Other considerations for CSF leak patients

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- No disclosures or conflicts

Patient EB

37 yo male with chronic fatigue, migraines and other types of headaches for the past 5 years. Unable to remain upright for any length of time. Cannot stand in line, cannot stand in the kitchen doing dishes or preparing meals. When standing, develops headache, tachycardia, myalgias, weakness, pulsatile tinnitus, blurry vision, nausea, facial flushing, rhinorrhea, pelvic pain.

Also has neck pain that restricts head/neck ROM with some radiation of pain down to shoulders, trapezii, and left proximal UE. History of allergies, asthma, eczema, MVA x 2 with whiplash injuries. Recurrent infections including VBD. Does not consider herself hypermobile.

Other sxs include paresthesias, shortness of breath, fatigue, insomnia, constipation with post-prandial distention.

Patient EB

Neuro exam normal. Beighton 3/9 (can touch floor and hyperextends elbows).

TTT positive for POTS. QSART abnormal. Skin biopsy positive for SFN and presence of synuclein. Muscle biopsy with Complex I deficiency. Labs with elevated MMP9, VEGF. Normal histamine and tryptase. ANCA (MPO) positive, elevated eosinophilic cationic protein. WGS with variant of SCN4A.

Diagnosed with MCAS, POTS, OI, SFN, eosinophilic vasculitis, IIH, suspected CCI with IJV compression, possible CSF leak, possible hypokalemic PP, acquired connective tissue disorder?

Patient EB

MRI brain w/wo with pachymeningeal enhancement.

MRI cervical spine wo with CCI and C1 tubercle compression appearing on right internal jugular vein – confirmed by CTA

MR total spine myelogram without obvious leak

CT Cisternogram with suggestion of leak at sphenoid

Patient EB

Repair of cranial leak improved symptoms but did not resolve symptoms.

ICT was positive for pathologic CCI, ICP bolt with increased pressure readings supine>sitting>standing but all increased. TCDs with low velocities.

Patient underwent C1 shave for decompression of IJV. Intraoperatively, surgeon noted chunky styloid and resected. Symptoms further improved.

Symptoms, though not as severe, returned three months later. Considered fusion but did not want further surgeries at this time.

Patient EB

Decided to proceed with pharmaceutical and other non-surgical management.

- Cromolyn
- Ketotifen
- LDN
- Dexamethasone
- Nimodipine
- Fludrocortisone
- Aspirin
- Dichlorphenamide
- TPE

Patient EB

Improved for 4 months

Symptoms returned

MR total spine myelogram with leak T6-T10 (history was acute back pain while moving boxes, then a few weeks of feeling really well, then recurrence of inability to be upright without being symptomatic)

MRV of abdomen and pelvis around that time with left iliac vein from compression by right iliac artery.

Patient EB

Had blood patch. No improvement.

Had second blood patch. Improvement. Improved headache, fatigue, able to be upright for longer periods of time. Still some symptoms (mainly due to other diagnoses).

Continued pharmaceutical management. Added mitochondrial protocol. Added peptide therapies, manual therapies, red light therapy, acupuncture.

Referred to vascular surgeon for MTS. Current plan is stenting.

Patient EB

- Currently doing well.
- Continuing to manage all comorbid diagnoses including IIH and neuroimmune dysregulation.
- Has had flares and have repeated imaging for leak twice but no leak identified.