

EAPM Conference Barcelona 2017

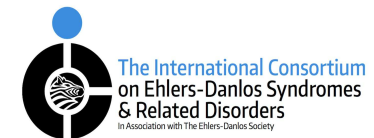
The European Association of Psychosomatic Medicine



Eating problems in the hypermobile Ehlers-Danlos syndrome (a.k.a. Joint hypermobility syndrome)

Problemas alimentarios en el síndrome de Ehlers-Danlos hiper móvil (o síndrome de hiperlaxitud articular)

Carolina Baeza-Velasco, MA, PhD.



No conflicts of interest to disclose

Sin conflictos de interés a declarar

Pas de conflit d'intérêt à déclarer

Clinical observations in the hypermobile Ehlers-Danlos syndrome (hEDS)

- A subgroup of patients with hEDS is underweight
- Suspicion or diagnosis of Anorexia Nervosa (AN)
- Eating-related complaints

Clinical observations in hEDS:

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Research: very few studies...

Hasija et al. (2008): Joint hypermobility is associated to malnutrition in children. Malnourished hypermobile children have more musculoskeletal symptoms than non-hypermobile children.

Sanjay et al. (2013): High percentage (57%) of healthy hypermobile children were underweight. Significant negative correlation between hypermobility and Body Mass Index (BMI).

Study “P-SED” Hospital Hôtel Dieu Paris (in preparation):

76 women with hEDS (mean age = 36,7) → **15,7 %** (n=13) with a BMI < 18,5 (underweight).

Recruitment of control group is currently underway, but underweight in French adults women: **1,8% - 11,4%** (HAS, 2010).

Clinical observations in hEDS:

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Research: very few studies...

Zarate et al. 2010: Case report of an hEDS patient with eating difficulties and underweight suspected with AN even if she strongly denied this fact.

Bulbena et al. 2013, 2015:

- Hypermobile secondary school students reported anorexic experiences to a greater extent than those who were non-hypermobile.
- Model “*Neuroconnective phenotype*” for hypermobility + anxiety : Ergotropic behaviors, such as decreased appetite and weight but increased activity and over control (features linked to AN).

Goh et al. 2014:

- Hypermobility was significantly more common in patients with AN than in controls.
- A connective tissue disorder could cause an eating disorder.

Clinical observations in hEDS:

- A subgroup of patients with hEDS is underweight
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Research: very few studies...

Berglund & Björck, 2012 :

«The most statistically significant differences between the subjects with EDS and the comparison group were found for OHIP (Oral Health Impact Profile), items 3, 4, and 8 »:

"I have had pain in the mouth»,

"I have had discomfort when eating»

"I have been forced to interrupt meals»

Clinical spectrum of hEDS (Colombi et al. 2015; Hamonet et al. 2014)

MUSCULOSKELETAL	NON-MUSCULOSKELETAL
<ul style="list-style-type: none"> • Ankle sprain • Arthralgias • Bursitis • Cramps • Carpal tunnel syndrome • Deviations of knee axes (genu varum and genu valgum) • Dislocation of joints • Dystonia • Epicondylitis • Flat feet • Fibromyalgia • Hypotonia • Mechanical back pain • Mild scoliosis • Osteoarthritis • Recurrent luxations and subluxations • Temporomandibular joint dysfunction • Tendonitis • Torticollis • Spinal anomalies 	<ul style="list-style-type: none"> • Cardiovascular: Low progressive aortic root dilatation, Pseudo-Raynaud's phenomenon, Mitral valve prolapse, Varicose veins. • Dental: Dental neuralgia, Gingivitis, Temporomandibular joint pain, dental pains to cold/ warm. • Gastrointestinal: Abdominal pain, Bloating, Bowel disturbance, Dysphagia, Food intolerances, Gastritis, Nausea, Reflux gastroesophageal. • Mucocutaneous: Gingival inflammation/recessions, Atrophic scars, Easy bruising, Hernias, Hyperextensible skin (mild), Hypoplastic lingual frenulum, Keratosis pilaris, Light blue sclerae, Resistance to local anaesthetic drugs, Soft skin texture. Striae rubrae and/or distensae in young age. • Neuropsychiatric: Anxiety, Cognitive impairment, Depression, Dysautonomia, Dysgeusia, Enhanced interoception, Hyperesthesia, Hyperosmia, Hyperacusis, Fatigue, Headache, Poor sleep, Proprioception dysfunction, Somatosensory amplification. • Ocular: Myopia, Palpebral ptosis, Strabismus. • Urogynaecological: Dysmenorrhea, Dyspareunia, Urinary stress incontinence, Meno/metrorrhagia, Vaginal and uterine prolapses.



GASTROINTESTINAL (GI) PROBLEMS : dysphagia, gastroesophageal reflux, abdominal bloating and pain, constipation/diarrhea, irritable bowel syndrome, nausea, etc. (Fikree et al. 2017; Castori et al. 2015)



HYPERALGESIA, ENHANCED INTEROCEPTION, SOMATOSENSORY AMPLIFICATION: influence the perception/tolerance to pain.

(Baeza-Velasco et al. 2011; Bulbena et al. 2015; Di Stefano et al. 2016; Feuerstein et al. 1995; Mallorqui-Bagué et al. 2015)



TEMPOROMANDIBULAR DISTURBANCES: dislocation, pain...

- Altered mastication patterns (Rodke et al. 2014)
- Avoidance hard foods (Rodrigues et al. 2012)
- Restriction of mandibular opening (Myiers, 1985)



SMELL AND TASTE ABNORMALITIES: hyperosmia, dysgeusia.

- Decrease food acceptability. Nutritional problems and weight changes (Mattes et al. 1990; Hamonet et al. 2014)



DENTAL PROBLEMS AND ORAL MUCOSA FRAGILITY: dental pain to cold/warm, caries, reduced tolerance to some food textures and temperatures (De Coster et al. 2005)



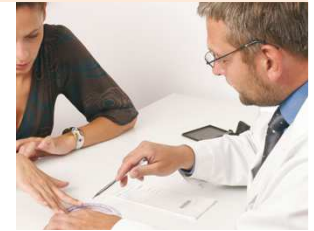
FOOD ALLERGIES AND INTOLERANCES: allergies (milk, egg, wheat and soy), and celiac disease (Cutts et al. 2012; Danese et al. 2011).



Illustrative case : Miss M, 18 years old, recently diagnosed with hEDS

Diagnostic criteria (Brighton et Villefranche criteria):

- Beighton score for hypermobility 7/9 (mother and sister also present hypermobility)
- Chronic pain (arthralgias, myalgias)
- Thin and mildly hyperextensible skin
- Recurrent dislocations (including the temporomandibular joint)



Other manifestations of the hEDS spectrum:

- Easy bruising, dysautonomia, chronic fatigue, sleep problems, respiratory problems, food intolerances, GI problems (constipation, abdominal pain, bloating, dysphagia, gastroesophageal reflux, nausea).

*“I can’t even swallow my own saliva”
“I feel when small pieces of food go down my throat”
“Chewing hurts my jaw and face”.*



Illustrative case : Miss M, 18 years old, recently diagnosed with hEDS

Current situation:

- Miss M lives alone. Her level of autonomy fluctuates. High level of school absenteeism.
- She often uses a stick to walk.
- She regularly consumes cannabis to relieve pain
- BMI = 15.8 «severely underweight». Her entourage suspected AN. She deny want to lose weight.
- - high food selectivity, eating avoidance
- she eats very slowly and sparingly
- eats small quantities
- cuts food into tiny pieces...

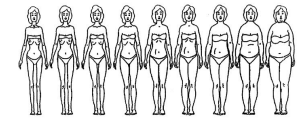


Related to hEDS manifestations



Anorexia nervosa?

- **Mini-DSM-IV** (Sheehan et al. 1980)
 - AN (-)
 - Social Phobia (specific) (+)
- **Contour Drawing Rating Scale (body image assessment)** (Thompson et al. 2009)
 - Proper perception of her body image.
 - Dissatisfied with her body but with a positive magnitude (i.e. she wants to increase her body size)



Clinical interview:

- **Intense fears and irrational thoughts about food**

- « Most foods and textures are dangerous to me »
- « If I eat a hamburger my jaw gets dislocated »
- « I'm afraid my stomach can crack »

- **Focalization on food**

- She thinks about meals several hours per day. Every meal and shopping at the supermarket last for hours.

- **Eating problems lead to avoidance behaviors in the social sphere**

- She is ashamed of her "slow and complicated" way to eat.
- The fear to be nauseous, to vomit or bloating in front of others makes she avoid restaurants and family meals.

- **Meals are no longer associated with a source of pleasure.**

Diagram illustrating possible relationships between some features or common co-occurring problems in hEDS might contributing to eating difficulty and weight loss.

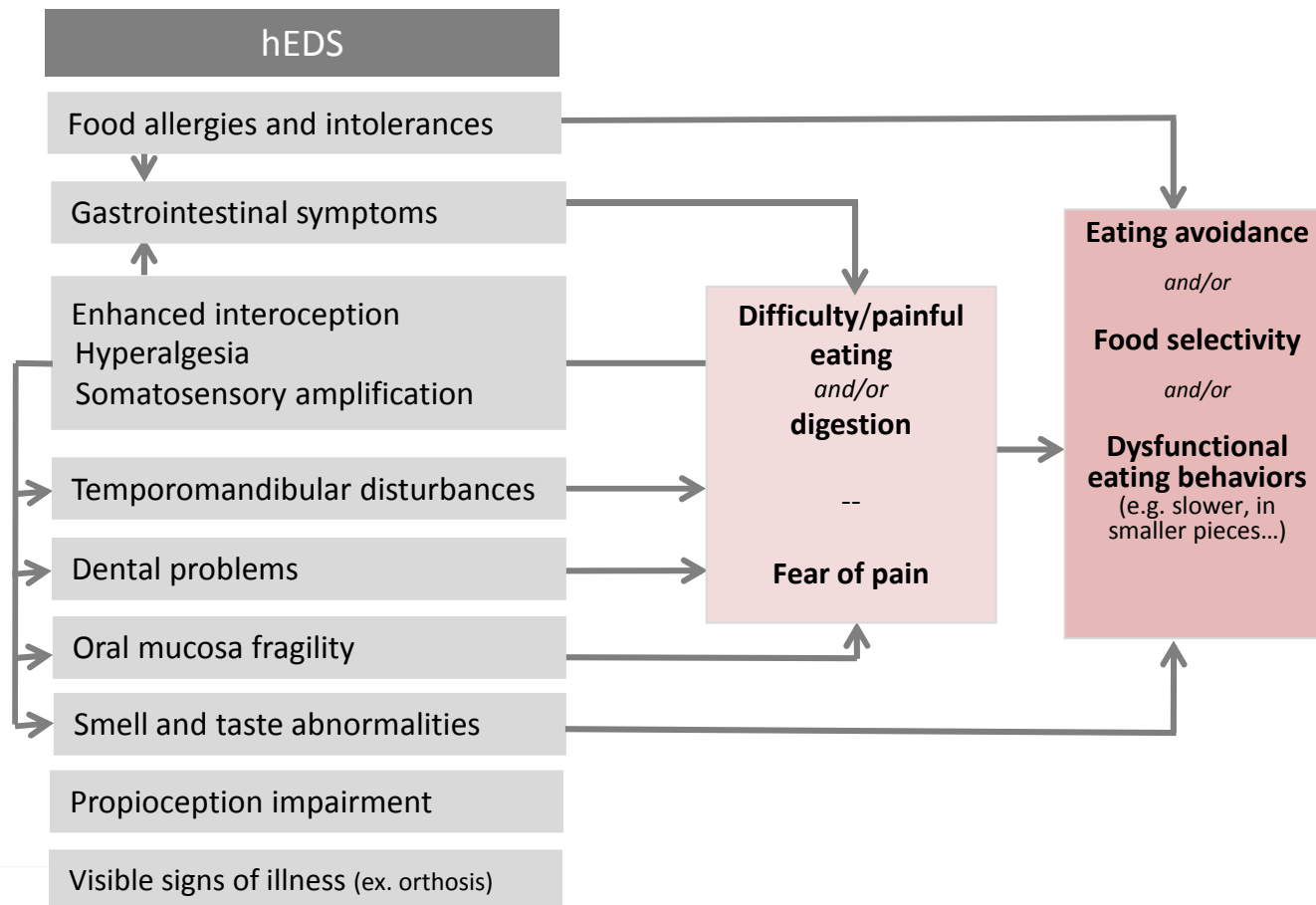


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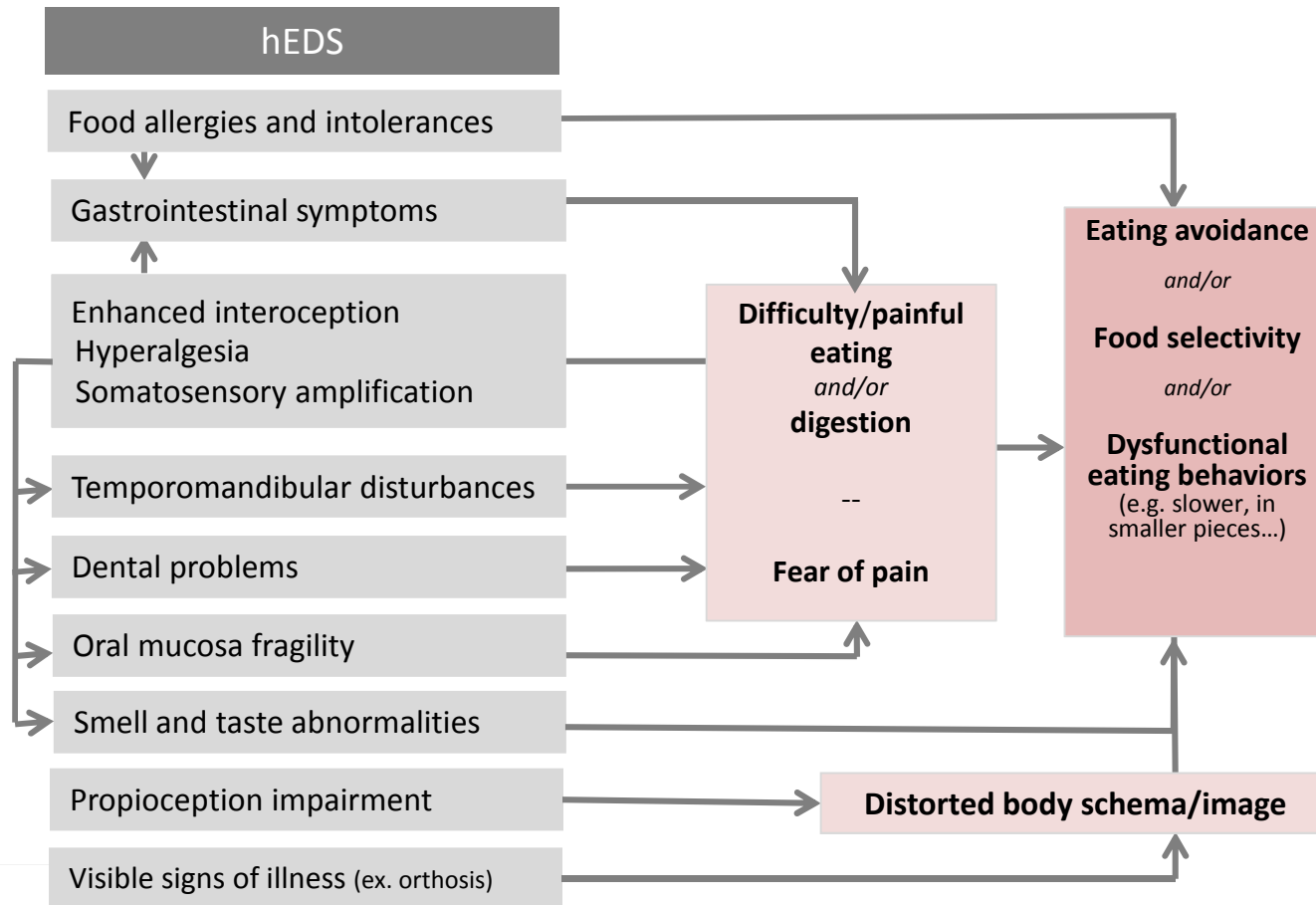
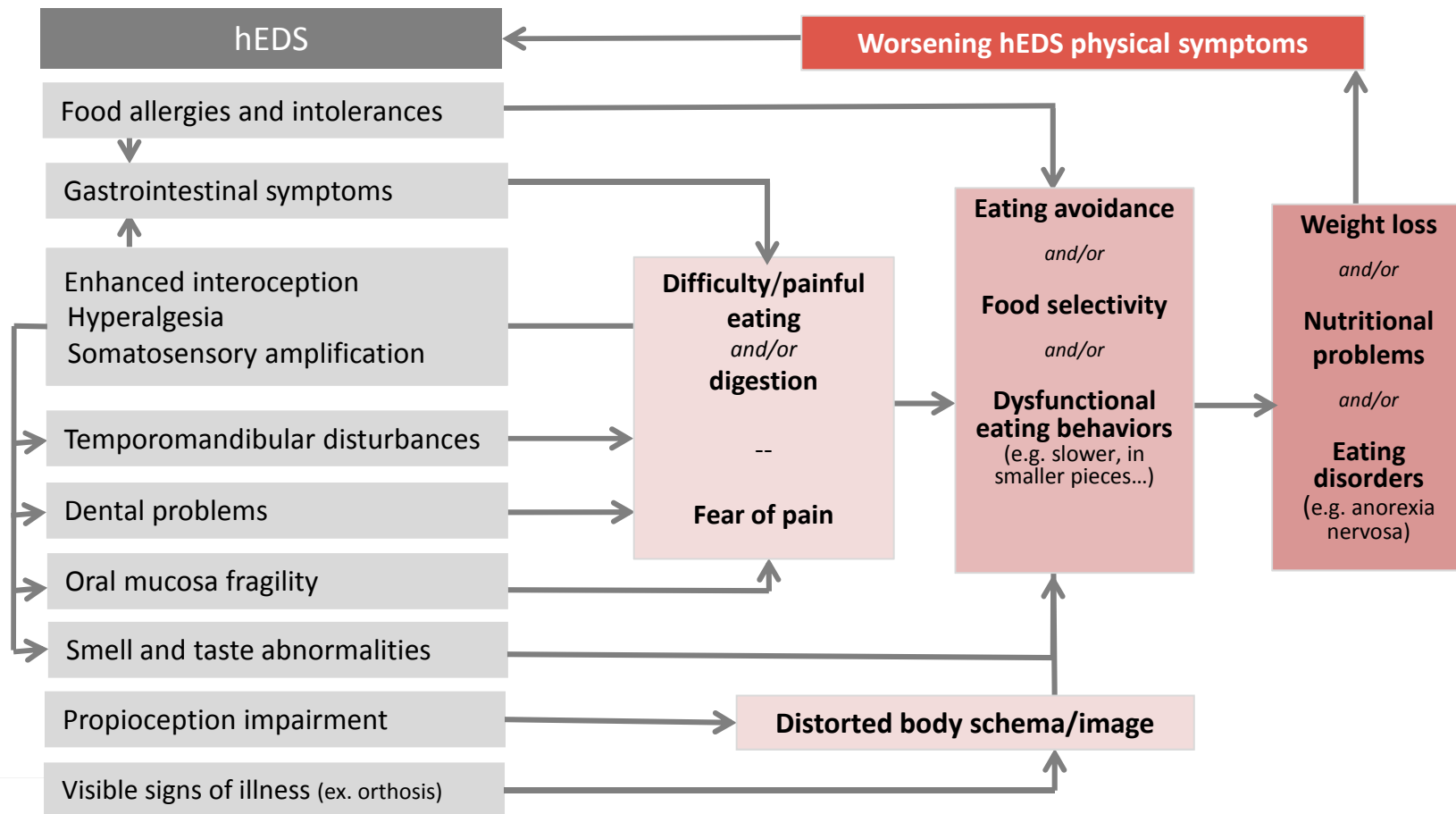


Diagram illustrating possible relationships between some features or common co-occurring problems in hEDS might contributing to eating difficulty and weight loss.



Conclusion

- Features and common co-occurring problems of hEDS may favor difficulty eating, significant weight loss and even eating disorders such as AN with consequent poor nutrition.
- The relationship between eating problems and hEDS merits more clinical and research attention.

Eat Weight Disord
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REVIEW

Difficulty eating and significant weight loss in joint hypermobility syndrome/Ehlers–Danlos syndrome, hypermobility type

Carolina Baeza-Velasco¹ · Thomas Van den Bossche² · Daniel Grossin³ · Claude Hamonet^{3,4}

Dr. T. Van den Bossche



Dr. D. Grossin



Pr. C. Hamonet



Gracias

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carolina.baeza-velasco@parisdescartes.fr