Vulvodynia—Who, What, Why?

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March 15, 2004

"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"!

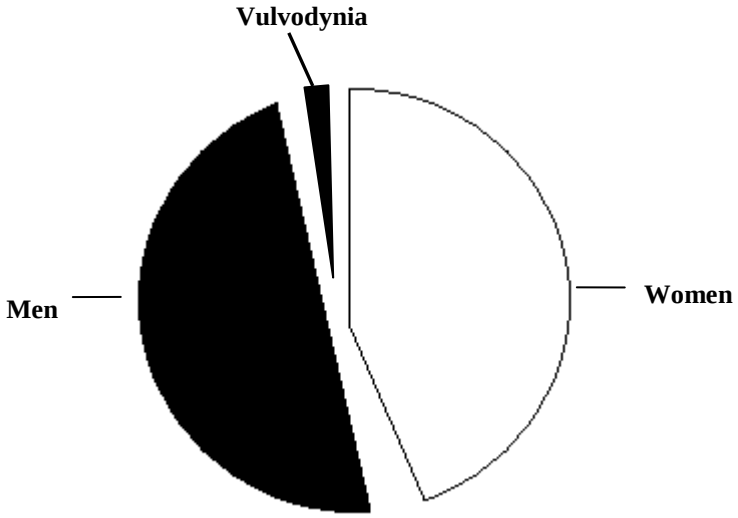
- Goetz – found 15% of women in her practice met the ISSVD definition if asked regarding symptoms and tested with Q-tip test (? 6 million women?)
- Dr. Harlow and colleagues reported a significant prevalence of vulvar pain among women responding to a survey in the greater-Boston area (13%, with 7% ongoing).
- 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 then 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

15 women in each Family Physician's practice

At least double that in Each Gynecology practice

2,400,000 women in the United States

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

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 sclerosus
- Lichen planus
- Chronic Candidal infection
- Vulvar Intraepithelial Neoplasia
- Allergic reactions
- Condyloma accuminata
- 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 (l st 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

Biofeddback 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 – vestibulectomy

- 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 (vestibulectomy) – 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