

Tethered Cord and Physiotherapy with Dr. Petra Klinge and Dr. Leslie Russek, PT, DPT, Phd, OCs

- Objectives
 - What causes the Pain?
 - How to recognize it?
 - How to minimize pain?
 - How to describe it to physical therapy
 - Manage in hypermobility
- Lumbar instability
 - Instability to control spinal movement in the neutral zone
 - A combination of
 - Passive structures in disc, facet joints and ligaments
 - Failure of the muscles and nerves to provide control
- Symptoms
 - Pain in the back but maybe buttocks or thighs
 - Catching, or locking in spine
- Onset
 - Might be triggered by specific injury
 - Often gets worse when LESS active or stop exercising
- Pattern
 - Pain in bouts
 - Become more frequent over time
 - Small movements
 - Prolonged sitting or standing
- **Occurs when muscles and nervous system do not effectively control stability and motion. It can come and go based on things you CAN control**
- Spine Anatomy
 - Vertebrae separated by intervertebral discs
 - Vertebrae connect facet joints
 - Ligaments in the front and back
 - Muscles control vertebral motion
- Spondylolisthesis “spondy”
 - One vertebra slips usually forward, on another
 - Most spondy’s do not cause pain or symptoms.
 - Typically occurs in the low back
 - Degenerative spondy occurs when disc is weak or damaged (older people and Zebra’s!
 - “Isthemic” spondy occurs if there is a fracture in the vertebra
 - Younger people from intense exercise

- X ray findings poorly correlated to pain
- Spinal canal in the lumbar has space
- Spinal cord has ended and only nerve roots here
- Symptoms when present
 - Buttock or posterior thigh pain
 - Back muscle spasm
 - Radiculopathy- compression of nerve root
 - Cauda equina syndrome: buttock numbness, bowel/bladder, acute pain
- **Spondy may or may NOT be causing your pain!!! There may and likely ARE other causes for this pain!**
- Mobilizer vs. Stabilizer Spinal Muscles – for pain we have to learn to Activate some more and some less
 - Know the differences in the back, the long dynamic muscles and the smaller stabilizing multifidae for ex.
 - Pelvic floor is key stability
 - Diaphragm key stability
 - Deep hip flexor and psoas key stability
 - The deep stabilizing muscles provide the body with proprioceptive feedback!
 - HSD/EDS doesn't get the same feedback as others during development
 - **Treatment must often start with restoring body awareness**
- When muscles don't function – response to pain
 - Local stabilizer dysfunction
 - Are inhibited by pain
 - Lead to instability and poor segmental control
 - Global stabilizer
 - Difficulty controlling movement
 - Become weak and long
 - Global Mobilizer
 - Respond by going into spasm
 - Tightness causing muscle imbalances elsewhere
- Theory based on what she sees in patients
 - Scale of underuse and overuse, difficulty getting to optimal activity exercise level
 - High pain in underuse/instability,
 - More control in optimal, slowly rising into overuse pain
 - **The RIGHT kind of exercises are vital**
- **Steps to managing lumbar instability**
 - Calm the central nervous system if it is in overdrive
 - Learn good posture and body mechanics
 - Breathing correctly using diaphragm muscle
 - Train body awareness, especially spine

- Learn to activate correct muscles and not overuse incorrect muscles
- Strengthen core safely
- Learn to isolate and activate appropriately or Stabilize during function
- Managing Central Sensitization
 - CNS become oversensitive
 - Turning the volume up on pain
 - Abnormal function of central nervous system
 - Can get stuck here
 - NOT psychogenic issue or psychological though mindfulness helps.
 - PT help support this area
- Posture
 - Learning how to stand
 - Learning how to sit
 - Learning how to lay down **all in neutral position without undue**
 - **activation**
 - **Find Pelvic NEUTRAL**
 - Using anterior and posterior tucks and tilts
 - Proper alignment
 - Teach motor control and awareness
 - Activate correct muscles
 - Learn to notice improper tension in muscles
- Diaphragmatic Breathing
 - Primary muscle for relaxed breathing
 - Coordinates with abdominal and pelvic floor
 - Stabilizes lumber spine
 - Strengthen abdominal and lumbar stabilizing muscles
 - **Problems with diaphragm dysfunction**
 - Increased arch in the low back, lumbar and pelvic instability
 - Low back muscle spasm; low back and sacroiliac joint pain
 - Weak abdominal muscles
 - Overuse of accessory muscles of breathing in the neck
 - Asthma, shortness of breath, decreased tolerance of activity
 - Decreased heart function, IBS
 - Decreased lymphatic flow
 - And more
- Managing body awareness and proprioception
 - People with HSD do not have good proprioception
 - If you don't know where your spine is you can't control it **feedback is important! Using touch, folded towels, mirrors to notice what is going on**
 - **Proprioception training options**

- Exercises on the large gym ball with eyes open and closed, moving arms around
 - Pressure biofeedback device
 - Using fingers on muscles to learn contraction and relaxation when lying on the floor
- Isolating Stabilizers
 - Multifidi
 - Transvers abdominus
 - Diaphragm
 - Pelvic floor
 - Decrease activation of superficial global muscles
 - Correct breathing patterns
 - **PROGRESS EXERCISES CAREFULLY!!! It is important to be sure the exercise is done correctly, and often typical PT exercises need to be walked back to even more simple activities in the progression.**
- Motor Control Exercises work
 - Research shows that motor control exercises are more effective for people with lumbar instability than general fitness (Frizziero, 2021)
 - Not all “core strengthening” are motor control or stabilization and can be very harmful in EDS!!! Like crunches.

Dr. Petra Klinge Seminar – tethered cord

- Tethered Cord Syndrome
 - Urinary – frequency, retention, frequent urinary tract infection greater than 3 per year, bladder and bowel incontinence, constipation
 - Back and leg PAINS AND WEAKNESS (aches, fatigue, soreness, tightness) asymptomatic and symptomatic
 - Neurological Findings (I find these are more important than bladder symptoms)
 - Increased LE ankle tone
 - LE spasticity
 - Foot clonus
 - LE weakness on Asia scale 3/5 to 4/5
 - Hyperreflexia 4+ and extended reflex zone
 - Decreased sensation (numbness)

- Orthopedic and skeletal abnormalities
 - Foot and leg deformities
 - With asymmetry, scoliosis, kyphosis, delayed or plateau in growth, joint subluxations (EDS).
- UDS Neurogenic bladder
 - Urodynamic study is used.
 - We know that it can not just be Detrusor Sphincter Dyssynergia for tethered cord syndrome!
 - 37% of patients have under reactivity. The muscle for emptying the bladder is under reacting.
 - 37% had the typical DSD signs
 - DO 10%
 - 5% each: SUI, PBNO, and AD
 - EDS – OTCS Study: Profile in these patients looking back n = 82
 - Majority present with true DSD
 - But we ALSO SEE in 17 patients increased bladder capacity, lost capacity to empty, decreased bladder capacity, and retention with leaking and stress urinary incontinence.
 - **We should not exclude patients because of not showing a classic bladder profile. In the setting of tethered cord, All bladder dysfunction is important.**
 - **Case study in female showed significant improvement in bladder symptoms 1 year post surgery in follow up study.**
- Fluctuating back and Non-dermatomal leg pains and weakness (aches, tired, sore, tight, hard to locate and often more in ONE leg not in both). People do not report pain in the same recurring spot!
 - Increased tone in leg muscles
 - Foot clonus
 - Leg weakness (see original chart list above for the rest)
 - What I have found is that the symptomatic leg show these neurological signs in exam and is very telling for an asymmetric finding most consistent with OTC.
 - **EDS-OTCS study: neurology before and after TCS n=82 3 mo and 1 year follow up visit**
 - **HUGE drops at the follow up visits across the board.**
 - **Also improvement in neurological findings at the 1 year mark.**
- Orthopedic and Skeletal abnormalities
 - I call it “functional” club foot (see photo of baby) not structural, but the babies foot when gently pulled and the foot turns in. Might be an early sign of noticing a baby with tethered cord



- Surgical Decision Making and Prospective Study Protocol
 - All three of these plus supported urodynamic study
 - 2/3 and or urodynamic study not supportive, look for more findings on MRI, filum measurement or fat filum, conus borderline, progressive syrinx, spina bifida occulta on x ray and maybe skin signs.
 - **CONSIDER COMORBIDITIES**
 - And if still not confident, monitor for symptoms of progression of OTC for say, 6 months, and then decide
 - EDS-OTCS Study after TCS n=82
 - Showing symptoms of bladder, bowel, neurological findings
 - High at first visit, lower at second for all except neuro, final visit a decrease in all compared to initial visit.
- MRI in Tethered Cord – Brown Radiology Study of the Conus level for adult in older children. Conus ending in L1, conus shifts to L2 and is relatively low compared to gen pop. **Consider taking this seriously for OTC diagnosis and surgical intervention.**
- **Management**
 - **Surgical –**
 - **Laminectomy L1-2 or L2-3**
 - **Non surgical**
 - **Monitoring**
 - **Medical control of co-morbidities**
 - **Master physical therapy**
 - **Mind nutrition**
 - Check every six months to document possible progression that would indicate surgical need.
- Retethering in OCTS: “Cauda equina tethering”
 - Retethering is more like a nerve that retethered to the site of the surgery
 - The nerves attach to the surgical incision of the site
 - These can cause as much tethering as the filum
 - Can occur with arachnoiditis and pseudo meningocele
 - Prevention: cotton to get blood out of the thecal sac!
 - Prevention 2: Autologous fat graft:

- Valsalva maneuver as a proof of watertight closure might not apply to EDS!

Julianna Spose – patient story

- Hypermobility, IBS, undiagnosed POTS and otherwise healthy until about age 11
- At age 11 had severe EBV, a year later diagnosed with ME/CFS,
- Between 2007 and Jan 2016 I was healthy just requiring more rest. In some kind of remission
- 2016 became ill again, crashed with ME/CFS again, not sleeping, not eating well, partying,
 - Pain, nausea, depression with suicidal thoughts, and more.
 - Went to a series of doctors appointments
 - Viruses had reactivated, leaky gut, food sensitivities, and elevated ANA with no explanation. More doctors said it was psychogenic.
 - Scalp lesions
 - Worsening headaches and brain fog
 - Health declining and professors helped her accommodate so she could graduate
 - Too ill to work but offered a scholarship for an MA in education
- July 2019 started half day teaching pos and health declined
 - Diagnosis with hyper androgenic pots
 - First myoclonic??? Seizure, lost speech function and other issues
- Jan 2021 – continue with issues
 - Triggered by rotating fans, flashing lights
 - No abnormal EEG – told psychosomatic or childhood trauma causing the seizures. ME/CFS believed it to be a hypersensory response
 - Rashes developed
 - Cannot work
- Feb 2021: CSF, SFT and Dural repair
 - Had cervical fusion
 - Testing for OTC and had tethered cord correction
 - Severe spinal infection
- April: diagnosed by geneticist
- August: trending upwards

Q and A

- How can I exercise safely with tethered cord?

- Klinge - Most things are safe but it is good to work on the core stability and mobility rather than over exertion.
- Russek – decrease bending and repetitive bending in the lumbar
- **Good PT?**
 - Should be watching closely, teaching you so you know what do to at home. Should back up quickly if they see that you cannot do an exercise correctly and start again.
- OTC with eating issues and GI
 - Gastroparesis is an element of having a connective tissue disorder so it might not necessarily be an indication for OTC, just another issue with EDS.
 - However, if you see that the tethering has an effect for the entire spine then you can see that issues in the upper and lower GI may be a secondary phenomena
 - I didn't believe it years ago, but after OTC people have described that they DO have improved digestion, better appetite, and real changes in how their digestive systems work. There is a link and we need to look further.
- What do physio's think of tune up therapy vs. black ball therapy? Which one is better for hsd/eds patients?
 - Depends on what patients are experiencing. There is no one therapy that is best for all.
- How does pelvic floor dysfunction interact with tethered cord and/or vice versa?
 - The functional unit of the region is impacted. The sacral nerves are impacted by the tethered cord and therefore causes pelvic floor dysfunction.
 - In males it's a bigger problem than in females.
 - Pelvic floor dysfunction IS a part of the sacral nerve dysfunction caused by tethered cord and symptoms improve after surgery.
- Muldowny protocol adapted for specific needs of the patient.
- Should CCI fusion or OTC be needed, which one first?
 - There isn't enough evidence to prove which really should happen first.
 - In Peds, OTC first because development may without tethering improve or benefit the CCI.
 - In adults we don't know.