Vulvodynia—Who, What, Why?

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“But I’ve never seen it !!!”
- Vulvodynia is more common than you might imagine!!!
- Commonly misdiagnosed
- Prolonged duration of treatment for “other things”

Outline for discussion
- What is it?
- Who gets it?
- How to make the diagnosis
- Treatment options

Is vulvodynia rare?
- Previously estimated at 150,000 to 20,000 in the United States (Vulvar Pain Foundation)

No longer considered a “rare disease”!
- Goetz – found 15% of women in her practice met the ISSVD definition if asked regarding symptoms and tested with Q-tip test (? 6 million women?)
- Dr. Harlow and colleagues reported a significant prevalence of vulvar pain among women responding to a survey in the greater-Boston area (13%, with 7% ongoing).
- Our recently completed Web Survey had similar findings in a very different population.

Web survey re: vulvar pain
- 3000 e-mail invitations to women participants in a Survey Sampling cohort
- 1024 responded
- 18-78 years of age

Vulvar Pain: Web survey
What does a prevalence of 1.7% look like?

What is vulvodynia?
- First described 1889 by Dr. A.J.C. Skeneas “excessive sensitivity” of the vulva
- 1928 – described by Dr. Howard A. Kelly as “exquisitely sensitive deep-red spots in the mucosa of the hymenal ring”
- Then NOTHING in the literature for 30 years!

“Vulvodynia” coined in 1983 by International Society for the Study of Vulvovaginal Disease (ISSVD)
- “Chronic vulvar discomfort that is characterized by the complaint of burning, stinging, irritation, or rawness”

What is it?
- No evidence of
  - Ongoing infectious etiology
  - Dermatologic etiology
- Neuropathic pain quality:
  - Hyperpathia
  - Allodynia
  - Ongoing pain after provocation
  - Often burning in quality

Making the diagnosis
- *BURNING, IRRITATING, even itching pain*
- *CHRONIC (> 3 months)*
- *INTERMITTENT or CONSTANT*
- *EXACERBATED* with intercourse or tampons typically
- *Vulva unremarkable* except possible mild erythema
- *Q-tip test* tenderness

15 women in each Family Physician’s practice
At least double that in Each Gynecology practice
2,400,000 women in the United States
Exclusions

- Untreated CVV
- Other genital infections/irritations
- Vulvar skin lesions –biopsy first
- Many women will report a “cause” –such as CVV, pregnancy, etc. This does not exclude VVD, and does not effect treatment, prognosis, etc.

Other causes of vulvar pain or symptomatology

- Lichen sclerosus
- Other genital infection/irritations
- Vulvar skin lesions –biopsy first
- Many women will report a “cause” –such as CVV, pregnancy, etc. This does not exclude VVD, and does not effect treatment, prognosis, etc.

Other causes of vulvar pain or symptomatology

- Lichen planus
- Chronic Candidal infection
- Vulvar Intraepithelial Neoplasia
- Allergic reactions
- Condyloma acumminata
- Vulvar atrophy

Definition evolution

- Definition continues to be tweaked
- What is consistent?
  - Discomfort at the introitus –burning, irritation, itch –often reproduced with gentle Q-tip test
  - Lack of dermatologic diagnosis
  - Lack of infectious disorder

Categorization of vulvodynia

- Classified by location and provokation
  - Vestibulodynia (formerly Vulvar vestibulitis) - -
    - Pain localized in the vestibule between the labia minora. Often point tenderness.
    - Occasional erythema in that area.
  - Dysesthetic vulvodynia - -
    - Pain may extend in wide area, including labia majora, clitoris, mons pubis, rectum, upper legs
    - Pain with intercourse and tampons (provoked), but may be constant and unrelated to touch (unprovoked)

Who gets vulvodynia?

- Wide age range -9 to 83 years old in my practice. Majority 20’s to 50’s
- Not associated with low SES or low education
- Not associated with promiscuity, new partners, or large numbers of past partners
- Most in stable relationships – with supportive partner

**Women have had YEARS of pain prior to diagnosis:**
- Time from pain onset to diagnosis:
  5.3 ± 6.8 years (range of 0 to 29 years)

**Number of previous physician seen for vulvar pain**

**Who are patients seeing?**

**Just how bad can it be?**

**Activities that worsen then pain**

**Activities that reduce the pain**

**Data about sexuality of women with vulvodynia are compelling**
- Women with vulvodynia
  - not sexually averse
  - are sexually active
  - are sexually interested

**Marital Status**

**Sexual activities in the past month**

**But…. There are negative findings as well:**

*Women with vulvodynia rate themselves MORE NEGATIVELY as sexual people than did controls.*

**But what Causes it?**
- Infectious
- Psychological risk factors?
- Toxins?
- Hormonal?
- Immunologic?
- Pelvic floor muscle spasm?
- Central pain sensitivity?
Infectious?
- Candida infection?
  - Typical history of Candida vulvovaginitis – often many times
  - Cultures of Candida at the time of evaluation are typically negative
  - Treatment doesn’t cure pain syndrome
- HPV – little support for this, data inconclusive
- HSV, other STDs – no support for these

Psychological?
- In 1997 – roles of sexual abuse, sexual aversion, and psychological mood disorders as risk factors for vulvodynia were unclear.
- Not infrequently patients were made to think their pain was due to psychological issues.

Psychological data
- In general – women with vulvodynia are psychologically very similar to controls.
- General psychological adjustment and relationship adjustment
  - (Meana, Deconstructing dyspareunia, 1995)
  - 54 VVS patients and normal, matched controls
  - No differences

Our data:
- Questionnaires sent to women seen for first visit to the University of Michigan
  - Center for Vulvar Diseases (4)
  - Chronic Pelvic Pain Clinic (17)
  - General Gynecology Clinic (19)

Marital satisfaction

Beck Depression Inventory

Perception of Sexual Activity

Sexual abuse
- Questionnaire study (L Edwards):
  - 89 women with vulvodynia
  - 65 with chronic vulvar symptoms due to other specific vulvar diseases
  - 166 controls from a general dermatology practice

- No difference in reported childhood sexual or physical abuse

Our data: Sex abuse – personal or family

Toxins?
- Oxalate
- One group of researchers found variations in oxalate in the urine over a 24 hour period correlated with fluctuations in pain
- Not replicated by others

**Immunologic?**
- Some studies suggest increase reported allergies among VVD women
- One theory – hypothesized a hypersensitivity reaction to Candida infection

**Pelvic floor muscle impairment**
- Theory – shared innervation via the pudendal nerve plexus to the
  - Superficial vulvar and vestibular tissues
  - Musculature of the pelvic floor
- May lead to interactive neuromuscular changes

- EMG of the pelvic floor (32 women with vestibulitis) – 88% had 3 or more of:
  - Resting baseline
  - Resting standard deviation indicating muscle instability
  - Contractile potential
  - Recruitment recovery after contraction

**Related to interstitial cystitis?**
- Common embryonic origin of the bladder, urethra, and vestibule
- Associated with a history of past UTI’s in 30-66% of participants (numbers small)
- Associated with interstitial cystitis in some studies
- Urethral muscle tone instability seen on testing that is similar to the pelvic floor muscle changes seen in VVD

**Sensory Processing Alteration?**

**Similar changes in periphery!**

**Summary of causality**
- History of Candida infection is increased. Not related to STD or STD risk
- Psychological wellness and marital relationships are comparable between women with vulvodynia and controls and the history of sexual abuse is not increased
- Minimal data on toxins or immune alterations
- Pelvic floor musculature function is altered
- Sensory sensitivity is noted in areas remote from the vulva - - suggesting central sensitization
- None of these proven to be causal

**Treatment – what can we do?**
- Most suggestions are anecdotal
- There are a few studies comparing 2-3 treatments
- Very few on some of the most common treatments used
Treatment options: Often used, but appear ineffective
- Topical steroids
- Topical antifungals
- Acyclovir and Capsaicin
- Intralesional interferon
- Estrogen

Treatment options – appear to be beneficial
- Amitryptiline
- Neurontin
- Biofeedback
- Cognitive-behavioral therapy
- ? Calcium citrate
- surgery

Amitryptiline (Elavil)
- Theory – if vulvodynia is a pain syndrome mediated by a neuropathy, this tricyclic might be expected to modulate the transmission of pain impulses
- Data – no randomized trials
- Anecdotal support from patients (and physicians)
- We’ve had a lot of success with this, and we usually use this first line
- Dose: Start 25 mg. (unless elderly)
  - Increase 25 mg q 2 wks.
  - Typical effective doses 50-100 mg.
  - Occasionally higher doses (to 250 mg.) required.
- Side effects:
  - Fatigue (1st week in particular)
  - Dry mouth
  - Less common – constipation or weight gain
- Most my patients tolerate this well. Try desipramine if side effects intolerable

SSRIs
- No data published
- My experience with small number of women intolerant to amitryptiline – fairly good response (Paxil - - in particular)
- Side effects - -
  - Usually well tolerated
  - Occasional anorgasmia, weight gain, fatigue

Gabapentin (Neurontin)
- Known for use as anti-epileptic
- Usually well tolerated
- Side effects usually minimal, but may include drowsiness, fatigue, dizziness, ataxia, nystagmus, and rarely behavioral changes, tremor or double vision
- Dosage: 900-3600 mg/day divided tid
  - Start 300 mg. Increase 300 mg every 4 days
Biofeedback and physical therapy
- Theory: Pelvic floor muscle abnormalities (increased resting tone, poor strength, high variability) improved with physical therapy/biofeedback training
- Instruct women in home use of EMG monitor
- After 16 weeks of therapy (Glazer et al):
  - Pelvic floor contractions increased in 95.4%
  - Resting tension decreased in 68%
  - Instability of the muscle at rest decreased by 62%
- 22 of the 28 women resumed intercourse, and 17 of 33 reported pain-free intercourse
- Long-term follow-up confirmed improvement in majority
- Recent randomized trial of surgery, cognitive behavioral therapy, and biofeedback revealed response in smaller percent when performed outside Glazer’s group

Cromolyn sodium cream
- Case series by Paul Nyrjesy, PhD,
  - Improvement in 6 of 7 women treated with 4% cromolyn sodium cream.
- Randomized trial followed
  - indicated no better than placebo.
- My recent patient – couldn’t tolerate any oral medication I tried. Topical cromolyn is working very well for her.
- Cromolyn sodium 4% in bland cream – apply tid.

Calcium citrate
- Theory: hyperoxaluria is associated with deposition of oxalate crystals in the genital tissues causing nerve irritation
- Data:
  - Very little
  - Only 1 Case report and one prospective, non-controlled trial by same group
  - Anecdotal support from patients
- Dose: 2-3 bid. Occasionally 4-5 bid if helping

Surgery – vestibullectomy
- Theory: removal of the painful tissue (introitus) with advancement of vaginal mucosa (less sensitive) downward to decrease discomfort
- The most data on treatment outcomes is available on this!
- Data: Many methodological limitations to the studies:
  - Often no control groups
  - Inclusion criteria unclear
  - No measurement of pain other than that with intercourse
  - Unreported adjunctive therapies
  - Variable surgical methods, etc.
- Report 60% or greater response (cure or significant improvement) to surgery

Recent data (2001 – Bergeron)
- Randomized trial – percent pain reduction
  - Surgery (vestibullectomy) – 70%
  - Cognitive Behavioral therapy - 29%
- EMG biofeedback – 24%
  ▪ Improvements maintained at 6 months

Surgery – Laser of vulva
  ▪ Theory: topical removal of the epidermis with regrowth may relieve symptoms if related to topical infection, inflammation, irritation
  ▪ No longer recommended, due to complications and poor results by others following early recommendations

Summary of treatment
  ▪ LITTLE data on non-surgical treatments
  ▪ Anecdotal evidence suggests several modalities may help

  These deserve further study – including amitryptiline, SSRIs, neurotin, and others

  ▪ Surgical treatment in selected cases refractory to other regimens appear to improve the condition in over half the cases who have symptoms localized to the introitus

Take home lesson
  ▪ Make the diagnosis - - do Q-tip in introitus routinely in patients with genital symptoms
  ▪ Listen
  ▪ Treat early
  ▪ Follow closely
  ▪ Expect improvement – don’t settle for less