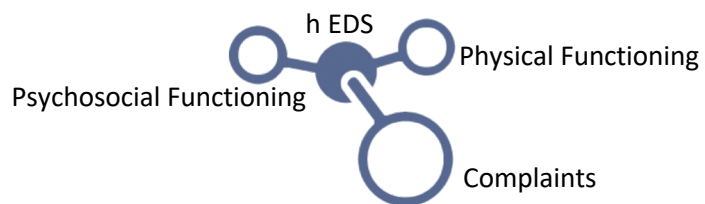
If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please contact the library: <https://www.amsterdamuas.com/library/contact/questions>, or send a letter to: University Library (Library of the University of Amsterdam and Amsterdam University of Applied Sciences), Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.

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

Janneke De Vries^{1,2,3}, Lies Rombaut⁴, Inge De Wandele⁴, Mark Scheper¹, Fransiska Malfait⁴, Raoul Engelbert^{2,3}, Patrick Calders⁴

¹Education of Physiotherapy, Amsterdam University of Applied Sciences, Amsterdam, the Netherlands ²Department of Rehabilitation, Academic Medical Center, University of Amsterdam, Amsterdam Movement Sciences, Amsterdam, the Netherlands ³ACHIEVE, Center of Applied Research, Faculty of Health, Amsterdam University of Applied Sciences, Amsterdam, the Netherlands ⁴Faculty of Medicine and Health Sciences, Department of Rehabilitation Sciences and Physiotherapy Ghent University, Ghent, Belgium

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

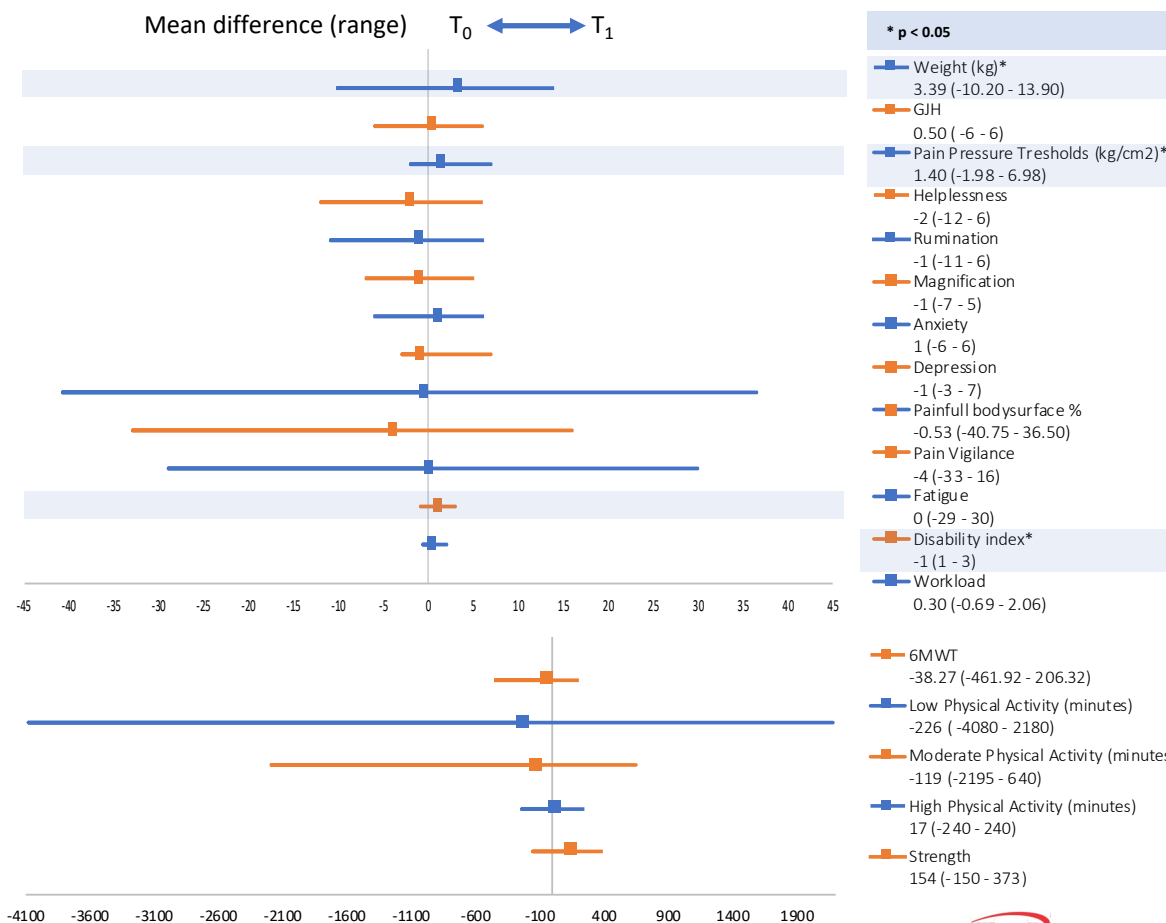


- height, weight, joint (hyper)mobility
- Physical functioning:** muscle strength, pain pressure thresholds, workload, 6MWT, pain disability, physical activity level, fatigue
- Psychosocial functioning:** anxiety, depression, pain, catastrophizing, pain vigilance
- Paired Sample T-Test or Wilcoxon Signed 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.