WOMEN’S HEALTH CONCERNS

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Gynecologic Issues and Ehlers-Danlos Syndrome/Hypermobility

- EDS is associated with a higher frequency of some common gynecologic problems.
- EDS is associated with some rare gynecologic disorders.
- Pubertal maturation can worsen symptoms associated with EDS.
Gynecologic Issues and Ehlers Danlos Syndrome/Hypermobility

- Menstruation
- Menorrhagia
- Dysmenorrhea
- Abnormal menstrual cycle
- Dyspareunia
- Vulvar Disorders
- Pelvic Organ Prolapse
Puberty and EDS

- Symptoms of EDS can become worse with puberty, or can begin at puberty
- Hugon-Rodin 2016 series of 386 women with hypermobile type EDS.
  - 52% who had prepubertal EDS symptoms (chronic pain, fatigue) became worse with puberty.
  - 17% developed symptoms of EDS with puberty
Hormones and EDS

• Conflicting data on effects of hormones on connective tissue, joint laxity, and tendons
  • Estriol decreases the formation of collagen in tendons following exercise
  • Joint laxity increases during pregnancy

• Studies (Non EDS)
  • Heitz: Increased ACL laxity in luteal phase
  • Park: Increased knee laxity during ovulation in some, but no difference in hormone levels among all (N=26)
Menstrual Cycle Hormonal Changes
GYN Issues EDS/HDS: Menorrhagia

- **Menorrhagia** – heavy menstrual bleeding 33-75%, worst in vEDS
- Weakness in capillaries and perivascular connective tissue
- Abnormal interaction between Von Willebrand factor, platelets and collagen
Menstrual cycle: Endometrium

Throughout the fertile period of a woman's life, hormonal changes control cyclical changes to the reproductive organs. Every month, an egg is released from the ovaries and the endometrium thickens in readiness to accept it—if it is fertilised. If conception does not take place, then this uterine lining is discarded and a menstrual bleed occurs.
HORMONAL CONTRACEPTIVE OPTIONS
GYN Menorrhagia: Hormonal Treatment

- Oral Contraceptive Pill
- Progesterone only medication
  - Progesterone pill: Norethindrone
  - Progesterone long acting injection: Depo Provera
- Long Acting Implant: Etonorgestrel
- IUD with progesterone
Hormonal treatment for Menorrhagia

- Hernandez and Dietrich, EDS adolescent population in menorrhagia clinic
- 9/26 fine with first line hormonal medication, often progesterone only pill
- 15/26 required 2 or more different medications until found effective one.
- Daily compliance with P or OCP an issue for some
- Goal amenorrhea, achieved by 70% at 2 years
GYN Bleeding: Hormonal Treatment EDS

- Hugon-Rodin, large series, adults
- EDS symptoms improved:
  - 15% on OCP
  - 25% on progesterone only medication
- Already had cyclic worsening of EDS each perimenstrual period:
  - 25% worse on OCP
  - 15% improved on OCP
GYN Menorrhagia Nonhormonal Treatment: Tranexamic Acid

• Antifibrinolytic
• Prevents breakdown of clots (inhibiting clot-dissolving enzymes)
• Taken during first 5 days of menstrual cycle
• Good option for women with migraines with aura
• Venous thromboembolic disease rarely reported, theoretical concern
GYN Menorrhagia Nonhormonal Treatment: Vitamin C

- Vitamin C can reduce blood vessel fragility
- Acts on the lining (endothelial cells) integrity
- Cofactor in crosslining of collagen fibers
- Like all water soluble vitamins, need to take a steady dose
Abnormal Uterine bleeding: Other

• Intermenstrual bleeding
  • More common in vascular EDS
  • Hormonal therapy after ruling out pathogenic etiologies

• Irregular menses
  • Reported in about 30% EDS females, both adolescent and adult
  • Polycystic Ovary Syndrome in some
GYN Issues EDS/HDS: Dysmenorrhea

- **Dysmenorrhea** – painful menses 73-93%
- Usually caused by increased prostaglandin release
- Made in lining of uterus, cause muscles and blood vessels of uterus to contract
Dysmenorrhea Treatment

- **NSAID** – non-steroidal anti-inflammatory drug, target prostaglandins
- Works best if start at very onset of menses
- Can help with nausea, diarrhea
- Alternative treatment options include Vitamin B₁, 100mg, Vitamin B₆, magnesium supplements, acupuncture
Dyspareunia

- Painful sexual intercourse
- Reported in 30-61% of sexually active women with EDS.
- Castori observed only seen in women who had dysmenorrhea, 31% in his series
- Etiologies include
  - Vaginal dryness
  - Fragile tissue, with spontaneous skin fissures or tearing after intercourse
  - Vulvar edema
  - Vulvodynia
Vulvodynia

- Vulvodynia: chronic pain/discomfort of the vulva for which no obvious etiology can be found.
- Incidence 32-77%. Always have a history of dysmenorrhea
- Etiology- peripheral sensitization of the vulva or generalized urogenital, pelvic and/or central nerve nervous sensitivity
Vulvar Edema

• Swelling of the vulva
• Make be persistent, or occur with/after intercourse
• Etiologies in EDS
  • Vasocongestion, due to laxity of blood vessel walls
  • Venous insufficiency, resulting in pooling of blood.
Persistent genital arousal syndrome

- Intrusive genital arousal
  - unrelated to sexual desire
  - unrelieved by orgasm
  - Painful in 30%

- During sexual arousal, blood flow to genitalia increases, leading to genital vasocongestion

- Persistent genital arousal syndrome may be associated with systemic vasocongestion secondary to laxity of blood vessels
Vulvar disorders/Dyspareunia: Treatment

- Skin care
- Physical therapy
- Psychotherapy
- Cognitive behavior therapy
- Exercises: Kegel/reverse Kegel
- Medications
Medications for vulvar disorders

• Gabapentin - treats neuropathic pain
• Benzodiazepines - less sensitive to stimulation (GABA brain receptors)
• TCA - Tricyclic antidepressants, increase norepinephrine and serotonin
• SSRI - Serotonin ("feel good") reuptake inhibitor, increases levels in brain
Pelvic Organ Prolapse

- Can involve bladder, uterus, rectum, or any combination of these.
- Can occur at all ages, typically post-pubertal.
- Need to keep in mind if vaginal mass seen, even in nulliparous women.
- More common after childbirth.
  - One study did not show increased risk after childbirth when compared with control population.
Pelvic Organ Prolapse
Other Gyn issues

• **Endometriosis**  6%-23%

• **Uterine myomas**  5-9%

• **Infertility**  Wide range reported for hEDS: Majority show no difference from general population, up to 48%
Menopause

- Improvement of EDS symptoms in 22%
- HRT used in 42%
  - 15% of these women founded symptoms improved.