

Physical therapy for Pelvic Floor Dysfunction in Clients with Hypermobility Spectrum Disorders

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Credentials

1. Board certified women's health specialist - ABPTS.
2. My first client with EDS in 2006.
3. Practicing clinician specializing in male and female PFD of all types.

Pelvic Floor Physical Therapy

- Hyperarousal/PGAD
- Pelvic organ prolapse
- Diminished or absent libido
- Pelvic Pain - pain with intercourse, painful bladder syndrome (IC), pelvic region pain (hips/SI joints/pubis bone/tailbone/sit bones or ischial tuberosity), Pelvic congestion
- Urinary Incontinence
- Fecal Incontinence
- Symphysis Pubis/Sacroiliac instability and pain
- Rectus Diastasis
- Constipation

EDS and Pelvic Floor Dysfunction

Journal of Reproductive Medicine - Sorokin et al published in 1994

Title: Obstetric and gynecologic dysfunction in the Ehlers-Danlos syndrome.

Women members of the newly formed Ehlers-Danlos National Foundation (EDNF) were surveyed with a very detailed questionnaire with 50 questions concerning family history and inheritance, past medical history, and obstetric and gynecologic problems.

They entailed the largest extant database on Ehlers-Danlos Syndrome (EDS) patients. The mean age of the 68 women who responded to the survey was 42 years; most had EDS types I, III, IV and unknown.

Amongst their various findings they found recurrent vaginal infections (53%), sexual dysfunction (61%)

Women with EDS also seem to have high frequency of dyspareunia.

EDS and Pelvic Floor Dysfunction

American Journal of Medical Genetics - Castori et al Published in 2012

Title: Gynecologic and obstetric implications of the joint hypermobility syndrome (a.k.a. Ehlers-Danlos syndrome hypermobility type) in 82 Italian patients

Common gynecologic findings were dysmenorrhea (82.9%), irregular menses (46.3%), and dyspareunia/vulvodynia (31.7%)

Major post-partum complications included abnormal scar formation after cesarean or episiotomy (46.1%), hemorrhage (19.4%), pelvic prolapses (15.3%), deep venous thrombosis (4.2%), and coccyx dislocation (1.4%). Prolapses were the most clinically relevant complication and associated with episiotomy.

EDS and Pelvic Floor Dysfunction

The Journal of Sexual Medicine - Dr. Jill Krapf and Andrew Goldstein - 2013

Title: Two case presentations of profound labial edema as a presenting symptom of hypermobility-type Ehlers-Danlos syndrome.

25-year-old female, severe labia minora swelling, bladder pressure associated with intercourse and persistent genital arousal. History revealed easy bruising, joint pain, and family history of aneurysm. 22-year-old female with intermittent profound labial swelling for 6 years, associated with sensitivity and pain with intercourse. The patient has a history of joint pain and easy bruising, as well a sister with joint hypermobility and unexplained lymphedema. The presenting symptom of profound labial edema led to the diagnosis of hypermobility-type EDS.

Patients with hypermobility syndrome exhibit an increased ratio of type III collagen to type I collagen, causing tissue laxity and venous insufficiency. Abnormal collagen may lead to gynecologic manifestations, including unexplained profound labial edema, pelvic organ prolapse in the absence of risk factors, and possibly persistent genital arousal.

This highlights the need for further research to determine incidence of labial edema in hypermobility-type EDS and to further elucidate a potential correlation between profound labial edema and collagen disorders.

EDS and Pelvic Floor Dysfunction

International Urogynecology Journal - Mastoroudes et al Published in 2013

Title: Lower urinary tract symptoms in women with benign joint hypermobility syndrome: a case-control study. Benign joint hypermobility syndrome is under-recognised by medical professionals and is poorly managed. The aim of their study was to determine whether lower urinary tract symptoms, including urinary incontinence (UI) and anterior compartment prolapse, are more common in women with BJHS than in the normal population.

Sixty individuals were recruited and matched with 60 healthy women. The prevalence of UI in those with BJHS was significantly higher than in controls (73.3 % vs. 48.3 %).

A significant number of women with BJHS suffer from voiding difficulties. Prolapse of the anterior vaginal wall was objectively more severe in those with BJHS.

CONCLUSIONS:

Women with BJHS have LUTS and anterior compartment prolapse, which significantly impair their QoL. It is important to identify women who are symptomatic. The addition of a systematic active case-finding approach may be more effective in identifying these cases.

EDS and Pelvic Floor Dysfunction

BJOG - An international Journal of Obstetrics and Gynecology - Mastoroudes et al Published in 2013

Title: Prolapse and sexual function in women with benign joint hypermobility syndrome.

Purpose: To determine whether pelvic organ prolapse and sexual dysfunction are more severe in women with benign joint hypermobility syndrome than in the normal population.

Population: Women diagnosed with BJHS (n = 60) at University College Hospital. Control participants (n = 60) recruited from King's College Hospital NHS Foundation Trust.

Results: In all, 120 women (60 in Study group, 60 in Control group) were recruited. All women in the study group were matched with healthy control women according to age, parity and ethnicity. There was a statistically significant difference between points Aa, Ba, Ap, Bp and C in study and control groups showing that prolapse is objectively more severe in those with BJHS. Significantly more women with BJHS felt that POP interfered with sex and defecation compared with the control group. The impact of prolapse symptoms on quality of life was statistically different in almost all nine P-QOL domains.

CONCLUSIONS:

A large number of women with BJHS have prolapse symptoms, which significantly affect their quality of life. POP is more severe in women with BJHS.

EDS and Pelvic Floor Dysfunction

Obstetrics and Gynecology - Hurst et al Published in 2014

Obstetric and gynecologic challenges in women with Ehlers-Danlos syndrome.

Population: 1,225 reported a typed diagnosis of Ehlers-Danlos syndrome.

Further stratification to the three most common types and reproductive-aged women (n=775) allowed conclusions to be made about differences in rates of obstetric complications and gynecologic dysfunction compared with the general population and between types of Ehlers-Danlos syndrome.

Gynecologic pain reported included dysmenorrhea by 92.5% and dyspareunia by 77.0%.

There is a much greater prevalence of obstetric and gynecologic issues reported by women with Ehlers-Danlos syndrome than in the general population. Additionally, rates differed significantly among the three most common types of Ehlers-Danlos syndrome with vascular type having the highest rates of adverse pregnancy outcomes and menstrual abnormalities. Physician providers should be aware of these challenges and should counsel patients with Ehlers-Danlos syndrome about relevant options and risks.

EDS and Pelvic Floor Dysfunction

Physiotherapy Research International - The Journal for Researchers and Clinicians in Physical Therapy - Russel et al Published in 2014

Title: United States Physical Therapists' Knowledge About Joint Hypermobility Syndrome Compared with Fibromyalgia and Rheumatoid Arthritis.

The aim of this study was to assess US physical therapists' knowledge about JHS compared with other causes of widespread pain and activity limitations: fibromyalgia, juvenile rheumatoid arthritis and adult rheumatoid arthritis. Only 26.8% of respondents were familiar with the Brighton Criteria for diagnosing JHS. Few respondents (11-19%) realized that JHS has extra-articular features such as anxiety disorder, fatigue, headache, delayed motor development, easy bruising and sleep disturbance. Physical therapists working in environments most likely to see patients with JHS underestimated the likely prevalence in their patient population.

CONCLUSIONS:

The results suggest that many physical therapists in the United States are not familiar with the diagnostic criteria, prevalence or common clinical presentation of JHS.

EDS and Pelvic Floor Dysfunction

Archives of Physical Medicine and Rehabilitation - Rombaut Published in 2011

Title: Medication, surgery, and physiotherapy among patients with the hypermobility type of Ehlers-Danlos syndrome.

Objective - To describe medication use, surgery, and physiotherapy, and to examine the effect of these treatment modalities on functional impairment and amount of complaints among patients with the hypermobility type of Ehlers-Danlos syndrome (EDS-HT).

Results - Patients reported a large number of complaints, a considerable presence of severe pain, and a clinically significant impact of disease on daily functioning. Most patients (92.4%) used medications, among which analgesics were the most prevalent. Fifty-six patients (70.9%) underwent surgery, including mainly interventions of the extremities and abdomen. Forty-one patients (51.9%) are currently enrolled in a physical therapy program, mainly comprising neuromuscular exercises, massage, and electrotherapy. Patients with a high consumption of analgesics, who visited the physiotherapist, or who underwent surgery had a higher dysfunction in daily life. Only 33.9% of the patients who underwent surgery and 63.4% of patients in physical therapy reported a positive outcome.

Conclusion - Patients with EDS-HT have numerous complaints and an impaired functional status that strongly determine their high rate of treatment consumption. The outcome of surgical and physiotherapy treatment is disappointing in a large percentage, which illustrates a strong need for evidence-based therapy.

EDS and Pelvic Floor Dysfunction

American Journal of American Genetics - Bathan et al Published in 2013

Title: Multidisciplinary treatment of disability in ehlers-danlos syndrome hypermobility type/hypermobility syndrome: A pilot study using a combination of physical and cognitive-behavioral therapy on 12 women.

There is a lack of evidence-based treatment approaches; a few studies have shown effect of physiotherapy. Many authors propose multidisciplinary treatment, but this has neither been described nor evaluated for this patient group. The aim of this pilot study was to investigate if a multidisciplinary rehabilitation program combining physical and cognitive-behavioral therapy was feasible, safe and effective for 12 women with EDS-HT/JHS.

Intervention was offered as a group program and consisted of three parts: (1) Two and a half weeks in a rehabilitation unit with testing, physical training, group discussions and lectures. (2) Individual home exercises for three months with weekly guidance by local physiotherapist. (3) Readmission four days for retesting and further training advice. All participants completed the intervention.

We found significant changes in perceived performance of daily activities, significant increase of muscle strength and endurance and a significant reduction of kinesiophobia. There were smaller changes in self-perceived pain. The participants also reported increased participation in daily life.

Clinical Reasoning

No aggressive joint mobilization or manipulation

Why?

Already hypermobile collagen, likely there is little need to increase the mobility of each joint and its mechanics.

Likely to cause muscles to become hypertonic or go into spasm to further support joints after irritation
= Increased Pain

Clinical Reasoning

Realign joints, especially in the spine and pelvis using gentle techniques where the client uses their own muscles to place themselves back into alignment.

Decreases risk of pain after treatment

Tends to decrease anxiety in the patient because although the practitioner is choosing which muscles to use, the client is in control of how hard the muscles are contracted

Debate over efficacy

Clinical Reasoning

Treat muscle hypertonicity/spasm and trigger points at each treatment on an individual basis

- With some patients, hypertonicity/TTPs must be fully cleared or the client will feel even worse than when they came in. With other patients they need some tone left in the muscles or they will have an even greater degree of hypermobility.
- The clinician can use max tolerable (must be tolerable without any patient cringing/guarding) myofascial release and soft tissue mobilization as well as connective tissue release.
- The clinician can use gentle techniques like strain counter-strain to fully reduce trigger points, internal and external.

Clinical Reasoning

Educate Client on current forms and use of proper orthotics, sacro Iliac joint stabilizer belts and teach the client how to use Kinesio Tape to augment stability at home. (youtube!)

Educate the client on body mechanics and posture to reduce risk of re-injury.

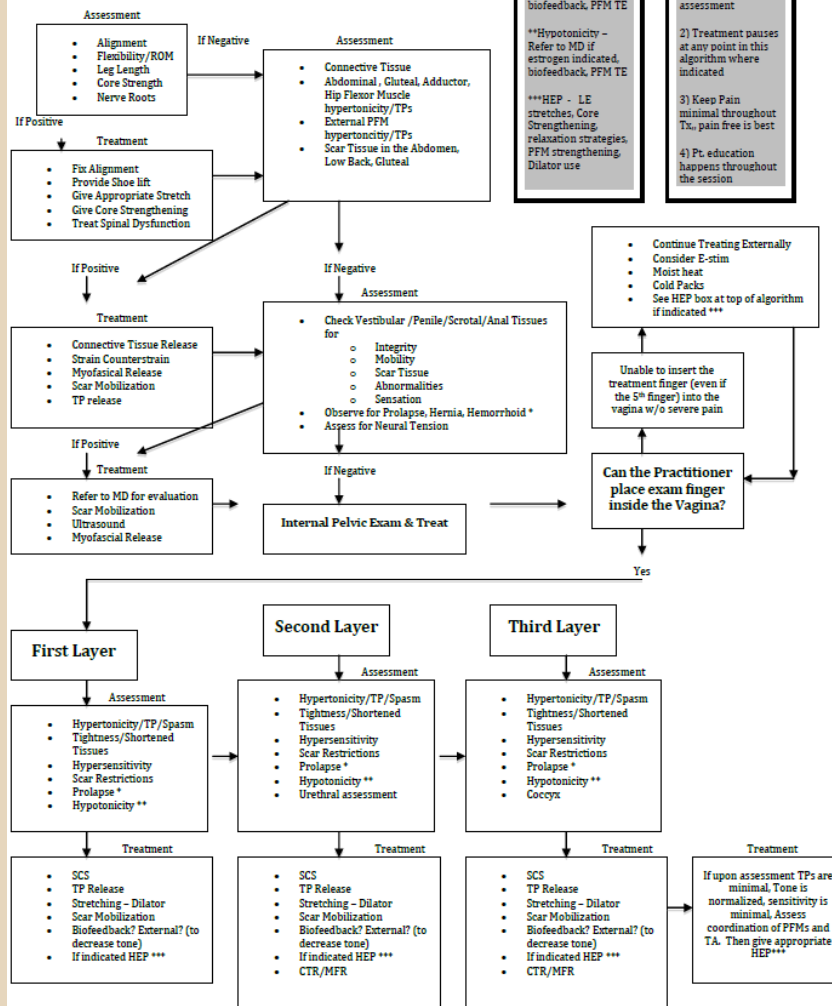
Clinical Reasoning

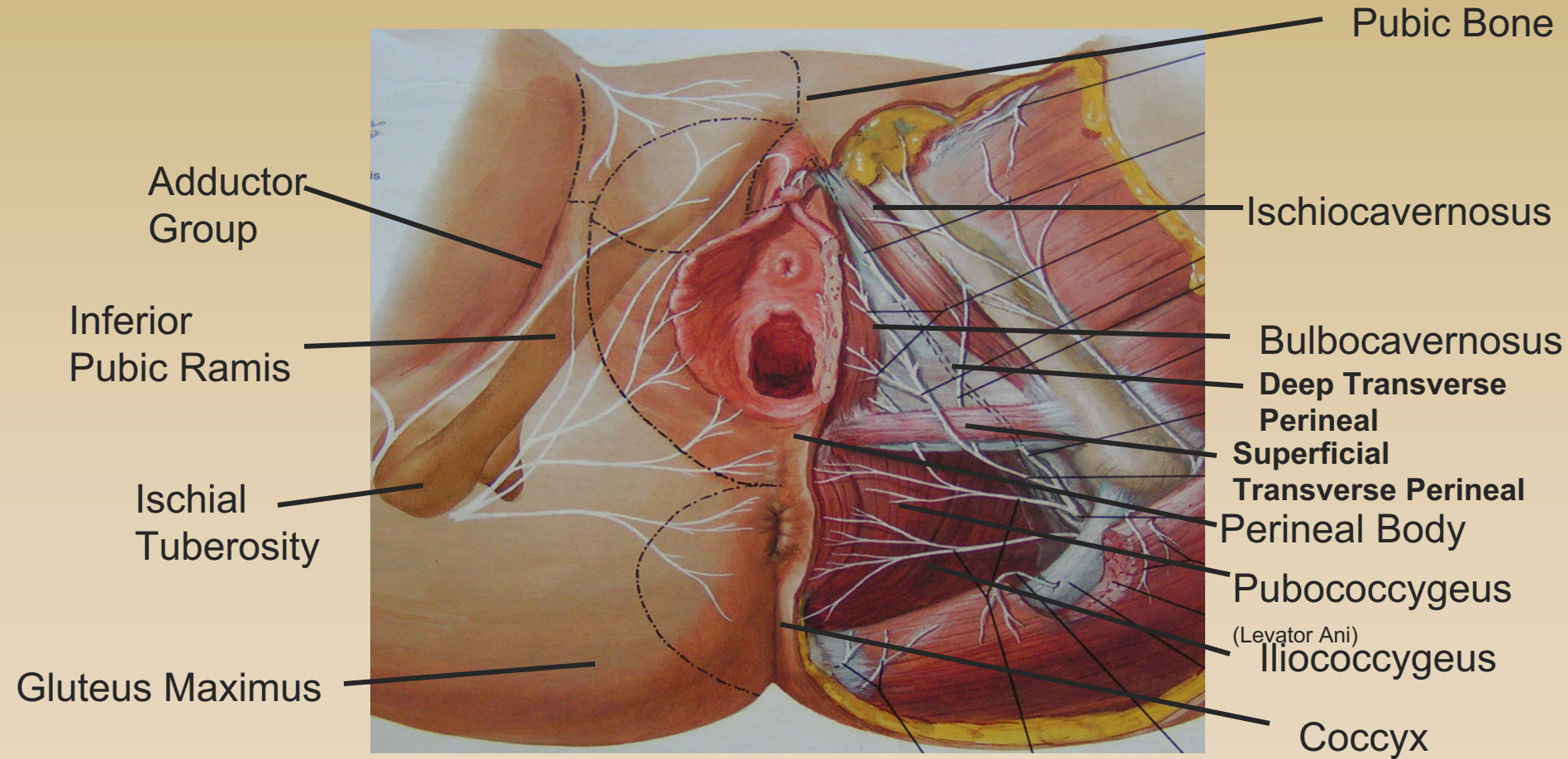
Give VERY CAREFUL Home Exercises -
considering all of the possible variables.

- 1.hypromobility
- 2.POTS
- 3.fatigue
- 4.vascular insufficiency
- 5.insomnia
- 6.etc...

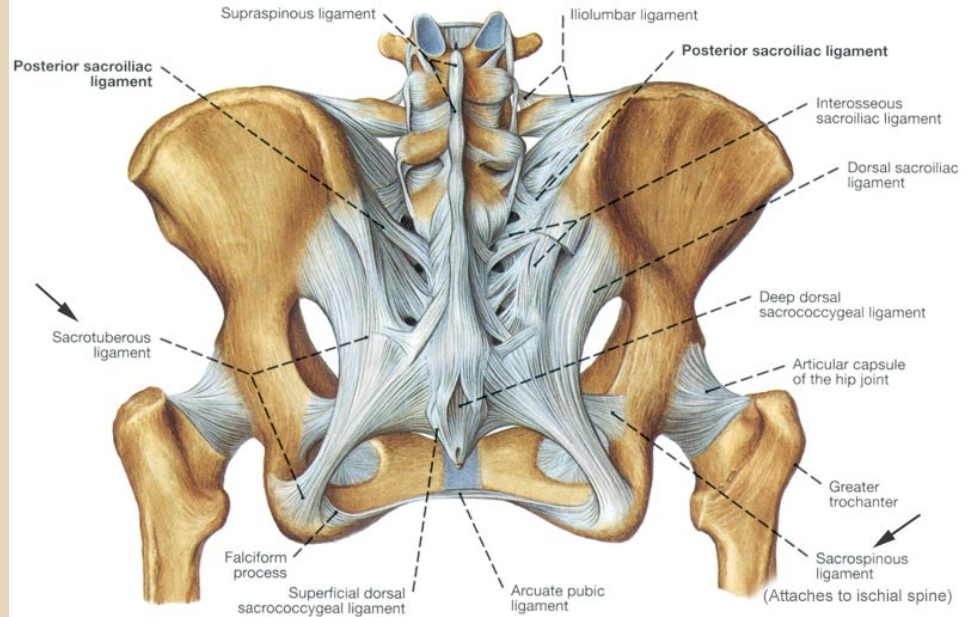
Algorithm

Pelvic Floor Dysfunction Evaluation and Treatment Algorithm





Pelvis and Ligaments, Rear View, Female



External Pelvic Muscles Examined and Treated in Clients with Pelvic Dysfunction

List of muscles to be assessed in examination of Pelvic floor dysfunction as trigger points in these muscles have been shown to refer pain to the pelvic region, lower abdominal region and perineal region:

- Adductor Magnus
- Adductor Longus
- Thoracolumbar Paraspinal Musculature
- Piriformis
- Gluteus Magnus
- Gluteus Minimus
- Gluteus Medius
- Quadratus Lumborum
- Iliacus
- Psoas Major
- Obturator Internus (often assessed internally)
- Tensor fascia lata (no direct referral to perineum or pelvis, however often found in clients with pelvic floor dysfunction)



Ways in which Trigger Points Develop

1. Vaginal ultrasound
2. Chronic or acute strain with defecation
3. Fall on tailbone, back, pelvis or hip
4. Sexual abuse
5. Physical abuse
6. Urinary incontinence
7. Fecal incontinence
8. Urinary urgency and/or frequency
9. Urinary tract infection (frequent or as few as one)
10. Yeast infection
11. Dyspareunia
12. Cycling
13. Vigorous high impact exercise
14. Vaginal childbirth
15. Episiotomy
16. Joint Hypermobility/Instability
17. Etc...

Three Layers of Muscles Internal Pelvic Floor

First Layer (Urogenital Triangle)

- Superficial Transverse Perineal Muscle
- Bulbospongiosus Muscle (Male)
- Bulbocavernosus (Bulbospongiosus) Muscle (Female)
- Ischiocavernosus Muscle (Female and Male)

Second layer (Urogenital Diaphragm)

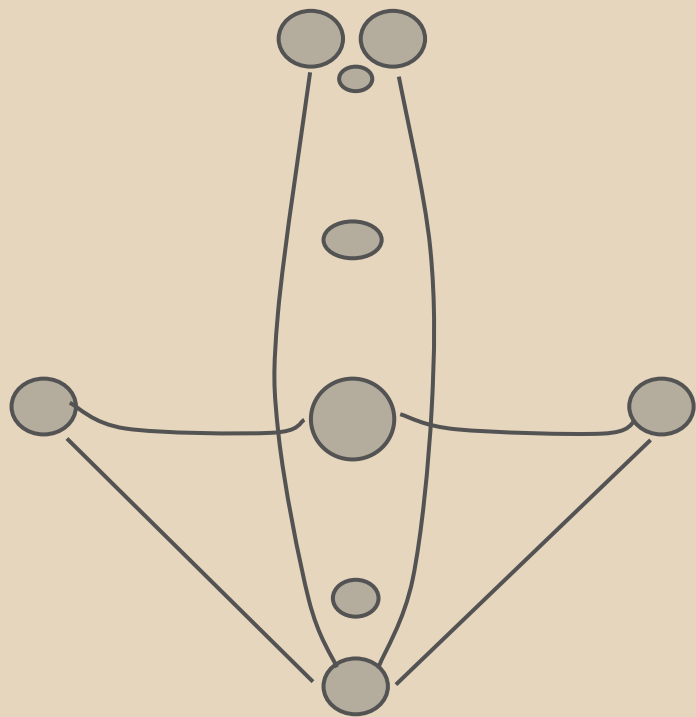
- Sphincter Urethra
- Urethrovaginal Sphincter
- Compressor Urethra
- Deep Transverse Perineal

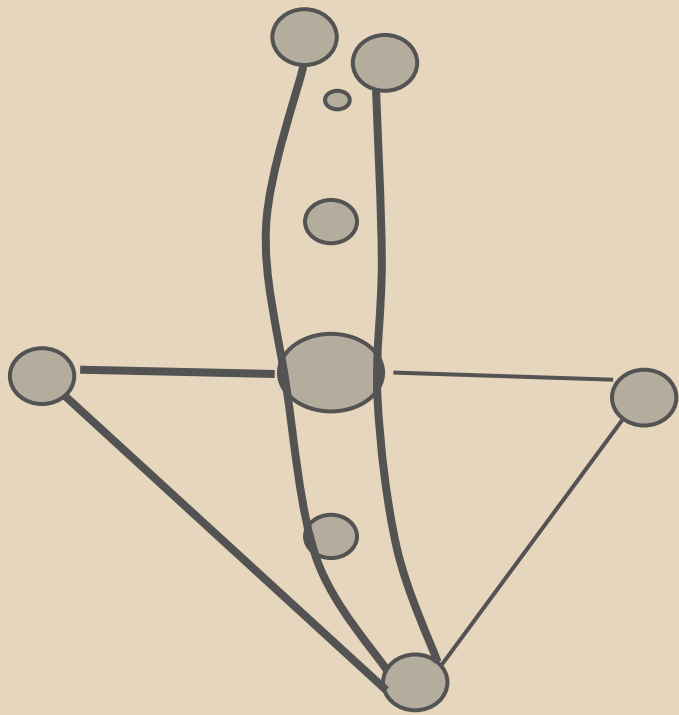
Third Layer (Levator Ani Group and Pelvic Diaphragm)

- Pubococcygeus
- Puborectalis
- Iliococcygeus
- Coccygeus (Ischiococcygeus)
- Piriformis
- Obturator internus

Muscle Energy Technique

- Muscle energy technique (MET) is a common conservative treatment for pathology around the spine, particularly lumbopelvic pain (LPP).
- MET is considered a gentle manual therapy for restricted motion of the spine and extremities and is an active technique where the patient, not the clinician, controls the corrective force.
- This treatment requires the patient to perform voluntary muscle contractions of varying intensity, in a precise direction, while the clinician applies a counterforce not allowing movement to occur.
- The theory behind MET suggests that the technique is used to correct an asymmetry by targeting a contraction of the hamstring or the hip flexors on the painful side of the low back and moving the innominate in a corrected direction.
- It is worth noting however, that evidence suggests that non-symptomatic individuals have also been shown to have pelvic asymmetries.





Strain and Counterstrain

Strain and Counterstrain, originally called “positional release technique,” was developed in 1955 by an osteopathic physician named Lawrence Jones.

Strain and Counterstrain is a manual therapy technique, meaning the clinician uses only their hands, to treat muscle and joint pain and dysfunction. It uses passive body positioning of spasmed muscles and dysfunctional joints toward positions of comfort or tissue ease that compress or shorten the offending structure.

The purpose of movement toward shortening is to relax aberrant reflexes that produce the muscle spasm forcing immediate reduction of tone to normal levels. This allows the joints influenced by the now relaxed muscle to function optimally increasing its range of motion and easing muscle pain. Strain and Counterstrain is an effective but extremely gentle technique because its action for treatment moves the patient's body away from the painful, restricted directions of motion.

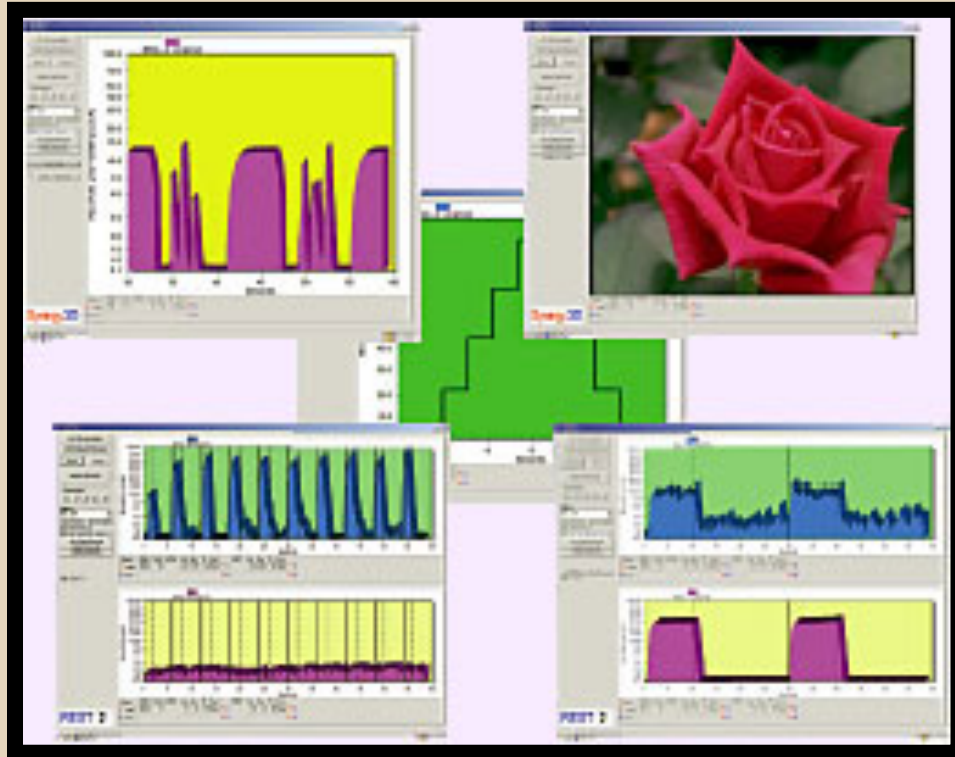
The gentleness of strain and counterstrain makes it safe and effective for treating fragile patients (i.e., infants with torticollis, elderly patients with osteoporosis, stress fractures, pregnancy or pelvic pain patients, post-operative pain, etc.) and the pain associated with excessive joint motion or hyper-mobility.

Strain and Counterstrain is valuable for the chronic pain patient because it will treat out a longstanding neuromuscular problem reducing the tone of a muscle in spasm. By diminishing the spasm muscle pain is abated and joint function is normalized.

Strain and Counterstrain



Biofeedback



Rotational mobilization

- Assess myotomes, dermatomes, reflexes
- Treat the spine at the corresponding level
- For example: If the patient has pain in the tissues around the vagina and rectum, I might evaluate the bulbocavernosus reflex to evaluate the S3-4 nerve root for involvement. If the patient's reflex is hyper or hyporeflexive, it would indicate the patient should be treated in the spine at those levels.
 - Another option is that I would evaluate the myotomes by testing the strength of the ankle dorsiflexors, toe extensors, toe flexors and hamstrings. These are innervated by nerve roots L4,5 and S1-2. Those same nerve roots innervate muscles in the vagina and rectum including the levator ani muscles, the urogenital triangle, the clitoris and vulva. If I improve the function of the toes extensors, I have improved the function of the vaginal muscles without having to touch the vaginal musculature.
- One option safe for treating the spine of the client with EDS is rotational mobilization.
- Light pressure through muscle on the side of the spine to rotate the spinous process of the level of the spine that you wish to treat.
- The theory is, this stimulates Type II mechanoreceptors, releasing serotonin and improving nerve root function which improves the function of everything innervated by that nerve root.

Sex and Sexuality - It's Complicated!

Psychosocial - Abuse, trauma

Socioeconomic - Leads to tongue in cheek accronyms
like: DINS

Testosterone and Estrogen...

Hormones are not the main neurobiological chemical
components of sexuality.

The Balance of Excitation and Inhibition

Excitation: Desire arousal: Dopamine, Oxytocin, Norepinephrine.

Inhibition: Opioids, Serotonin

Hypoactive Sexual Desire Disorder - may be a result of hypofunction of excitation, hyperfunction of inhibition or a mix of both. Compare to Persistent Genital Arousal Disease.

Progesterone

High levels cause a relaxing or loosening of the supporting ligaments in the back, pelvic and knees.

Higher level of injury right before menses

Relaxes the smooth muscle of the intestines

Estrogen Deficiency and Sex

- Changes in urogenital anatomy
- Shortening and loss of elasticity of the vagina
- Diminished secretions (bartholin/skenes glands)
- Increased pH (more alkaline so it doesn't fight off bacteria as well as an acidic environment)
- Thinning of vaginal epithelial layers
- Reduced Blood Flow
- Reduced Nerve Transmission

Testosterone

- The hormone of desire
- Made in the ovaries and the adrenals (from DHEA-s)
- $\frac{3}{4}$ of it turns into estrogen
- Lose 50% of your testosterone after menopause
- Activates the sexual circuits in the brain
- Promotes healthy sexual desire

Stress

Causes excessive cortisol release from the adrenals which *suppresses the ovaries* and their function

Decreases estrogen and testosterone production

Decreases sleep

Increases generalized pain – which disrupts sleep

Causes increase muscle tension - fist effect

Increases urinary urgency and frequency

Sexual Concerns for Clients with EDS

Lack of Sexual interest and desire

Lack of orgasm with intercourse – clitoris and/or weak or spasming muscles are key

Difficulty finding a position and performing pelvic movements

Fear of pain with penetration or deep pain

Fear of orgasm or no orgasm due to onset of pain after intimacy

Diminished lubrication

Hip/Pelvic/Back Pain

So how can you improve your sex life?

Let go of a goal-oriented approach to intercourse - VENIS

Let go of a goal-oriented approach to orgasm

Enhance awareness of erogenous zones

Communicate likes and dislikes

Educate yourselves about anatomy

Fantasize

So How Can You Get Better Sex?

Use Water Based Lubricants!

Not vaseline, baby oil or mineral oil

No Glycerin

Avoid Nonoxynol-9 a spermicidal lubricant

No KY Jelly which has chlorohexadine and propylene glycol!

www.goodvibes.com

Olive, Almond, or Grape seed Oil

Use Supportive cushions like the Liberator

Get advice on positions to avoid dislocation/subluxation during intercourse

Physical Therapy's Goal for Pelvic Dysfunction

- Increase awareness and proprioception of the PF joints and muscles with biofeedback and education
- Decrease fears of vaginal penetration
- Desensitize painful areas
- Improve continence and/or voiding dysfunction, prolapse, and back/pelvic pain to reduce fear
- Normalize muscle tone – improve stability
- Improve voluntary muscle relaxation
- Address any loss of sensation
- Work *with* physicians who can address hormonal issues, neurotransmitter issues, urologists, urogynecologists and gastroenterologists familiar with the role of physical therapy.

The Ortiz Proposal for Physical Therapy Treatment Of Sexual and Pelvic Floor Dysfunction in Clients Diagnosed with Hypermobility Spectrum Disorders

Very little current research - Trench war analogy.

Based on common sense, critical thinking and clinical experience.

Physical Therapy as Part of Multidisciplinary Care for Sexual Dysfunction in EDS

1. Check and address alignment - MET - if possible teach the patient and/or family members how to do this as well.
2. Improve muscle function and normalize reflexive function along myotomes by addressing the spine.
3. Decrease mm hypertonicity, spasm, trigger points and connective tissue restrictions - SCS first, then MFR/STM.
4. Provide support where needed in the form of orthotics/belts and KT tape.
5. Give careful therapeutic exercise, always starting with isometrics, only stretching where indicated and then progressing to higher intensity strengthening steadily.
6. Work with EDS fluent physicians and pelvic pain specialists to augment sexual function sooner than later.
7. Work with EDS fluent psychotherapists.

Exercises - PROCEED WITH CARE!

- Bridge with legs on folded blankets
- Bridge with rolled blanket behind knees
- Slow knee roll outs feet supported on chair/wall
- Slow knee roll outs, feet supported on chair/wall with heel press (prone option)
- Pelvic Drop
- Transverse abdominus contraction with BKFO



Kristen Joyce, Stephanie McKay, Amanda Marino
Any Questions?