Functional Gastroenterology Bolus

by Steven Sandberg-Lewis, ND, DHANP

Collagen, Joint Hypermobility, Digestion, and Psychology

The spectrum of rare, genetic, altered collagen syndromes (i.e. Marfan's) has particularly garnered the attention of rheumatologists and cardiologists. In gastroenterology, Ehlers-Danlos syndromes have major significance – particularly the more common joint hypermobility form of Ehlers-Danlos syndrome (hEDS), which has multiple effects on digestive anatomy and physiology. Common examples are hiatal and abdominal/pelvic hernias; gastric, small bowel, colonic or rectal prolapse; intussusception; and weakness of the lower esophageal sphincter and ileocecal valve. Digestive symptoms commonly associated with hEDS include dysphagia, gastro-esophageal reflux, dyspepsia, irritable bowel syndrome, recurrent abdominal pain and either constipation or diarrhea.[1] The screening for hEDS begins with the Beighton score – an easy 3 minute in-office joint flexibility test. See https://www.ehlers-danlos.com/assessing-joint-hypermobility/ for details. I do a Beighton score on every new patient. A positive score is 5 or more hypermobile joints for those ages 10-59, and 4 or more for those over age 60. To open the discussion with adults, you may ask about a history of being able to perform "the splits" or other "double-jointed" activities when younger.

hEDS may also have psychological manifestations. Examples of these emotional states include depression, anxiety,[2] low self-confidence, hopelessness,[3] and negative thoughts. A recent paper points to a possible connection between attention deficit hyperactivity disorder and hEDS.[4] Sleep quality is frequently poor and leads to fatigue in this population.[5] In addition, women with hEDS are much more prone to balance issues and falls.[6] Chronic pain and its effect on stress hormones and the HPA axis may be a major factor in the mood disorders of hEDS. Because most physicians neglect to screen for hypermobility syndrome, they do not know that some of their patients have it. Patients may feel misunderstood, marginalized and that their real concerns are not taken seriously by the healthcare practitioners.[2]

When I know that the patient has hEDS it affects my management and treatment in several ways. First, I will make sure to screen them for hiatal hernia and hiatal hernia syndrome (for more detail see chapter 12 of my textbook – second edition) and ileocecal valve syndrome (for more detail see chapter 15 of my second edition). It tempers my expectations for results of treatment since hEDS presents key structural changes ("floppy" collagen). This not only creates instability of joints but also laxity of sphincters, the omentum, ligaments, and tendons, which often creates a life-long tendency for GI issues. I may review imaging reports to check for prolapse and tortuosity of the intestines.

The presence of hEDS will inform my recommendations for bodywork personally and by other practitioners the patient may visit. Spinal manipulation using force (grade 5) should generally be reserved for rare situations. Myofascial work should also involve less force and shorter duration. Musculoskeletal techniques that preserve and enhance stability of joints, such as prolotherapy, platelet-rich plasma (PRP) injections, and toning exercises should be first choices.

It will also remind me to include nutritional treatments that have the potential to support collagen. These include vitamin C, bone broth, collagen extracts, and methylsulfonylmethane, although formal nutrition research is speculative.[1,7,8]

Along with my colleagues, I suspect that the lack of joint integrity in the cervical spine becomes a strong risk factor for traumatic brain injury. Perhaps even the slightest whiplash (shaking the brain) may become a source of significant neuronal reorganization or degeneration.[9]

References

1. Castori M et al. Gastrointestinal and nutritional issues in joint hypermobility syndrome/Ehlers-Danlos syndrome, hypermobility type. *Am J Med Genet C Semin Med Genet*. (2015)
2. Baeza-Velasco C. Joint hypermobility syndrome: problems that require psychological intervention. *Rheumatol Int*. 2011 Sep;31(9):1131-6.
3. Branson JA. Managing chronic pain in a young adolescent girl with Ehlers-Danlos syndrome. *Harv Rev Psychiatry*. 2011 Sep-Oct;19(5):259-70.
4. Baeza-Velasco C, et al. Attention-deficit/hyperactivity disorder, joint hypermobility-related disorders and pain: expanding body-mind connections to the developmental age. *Atten Defic Hyperact Disord*. 2018 Feb 14.
5. Voermans NC, et al. Fatigue is a frequent and clinically relevant problem in Ehlers-Danlos Syndrome. *Semin Arthritis Rheum*. 2010 Dec;40(3):267-74
6. Rombaut L. Balance, gait, falls, and fear of falling in women with the hypermobility type of Ehlers-Danlos syndrome. *Arthritis Care Res* (Hoboken). 2011 Oct;63(10):1432-9.
7. Tinkle BT. *Joint Hypermobility Handbook - A Guide for the Issues & Management of Ehlers-Danlos Syndrome Hypermobility Type and the Hypermobility Syndrome*. Greens Fork (US): Left Paw Press; 2010.
8. Mantle D, A novel therapeutic strategy for Ehlers-Danlos syndrome based on nutritional supplements. *Med Hypotheses*. 2005;64(2):279-83.
9. Hamonet C. Brain injury unmasking Ehlers-Danlos syndromes after trauma: the fiber print. *Rare Dis*. April 22, 2016;11:45.

◆