

# SPECIAL TOPIC || VULVODYNIA

# Live Online Virtual Conference July 13, 2024

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# SPECIAL TOPIC || VULVODYNIA

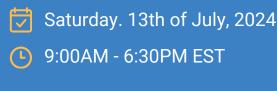




**Jessica Reale** PT, DPT, WCS @southernpelvichealth

Nicole Cozean PT, DPT, WCS @nicolecozeandpt

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**Alex Milspaw** PhD, MEd, LPC, CST, BCH @dralexmilspaw



**Carolyn Vandyken BHSc (PT)** @carolynvandyken



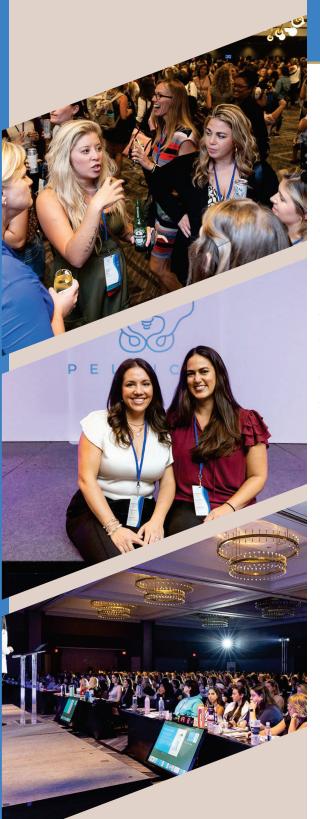
**Stephanie** Prendergast PT, MPT @saprendergast



**Jessica Drummond** DCN, CNS, PT, NBC-HWC @jessrdrummond

# THE SPEAKER LINEUP





# Stay in Touch!

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Welcome & Agenda

We are thrilled to have you join the first-ever multidisciplinary online symposium on Vulvodynia, brought to you by PelviCon!

We hope this increases your confidence in treating vulvodynia and results in better patient outcomes.

Would love to see you at an in-person PelviCon event in the future!

9am EST - Nicole and Jessica Introduction 9:20am - Jill Krapf: Medical Management of Vulvodynia 10:15am - Alex Milspaw: Psychological Considerations for Vulvodynia 11am - Jill Krapf and Alex Milspaw Q&A 11:30am - Ashley Winter: Hormonal Considerations for Vulvodynia 12:15pm - Jessica Drummond: Optimizing Vulvar Health 1:00pm - Ashley and Jessica Q&A 1:15pm - LUNCH 2:15pm - Stephanie Prendergast: Vulvodynia: **Differential Diagnosis of Nerve Involvement** 3:00pm - Carolyn Vandyken: Pain Science: A Panacea or Philosophy? 3:45pm - Stephanie and Carolyn Q&A 4:15pm - Stephanie Buehler: Sexuality Counseling Approaches for Patients with Vulvodynia 5:15pm - Nicole and Jessica: Practical Considerations and Treatment for the Pelvic Rehab Provider 6:15pm - Wrap-Up and Close

In health, Nicole & Jessica





# About Me

- Board-certified Obstetrician Gynecologist specializing in Final Security and the security of the security for the security of the security of the security of the security for t
- Society for Vulvovaginal Disorders (ISSVD), serving as Chair of the Social Media Committee for ISSWSH.
- Co-author of the book When Sex Hurts: Understanding and Healing Pelvic Pain.
- Active in research on vulvodynia and vulvar lichen sclerosus.
- Associate Editor for the medical journal Sexual Medicine Online Access, as well as for the textbook Female Sexual Pain Disorders, 2<sup>nd</sup> Edition.

# What IS vulvodynia?

- B. Vidrovprin roburg pain of a least 3 month? duration, without clear identification cause, which may have potential associated factors. The following are the descriptors: Localized (e.g., vestibuledynia, clineodynia) or generalized or mrised (localized and generalized) or mrised (localized and generalized) (provoked a generalized) asportaneous)
- Onset (primary or secondary) Temporal pattern (intermittent, persistent, constant, immediate, delayed)
- "Women may have both a specific disorder (e.g., lichen sclerosus) and vulvodynia,

The vulva hurts... It's been lasting for more than a few months... Everything looks normal... No one why it hurts...



# How to THINK about chronic vulvar pain:

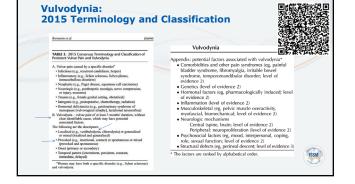
## Specific disorder (things that are researched and accepted)

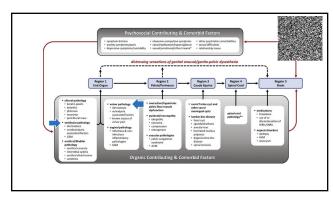
- Infectious: candidiasis, HSV, STIs
- Inflammatory: LS, LP
- Neurologic: ??
- Hormonal: VVA, atrophic vaginitis
- Muscular: ??
- Vulvodynia (things that are not yet adequately researched)
  - Infectious: aerobic vaginitis, ?DIV, ?CV
- Inflammatory: LS, LP, PCV, MCAS
- Neurologic: PN, neuroproliferative PVD

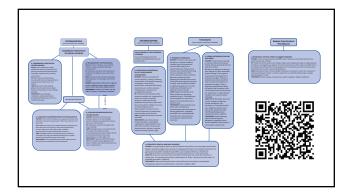
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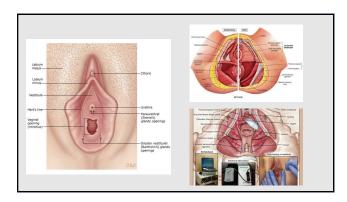
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- Hormonal: HAVD→GSM, GSL, DIV
- Muscular: overactive/hypertonic PFD





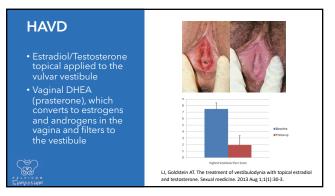


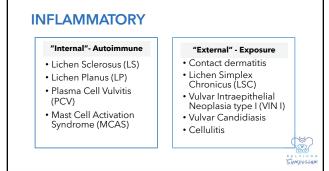


# Treatment depends upon Diagnosis

- Hormonally-mediated PVD
- Inflammatory
  - Auto-immune: Lichen Sclerosus, Lichen Planus
     Hypersensitivity: contact dermatitis, LSC, MCAS
     Infectious: bacterial, fungal, viral
- Neuropathic
  - PVD: primary or secondary neuroproliferative vestibulodynia
  - Region 1 and 2 (possibly 3-4) → Pudendal Neuralgia/Spinal Radiculopathy
- Overactive PFD

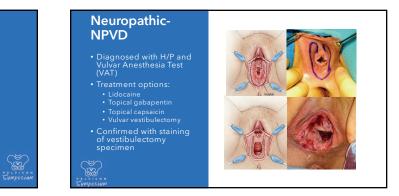


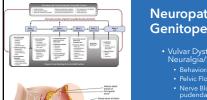






# Inflammatory





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# Neuropathic-**Genitopelvic Neuralgias**

- Vulvar Dysthesia/Pudendal Neuralgia/Spinal Radiculopathy
   Behavioral measures
   Pelvic Floor Physical Therapy
   Nerve Blocks (dorsal clitoral, pudendal, epidural, ganglion impar)
   Systemic Medications:

   Amitripyline/Nortripyline
   Gabapentin/Pregabalin
   Duloxetine

   Neurostimulation, cryotherapy, ablation, pudendal nerve entrapment and/or spinal surgery S.

# **Overactive PFD**

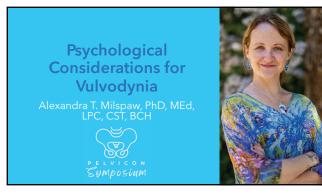
- Pelvic Floor Physical Therapy
   Medical Adjuncts:

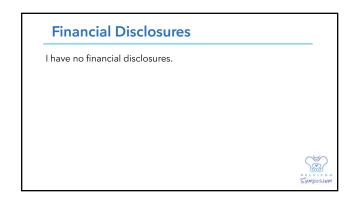
   Muscle relaxant suppositories
   Levator ani/superficial perineal BoNT injections
- Address functional Pudendal Neuralgia

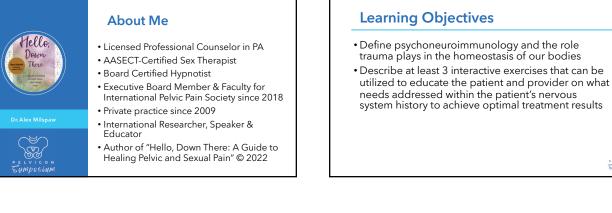
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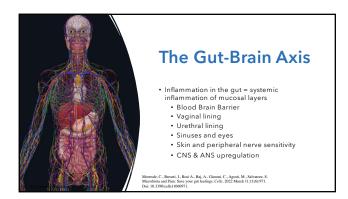


# Psychoneuroimmunology

 "The fundamental idea is that anything which produces prolonged stress or other strong emotions leads to biochemical changes, that, by affecting systems such as the immune or cardiovascular system, can produce disease; and, conversely, anything that relieves the stress can help reverse those effects, restore homeostatic balance, and, perhaps, improve health."

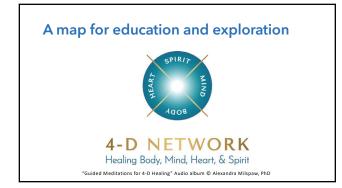
AKA: "IT'S ALL CONNECTED!"

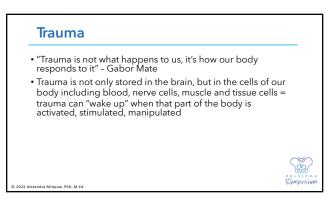
Kelly, E. F., Kelly, E. W., Crabtree, A., Gauld, A., Grosso, M., & Greyson, B. (2007). Irreducible mind: Toward a psychology for the 21st century.

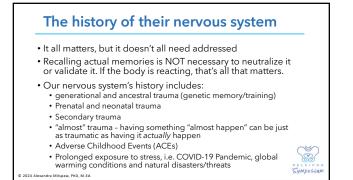


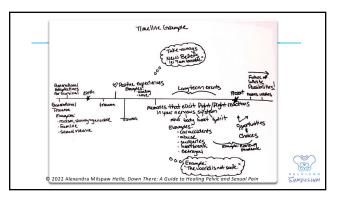
 The Ecosystem of Sex and Sexual (Dys)Function

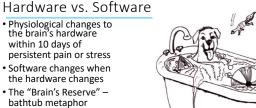
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 We need to help them turn off their "faucet of fear"



AUTOIMMUNE

FÉAR

# Software changes:

- Altered perception
- Interrupts executive functions
- Decreased focus/concentration Decreased inhibition
- \* Disrupted sleep patterns
- Working memory disruption
  Short- & long-term memory loss Mood fluctuation
- Anxiety & depression
- ANS dysregulation, including GI dysfunction, HRV, and temperature regulation
- Decreased libido 4 Alexandra Milspaw, PhD, M.Ed



## Long-term effects of amplified Autonomic Nervous System

- Chronic Pain
- Autoimmune Diseases
- Increased Systemic Inflammatory Response
- Post-Traumatic Stress Disorder (PTSD)
- Fibromyalgia

2024 Alexandra Milspaw, PhD, M.Ed.

- Chronic GI disorders
- Cancer and benign tumors

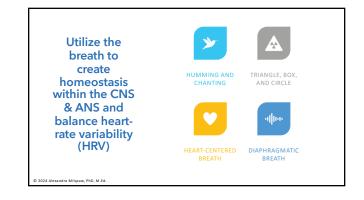


How	It's at the core of what we do, how we move and who we are
pelvic	It's a part of the body we can't ever fully rest. We're always using it!
and	It's in a private area – an area we learn not to talk about
sexual	It's in an area of the body that physicians and other healthcare providers tend to feel "allergic" to, leading them to avoid the conversation or tell you it's out of their scope
pain is different	It's a main area of where our body holds stress (GI system especially)
umerent	It affects our everyday life – toileting, relationships, hobbies, movement, intimacy, daily functioning



# Exercises to help turn off the faucet of fear

- Bilateral stimulation • Dr. Jeffrey Thompson, www.scientificsounds.com
- Nasal breath work
- More oxygen receptors in the back of the nasal cavity Meridian tapping
- www.thetappingsolution.com & www.eftuniverse.com • Brainspotting fear-based images www.dralexmilspaw.com/books/hellodownthere/exercises
- Visualization and utilization of metaphors
- Know your patient what do they know? Use a genre/memory they're 
   already familiar with Sympos ndra Milspaw, PhD, M.Ed.





# Language, Metaphors and the Subconscious • You can't command or demand anything from the body you "invite" and "allow"

- Visualization has been used for decades in sports psychology for athletic performance **imagine what** success feels like
- Patients can get stuck on the "how" instead of the "what" • Metaphors are the back door to the subconscious - a way
- around the rational mind \*\*co-create a metaphor based on a theme that is already familiar with the patient = there's already a file folder in the brain for the concept\*\*

andra Milspaw. PhD. M.Ed

**Experiential Learning**  Sexual dysfunctions are symptoms of something else • Fear-based learning can ONLY BE UNLEARNED EXPERIENTIALLY Sex, pain, and disability: beyond the physical quadrant of hormones, surgeries, and • The more you incorporate ANS regulation techniques during session, the more likely they will do the same at how to have nonhome. medicalized sex • Patients need to recognize that sex is much more than the • Partner inclusion starts at the beginning\* therapy for sexual • No current partner? Encourage the use of imagination so functioning of their parts...and if they don't acknowledge this, "dysfunction" the brain can get used to exploring variables needed/wanted to feel comfortable, safe, relaxed, etc. sustainable, let alone effective 🛛 🏹 , M., & Meulders, A. (2023). Fear learning in genital pain: Toward a biops ournal of Sex Research. Advance online publication. <u>https://doi.org/10.10</u> lexandra Milspaw, PhD, M.Ed. 2024 Alexandra Milspaw, PhD, M.Ed.

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# Take-aways $\rightarrow$ "Feel it to heal it!"

- Utilize bilateral stimulation music during treatment sessions and encourage use during home practice
- Encourage curious, compassionate dialogue with the body - use the 4-D Wheel as a "map" to access all perspectives and "voices"
- Co-create metaphorical images to demonstrate the patient's goal focus on the "what" of the goal, not "how" the body is going to get there

2024 Alexandra Milspaw, PhD, M.Ed.







# References

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Symposiu





## **Disclosures**

- Consultant for Marius
   pharmaceuticals
- Contractor for Midi Health
- Director of FemmeTech at Firmtech

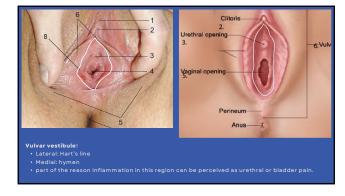


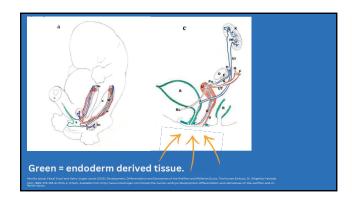
# 3 take aways

- The vulva is a hormone sensitive organ (estrogens and androgens)
- Multiple life factors or medications can cause a low hormone state that contributes to hormone-mediated vulvar pain
- Treat by addressing root cause and adding topical hormone therapy when appropriate

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# Pain in the vulvar vestibule that is caused by a low hormone state is called hormone-mediated vestibulodynia



## How does a low hormone state causes vulvar pain?

)

- Reduction in pain threshold
- Increased inflammation estrogen is anti-inflammatory!
- Reduced lubrication
   glands in the vulva are androgen-dependent
- · Direct changes to epithelium (thinning)

# When can a low-hormone state occur?

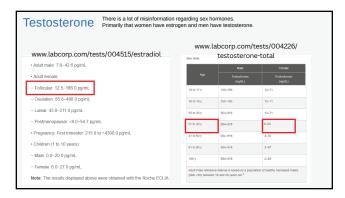
Menopause

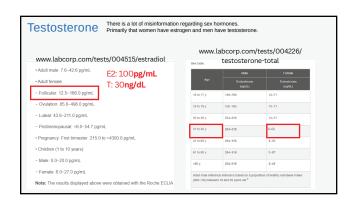
- subset of genitourinary syndrome of menopause
   Hormonal contraceptives
- combined oral contraceptives most common offenders
- Lactation
  Hormonal treatments for acne
- ex: spironolactone · Breast cancer treatments

• ex: aromatase inhibitors, tamoxifen

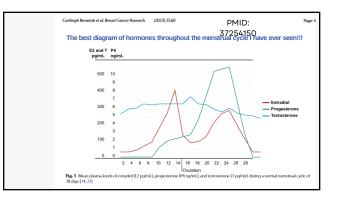


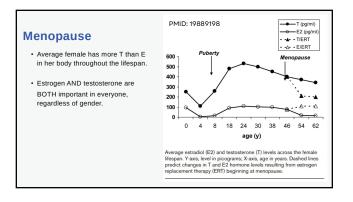
### Testosterone There is a lot of misinformation regarding sex hormones. Primarily that women have estrogen and men have testos www.labcorp.com/tests/004226/ www.labcorp.com/tests/004515/estradiol testosterone-total Adult male: 7.6-42.6 pg/mL Adult female: - Follicular: 12.5-166.0 pg/mL - Ovulation: 85.8-498.0 pg/mL 18 to 19 y 150-785 - Luteal: 43.8-211.0 pg/mL 20 to 30 y 264-916 - Postmenopausal: <6.0-54.7 pg/mL 31 to 40 y 254-916 8-60 Pregnancy: First trimester: 215.0 to >4300.0 pg/mL Children (1 to 10 years): 264-916 3-67 61 to 80 y - Male: 0.0-20.0 pg/mL >80 y 254-916 2-45 - Female: 6.0-27.0 pg/ml Adult male refer (BMI <30) betw Note: The results displayed above were obtained with the Roche ECLIA

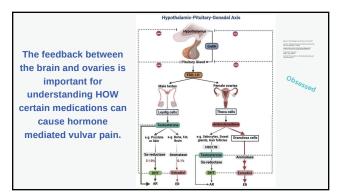


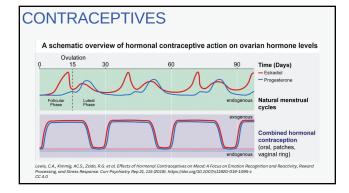


estosterone	There is a lot of misinformation regarding sex hormones. Primarily that women have estrogen and men have testosterone.			
www.labcorp.com/tes	sts/004515/estradiol	www.l	abcorp.com/to testosterone	
Adult male: 7.6-42.6 pg/mL	E2: 100pg/mL		Male	Female
Adult female:	T: 30ng/dL	Age	Testosterone (maktL)	Testosterone (naML)
- Follicular: 12.5-166.0 pg/mL	UNIT	16 to 17 y	150-785	12-71
- Ovulation: 85.8-498.0 pg/ml.	conversion!	18 to 19 y	150-785	1371
- Luteal: 43.8-211.0 pg/mL	E2: 100pg/mL	20 to 30 y	264-916	13-71
- Postmenopausal: <6.0-54.7 pg/n	🛯 T: 300p <b>g/mL </b> 🖌	31 to 40 y	254-916	8-60
Pregnancy: First trimester: 215.0	to >4300.0 pg/mL	41 to 60 y	264-916	4-50
Children (1 to 10 years):		61 to 80 y	264-916	3.67
- Male: 0.0-20.0 pg/mL				
- Female: 6.0-27.0 pg/mL		>80 y	264-916	2-45
10	were obtained with the Roche ECLIA		ce interval is based on a popular n 19 and 39 years old. <sup>2</sup>	ion of healthy nonobese males











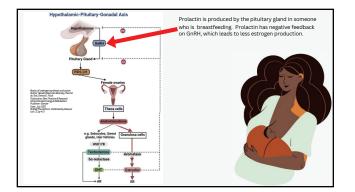






# Breastfeeding causes low estrogen state as well!

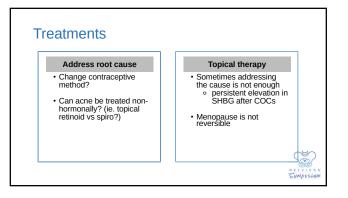
Causes similar genitourinary AND overall symptoms to menopause.







# Treatments







- The vulva is a hormone sensitive organ (estrogens and androgens)
- Multiple life factors or medications can cause a low hormone state that contributes to hormone-mediated vulvar pain (ask!)
- Treat by addressing root cause and adding topical hormone therapy when appropriate

S.





Optimizing Vulvar Health with A Nutrition and Functional Medicine Approach Jessica Drummond, DCN, CNS, PT, NBC-HWC









# About Me



- Founder of IWHI
- Global speaker, PT, DCN, NBC-HWC
- 2X Bestselling author
- Private client care and women's health professional education since 1999
- Lived experience with a chronic illness + menopause transition

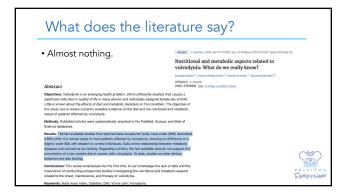
# Objectives

- Vulvar pain and immune health
- Psycho-neuro-endocrine-immunology and vulnerability to vulvar pain syndromes.
- The intersection between the immune system, digestive system, and gut microbiome in vulvar pain.
- Where to begin?









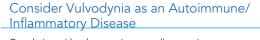


# We are asking the wrong question?

It's not... what food or diet "cures" vulvodynia?

Instead... What nourishment (including food/ nutrients/ herbs) can support nourishing the system, so that it does not need to express the "red flag" signal of vulvar pain because the system is now functioning more optimally.





Correlation with other autoimmune diseases, immune deficiency, and allergies/ atopy conditions

# The Association Between Immune-Related Conditions Across the Life-Course and Provoked Vulvodynia

leman <sup>2</sup>, Hanna Mühlmad <sup>3</sup>, Jacinth Yan <sup>4</sup> <sup>9</sup>, Nima Bohm-Starke <sup>7</sup>



# What is Vulvodynia?

• "In this new taxonomy (2015), vulvodynia is defined as vulvar pain lasting at least 3 months, without a clear identifiable cause, which may have potential associated factors. An important difference between the new terminology used in the 2015 taxonomy compared to that of 2003 is the addition of the potential associated factors. **This addition implies a paradigm shift derived from research showing that some** factors may be associated with the development and perpetuation of this clinical condition so that vulvodynia begins to be considered a multifactorial process." (Torres-Cueco & Nohales-Alfonso, 2021) S

## **Functional Nutrition** Approach

- System-by-system approach. Aims to optimize the health of physiologic systems to support overall symptom relief.
- The goal is not to simply "quiet" any particular symptom.

able 1	
115 Consensus Terminology and Classification of Persister	nt Vulvar Pain and Valvodynia (ISSVD, ISSWSH, and IPPS) []]
ulvar Pain Caused by a Specific Disorder	Vulvodynia
infectious (e.g., recurrent candidiasis, herpes)	Vulvar pain of at least 3 months' duration, without clear identifiable cause, which may have potential associated factor
inflammatory (e.g., lichen sclerosus, lichen planus, mmunobullous diserders)	Localized (e.g., vestibulodynia, clitorodynia) Generalized
Scoplastic (e.g., Paget disease, squamous cell carcinoma)	Mised (localized and generalized)
Neurologie (e.g., postherpetic neuralgia, nerve compression, or injury, neuroma)	Provoked (e.g., insertional, contact) Spontaneous
Frauma (e.g., female genital cutting, obstetrical)	Mised (provoked and spontaneous)
atrogenic (e.g., postoperative, chemotherapy, radiation)	Onset (primary or secondary)
formonal deficiencies (c.g., genitourinary syndrome of nenopulse, lactational amenorthea)	Temporal pattern (intermittent, persistent, constant, immediate, delayed

(Torres-Cueco & Nohales-Alfonso, 2021)

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### **Functional Nutrition** Approach Table 2 • Often our clients with vulvodynia ALSO have 2015 ISSVD, ISSWSH, and IPPS Consensus Te Vulvedynia—Potential Associated Factors [12]. ntial Factors Associated with Vulvodynia headaches, ties and other pain syndromes (e.g., painfal blad frome, temperomandibular disorder; level of evi endometriosis, bladder pain, autoimmune conditions, digestive issues, TMJ, tors (e.g., plurmacol (level of evidence 2) pine, brain; level of evidence 2)

depression, anxiety, fatigue, etc.

ž

# aroproliferation (level of e ors (e.g., mood, interver-

(Torres-Cueco & Nohales Alfonso, 2021)

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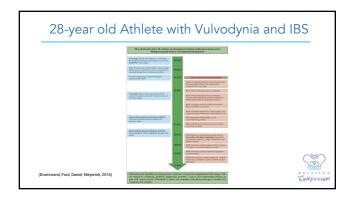
# Our Goal is Whole Person Health • The vulvodynia is a "red flag" for many potential systems functioning suboptimally.

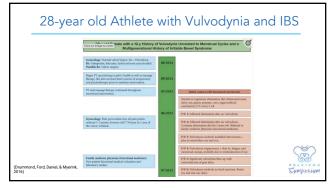
- "...some factors may be associated with the development and perpetuation of this clinical condition so that vulvodynia begins to be considered a multifactorial process."
- Suboptimal autonomic nervous system function (h/o trauma, concurrent trauma, stress, infection, etc.) could show up as myofascial dysfunction.
- Suboptimal digestive function
- Suboptimal psycho-neuro-digestive-immune-endocrine function

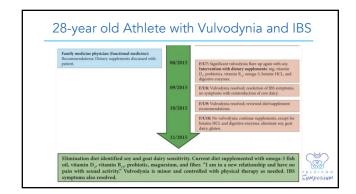


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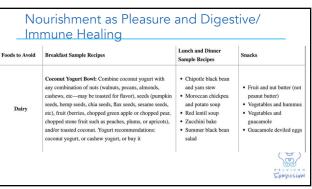






• Food can be an immune/ endocrine/ digestive system irritant, but ALSO a nervous system soothing tool.





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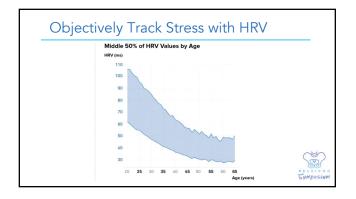
Symposi

	ent as Pleasure Iealing	e and D	igestive	/
Say	Smoothie: Combine: 1 cap of frozen fruit (herries, poaches, cherries, ecc) 1 arcocado or 2-3 tablespoons of almond, sesamo, or cadowe butter 1 cap of chopped greens (three, kale, spinsch, Swissi chad, edc) 1 - 2 caps of harmy, almond, canbew, or ecocons mills, or ward, other for knowledge (chonse PurtPeak vanills, portex), or unsweetend herm proteinio	Vegetable omelets	-	
Grains (except quinoa)	Breakfast hash (can serve over quinoa, but avoid other grains for now)	<ul> <li>Quiche (leave out the meat)</li> </ul>	-	
Corn	-	Vegan chili	-	S
Peanuts	-	Stir fry (substitute coconut for soy)	-	Symposium

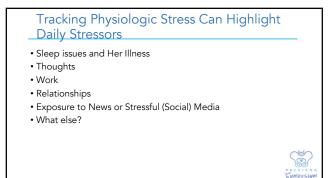
# When our Clients Feel Guilty About Self-Care

- Coaching: Personify the "voice in her head" that drives worthiness, pressure, inner critic.
- Boundaries
- When she takes the time to take care of herself prepare her food, go to bed early, take a day off... What does the inner critic say? Exercise to separate that voice from her own.

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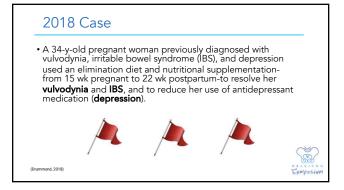


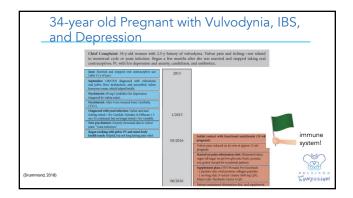


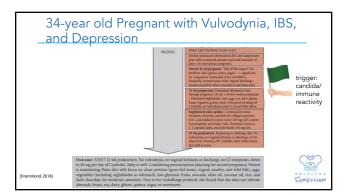
# Note

- That study was published in 2016, I no longer call this an "elimination diet". WAY too much disordered eating in the chronic pain community to focus on "elimination".
- Now: Start with Autoimmune paleo backbone
- I teach clients that this nutrition plan is where we will begin because of its extensive research efficacy in terms of supporting healing the functioning of the immune system in MS, Hashimoto's, IBD, etc.
- But, we personalize and consider client's relationship with food.

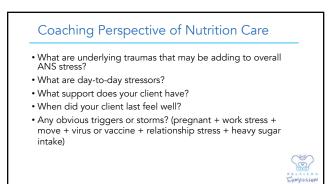


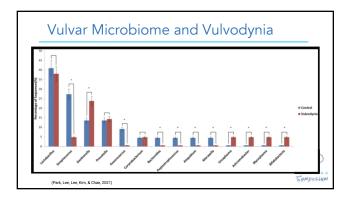


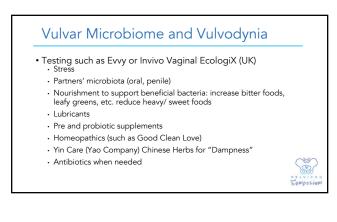




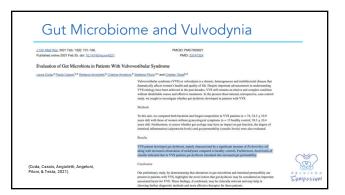








# Oursider lubricants that don't irritate the vulvar microbiome, such as Good Clean Love and Desert Harvest Nourish vulvar health: estrogen, vulvar moisturizers (especially if peri/menopausal) (Verebegitte, Dorder, Megleson, Edward, Webbe, 2016)



# Probiotics

- There is not a current standard probiotic preparation to optimize the gut microbiome in those with vulvodynia.
- Instead think: Is this client eating enough prebiotic fiber? Personalize probiotic to GI MAP or Urinary OAT as needed.
- Does she have e.coli or yeast overgrowth on testing?
  - Stress
  - Sugar (Don't give a "Candida Diet" that will add stress + medical trauma to NS long term same approach of *nourish* to heal)
- Consider lubricants that don't irritate the vulvar microbiome, such as Good Clean Love and Desert Harvest

SUMPOSIUM



# Summary

Coaching to Unwind Stress & Trauma

- Personify inner critic • Notice themes of worthiness, challenges with receiving support, and chronic stress or triggers.
- Identify daily stressors

Nourish with Delicious Foods That Support Systems		
<ul> <li>Autoimmune paleo nourishment</li> </ul>		
<ul> <li>Support cellular health with nutrient deficiencies</li> </ul>		

• Herbs, pre- & pro-biotics for microbiome health 

Symposi

# Learn More

Free Workshop on Endometriosis and Pelvic Pain

https://www.integrativewomenshealthinstitute.com/ webinar-reg-page-ecp



# Takeaway 1

Step 1: Does the environment when your client works with you helps to regulate or dysregulate her nervous system?

- Waiting room Office staff Your telehealth setting Your nervous system Noise, Sounds, Temperature

Your NS and space can help model & teach her how to regulate in other with environments



# Takeaway 2

Is she tracking her daily stress, and have support & tools to support her brain and NS to heal from her trauma history?

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SUMPO

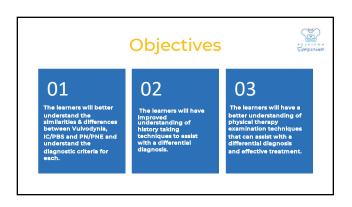


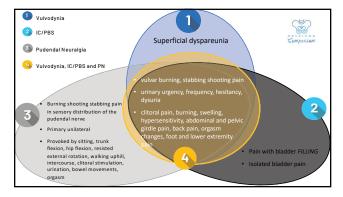
# Takeaway 3

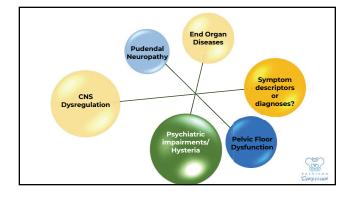
ls she eating to strengthen and balance her immune

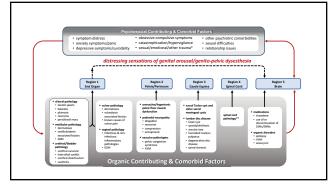
Does her nutrition plan feel nourishing and safe cellularly and to her nervous system?











	egion 1 d Organ dality * catastro sexual/e	Region 2 Pelvis/Perineum	<ul> <li>Vulvodyni</li> <li>Interstitia</li> <li>Pudendal Neuralgia,</li> </ul>	
keratin pearls     balanitis	vulvar pathology     odermatoses	• overactive/hypertonic	Region 4 Spinal Cord	Region S Brain
phimosis     neuroma     periclitoral mass	vulvodynia associated factors     known causes of vulvar pain	<ul> <li>pelvic floor muscle dysfunction</li> <li>pudendal neuropathy</li> </ul>	Î	1
• dermatoses • vestibulodynia associated factors	phimosis     neuroma     periclitoral mass	idiopathic     neuroma     compression     entrapment	spinal cord pathology**	medications     trazodone     use of or     discontinuation     of SSRIs/SNRts
• GSM • urethral/bladder pathology • urethral caruncle • interstitial cystitis	vaginal pathology     infection & non-     infectious inflammatory     pathologies     (GSM	<ul> <li>vascular pathologies</li> <li>pelvic congestion syndrome</li> <li>AVM</li> </ul>	)	<ul> <li>organic disorders</li> <li>epilepsy</li> <li>AVM</li> <li>aneurysm</li> </ul>

# **Neural Considerations**

- Congenital and Acquired Neuroproliferative Vestibulodynia (region 1)
- Pudendal Neuralgia (region 2)
- Tarlov Cysts (region 3)
- Spinal Pathology/Annular tears (region 3)

# **Meet Becky**

- DOB: November 1989
- G0P0. Professional dancer before studying law, resides in Europe, single
- Contacted PHRC in January 2023
- Intake forms: I have had Pudendal Neuralgia for two years



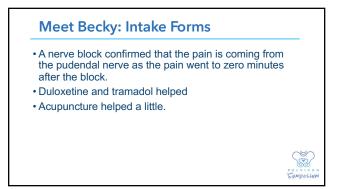
# Meet Becky: Intake Forms

- My symptoms are:
- Shooting burning pain in the vagina, clitoris, labia, to a debilitating degree, especially after defecation
- Numbness/electrifying sensation on my left side starting from the labia all the way to the perineum
- Urinary urgency, frequency, dysuria
- Lots of pain in the coccyx when sitting
- My left side is generally worse and more sensitive/reactive than my right side Symposiu

# Meet Becky: Intake Forms • Triggers for the symptoms are: bowel movements

- urination
- sex
- sitting for the coccygeal pain





# Meet Becky: Intake Forms

- · Pelvic floor PT: made my symptoms worse.
- Overall, the pudendal nerve is extremely reactive, any internal massage/manipulation that is not super gentle will make things worse for a very long time or even permanently
- Saw 10+ PFPTs in Europe
- 30+ urologists, gynecologists, pain management doctors



# **Meet Becky: Intake Forms**

- Underwent B Pudendal Nerve Decompressions and Endometriosis excision surgery (9 months ago)
- Nerve was compressed bilaterally, on the right side from enlarged veins and on the left side by the sacrospinous ligament, which was shortened by 2-3 cm.
- + biopsy for endometriosis

# Meet Becky: Intake Forms

- The most debilitating symptom is clitoral and vaginal pain after bowel movements.
- An MRI I did showed bone swelling/edemas in the coccygeal vertebrae.



# Meet Becky: Intake Forms

- Bilateral Pudendal Nerve Neuromodulator placed: March 2023
- Unable to get effective pain coverage after 3 weeks of trials with various settings
- Becky decided to continue on to Los Angeles to undergo an evaluation with me

# 1st Remote Visit with Becky: My Questions

- Goal: cannot tolerate internal MFR: HMV, congenital/acquired vestibulodynia, PN should be off the table...or should it not be?
- Did you experience vulvar burning at first insertional attempt?
- What is your history with oral contraceptives, acne medications, or medications for presumed endometriosis because of dysmennorhea?

PELVICON Symposium

# 1st Remote Visit with Becky: her answers

- Superficial dyspareunia from first intercourse attempt age 18, tampons painful
- Not menstruating as dancer, put on oral contraceptives to 'regulate' her period
- PCOS, high testosterone
- Frequent UTIs and yeast infections ages 18 31
- · History of constipation

# 1st Remote Visit with Becky: her answers

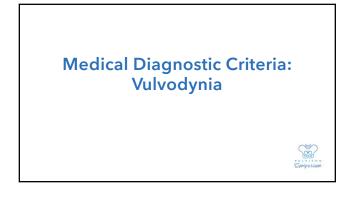
- Age 31, intercourse, UTI, stabbing clitoral pain and vaginal pain
- · Coccyx pain began
- Most medication not therapeutic
- L > R severe clitoral pain brought on by bowel movements and urination
- · Clitoral and vaginal pain not worsened with sitting, but did report pain with sitting but at coccyx

# **Surgical Neural Considerations**

- Congenital Neuroproliferative Vestibulodynia
- (region 2)
- Acquired
- Neuroproliferative Vestibulodynia
- (region 2) Pudendal Nerve
- Entrapment (region 2)

Symposiu

Tarlov Cysts's (region 3)



# Vulvodynia

2015 ISSVD, ISSWSH and IPPS Consensus Terminology and Classification of Persistent Vulvar Pain and Vulvodynia

"Chronic pain of unknown origin in the vulva persisting at least 3 months". - 2003 ISSVD

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# Table 3. 2015 Consensus Terminology and Classification of Persistent Vulvar Pain and Vulvodynia

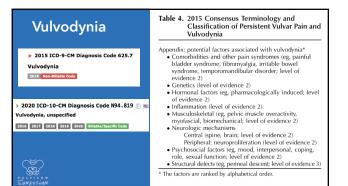
• Lumbar pathology (region 3)

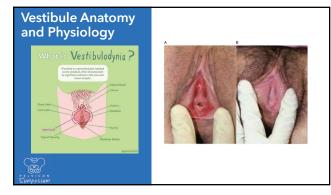
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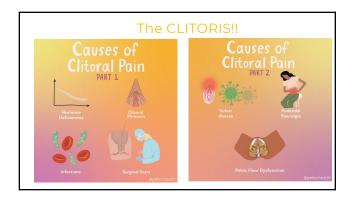
- Infectious (eg. recurrent candidiasis, herpes)
   Inflammatory (eg. lichen sclerous, lichen planus immanobilous disorders)
   Neoplasic (eg. Paget disease, squamous cell carcinoma)
   Neurologic (eg. postherpetic neuralgia, nerve compression or injury, neurona)
  - ital cutting, obstetrical) atiwa, chemotherany, ra somonal deficiencies (eg. genitou of menopause (vulvovaginal atrophy amenorrhea) sdynia--vulvar pain of at least 3 mo ithout clear identifiable cause. whi-stential associated es (eg. genitourinary s

# withou clear identifiable cause, which may potential associated factors: I localized (eg. vestibulodynia, clitorodynia, generalized or mixed (localized and gener Provoked (eg. insertional, contact) or spon mixed (provoked and spontaneous) Onset (infranzy or secondar)

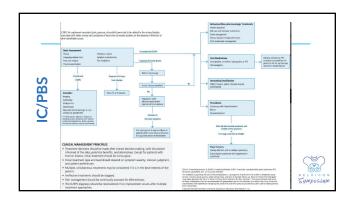
primary or secondary) al pattern (intermittent, persistent, constant, ate. delaved) Vomen may have both a specific disorder (eg, lichen sclero and vulvodvnia.





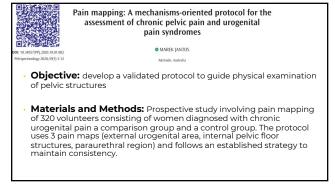


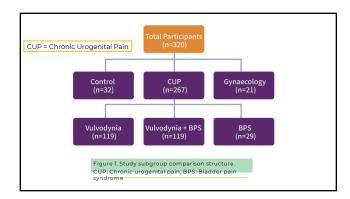
Medical Diagnostic Criteria	
Interstitial Cystitis/Painful	
Bladder Syndrome	
AUA Guidelines 1 <sup>st</sup>	
published in 2011, updated	
in 2014 and 2022!	
	S.
	Symposium

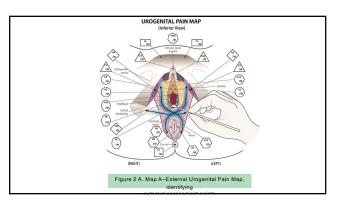


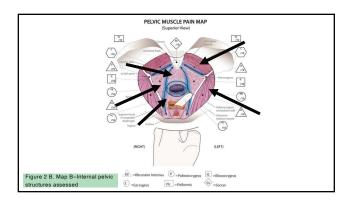


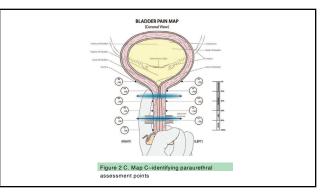


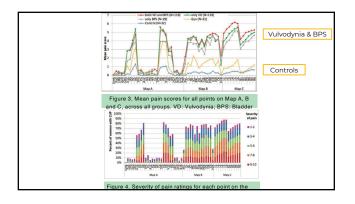






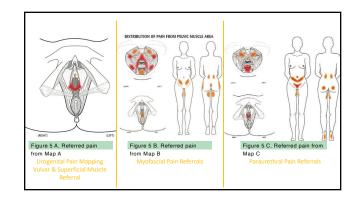






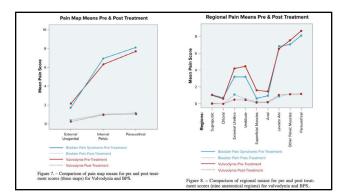


### Methods Intervention 70 patients with CUP and 28 EMG assisted pelvic floor asymptomatic controls relaxation training Pain mapping in lithotomy position . Internal and external on empty bladder myofascial therapy Each palpation point subjective Desensitization of the reports of paraurethral points • 1 – 10 VAS 3 pain maps performed after Characteristic of pain (modified treatment McGill Questionnaire) Spatial distribution and referred pain



# Paraurethral Desensitization Protocol

- Gentle compressions to the paraurethral pain points, held for 10–15 seconds, pain from technique not to exceed 6/10 on verbal reporting scale
- Repeated multiple times until patient reports of subjective improvement to the technique
- Concurrent: diaphragmatic breathing
- Subsequent visits: lateral mobilization of fascia (starting at urethral edge)



# Relationship: 9 pain regions, treatment, diagnosis

- · Main effect of treatment was statistically significant
- Patient pain scores statistically significant after treatment
- Treatment by diagnosis was NOT significant, suggesting same treatment needed for IC and vulvodynia
- Post treatment pain scores had similar findings in controls, vulvodynia, IC
- High paraurethral pain scores suggestive of important diagnostic and therapeutic relevance

# Medical Diagnostic Criteria: Pudendal Neuralgia and Pudendal Nerve Entrapment

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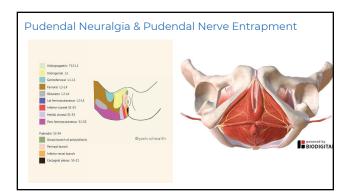
# Pudendal Neuralgia/Pudendal Nerve Entrapment

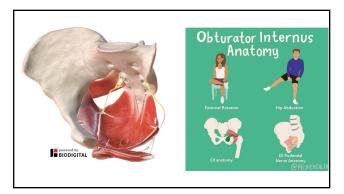
- Nantes Criteria: Essential Criteria
  - Pain in the territory in the nerve
  - Pain is predominantly experienced when sitting
  - The pain does not wake the patient at night
  - Pain with no objective sensory impairment
  - Pain relived with diagnostic sensory block

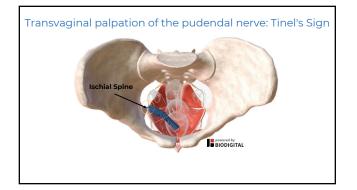


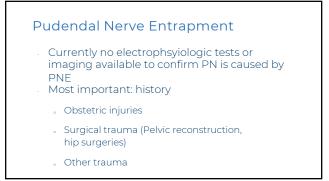
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# Pudendal Neuralgia Primarily unilateral Provoked by sitting, trunk and hip flexion Provoked by external rotation Provoked by hamstring and piriformis stretching









# Pudendal Nerve Entrapment

- Do not assume failure to respond to conservative treatment means PNE
- · Consider CNS involvement versus mechanical entrapment
- Consider Tarlov Cysts
- Pudendal nerve blocks are NOT diagnostic of PNE or even PN



# **Becky's Physical Examination**

- External Examination
  - oSevere connective tissue changes: bony pelvis, abdomen, gluteals, medial and posterior thighs
  - •Myofascial Trigger Points in L > R Obturator
  - Internus and Pirifromis muscles
  - Hyperflexed coccyx
  - oSIJ/lumbar spine/hip unremarkable



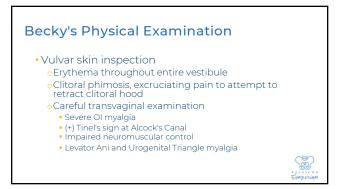
# **Becky's Physical Examination**

• Vulvar skin inspection • Erythema throughout entire vestibule

# **Becky's Physical Examination**

Vulvar skin inspection

- oErythema throughout entire vestibule
- oClitoral phimosis, excruciating pain during attempt to retract clitoral hood



## Assessment

- Linking history to physical findings
- Vestibulodynia: possible congenital or initially HAV, hormone deficiencies with amenorrehea and OCPs, developed PFD, infections, PN
- PN block not diagnostic of PNE, pain went "to zero" but the PN innervates the vestibule and the clitoris
- Questionable PN(E) mechanism
- Medical management needed

# STATION SUMPOSIUM

# Next Steps

- Transvaginal manual therapy too provocative and not therapeutic due to the state of the vestibule and (+) Tinel's Sign
  - oClitorodynia not PN, but clitoral phimosis
  - oMedical management needed: lysis of
  - adhesions, initiate estradiol/testosterone topical

    High circulating testosterone, no systemic testosterone
    needed
  - oObturator Internus, Levator Ani botulinum toxin

## Over the next year

- Clitoral pain after bowel movement 90% eliminated after lysis of adhesions, clitoral pain after urination completely eliminated • Able to tolerate clitoral stimulation and orgasm
- Botox: reduced myalgia, Tinel's sign (-), able to tolerate internal manual therapy when avoiding vestibule, transanal work



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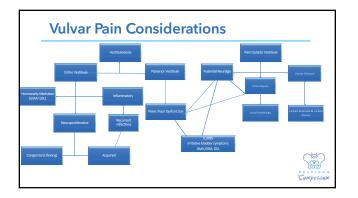
# Over the next year

Vestibulodynia did not change with E/T
Congenital or acquired neuroproliferative the new differential diagnosis
Underwent vestibulectomy
All vulvar pain resolved
Started internal transvaginal manual physical therapy

# Current situation

- Able to tolerate and enjoy pain free intercourse
- Able to run and dance
- Normal urinary function, no symptoms
- Intermittent return of pain after bowel movements, 10% of previous severity oCentrally mediated?





# Summary

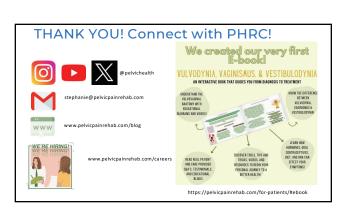
- Subjective questions

   Hormonally mediated, congenital, infectious, acquired?
   Mechanical provocation? Territory of the pudendal nerve?

   Testing: lab work to evaluate SHBC, bioavailable testosterone, infections converse. infections causes

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- MRI to rule in/out Tarlov Cysts/Annular Tears
- Physical Examination:
   Cliteral hood
   Visual and Q-tip examination
   Transvaginal muscle palpation and PN palpation

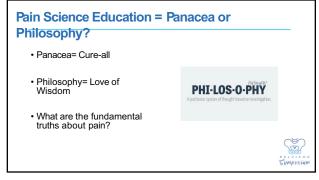




# About Me

- I am a.....Canadian, Clinician, Educator, Researcher and Advocate
- I Love Curiosity and Simplicity
- I am a Facilitator NOT a Fixer

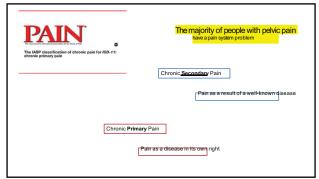


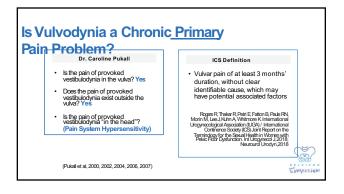












Pelvic Pain Diagnoses	WHAT'S IN A NAME?
Strengths:	Vulvodynia
Allows us to collaborate	Vestibu
<ul> <li>Names the tissues that are painful</li> </ul>	lodynia
Challenges:	Painful
<ul> <li>Leads to challenging "rabbit holes" on Dr. Google</li> </ul>	Bladder
<ul> <li>Keeps us focusing on "fixing" tissues</li> </ul>	Syndrome/Interstitial Cystitis
	Pudendal
Symposium	Neuralgia

# PAIN<sup>®</sup>

"I wish I knew then what I know now" - pain science education concepts important for female persistent pelvic pain: a reflexive thematic analysis

Amelia K. Mardon<sup>a,b</sup>, K. Jane Chalmers<sup>a,b</sup>, Lauren C. Heathcote<sup>b,c</sup>, Lee-Anne Curtis<sup>a</sup>, Lesley Freedman<sup>d</sup>,

Four themes of those women with "improved" pain Theme #1: A sensitized nervous system leads to an overprotective pain system

Meaning to patients: Their pain is real

# PAIN<sup>®</sup>

"I wish I knew then what I know now" - pain science education concepts important for female persistent pelvic pain: a reflexive thematic analysis Amala K. Mardon<sup>ab</sup>, K. Jane Chalmers<sup>ab</sup>, Laure C. Heathcote<sup>bo</sup>, Lee Ame Cutle<sup>a</sup>, Leely, Freedman<sup>d</sup>,

Four themes of those women with "improved" pain Theme #2: Pain does not have to mean that the body is damaged

Meaning to patients: Increased pain does not mean that their condition is worsening

#### **Research** Pap PAIN

#### "I wish I knew then what I know now" - pain science education concepts important for female persistent pelvic pain: a reflexive thematic analysis

Amelia K. Mardon<sup>a,b</sup>, K. Jane Chalmers<sup>a,b</sup>, Lauren C. Heathcote<sup>b,c</sup>, Lee-Anne Curtis<sup>a</sup>, Lesley Freedman<sup>d</sup>,

Four themes of those women with "improved" pain

Theme #3: How I think about, "see" and feel my pain can make it worse

Meaning to patients: I can find many ways to manage my pain



"I wish I knew then what I know now" - pain science education concepts important for female persistent pelvic pain: a reflexive thematic analysis Amelia K. Mardon<sup>a,b</sup>, K. Jane Chalmers<sup>a,b</sup>, Lauren C. Heathcote<sup>b,c</sup>, Lee-Anne Curtis<sup>a</sup>, Lesley Freedman<sup>d</sup>,

Four themes of those women with "improved" pain

Theme #4: I can change my pain... slowly

Meaning to patients: Provided hope that pain can improved and empowered them to pursue pain improvement as a viable goal



 Simple education helps reduce fears associated with LBP It is almost unethical for clinicians not to focus on reducing patients fears and false beliefs

Louw et al, 2012

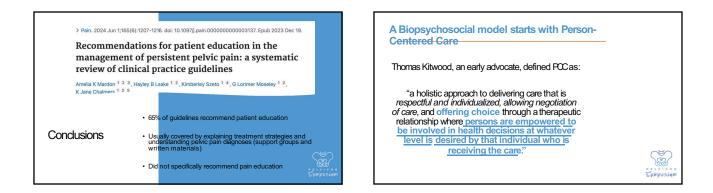
Pain Education = Level 1 Evidence

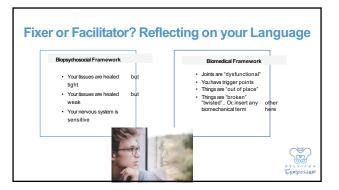


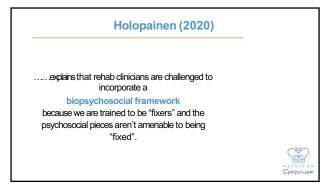


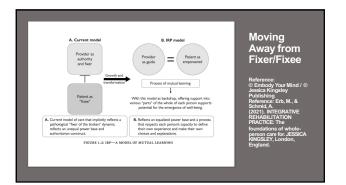
# Biossi inserted in the woman's vaginas as belawns to retrain the gride informatical with the woman's vaginas as belawns to retrain the gride informatical with a state woman's vaginas as belawns to retrain the gride informatical with the woman in the gryneeological retrain the gride informatical with the woman in the gryneeological retrain the gride informatical with the woman in the gryneeological retrain the gride informatical with the woman in the gryneeological retrain the gride informatic with the dealers of the woman's woman's as the learns to the gride informatical woman's woman's assess of the gride informatical woman's woman



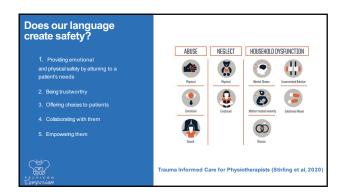












## Research Paper

"I wish I knew then what I know now" - pain science education concepts important for female persistent pelvic pain: a reflexive thematic analysis Amela K, Mardon<sup>hb</sup>, K. Jane Chalmers<sup>hb</sup>, Laure C. Heathcote<sup>ho</sup>, Lee-Ame Curite<sup>n</sup>, Lesley Freedman<sup>d</sup>,

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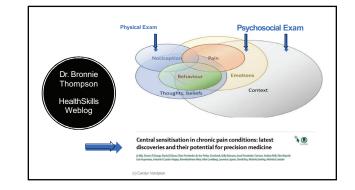
Meaning to patients: Their pain is real

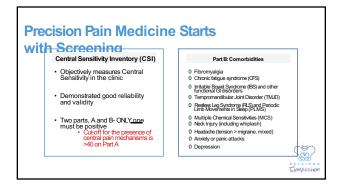
#### Hashmi et al 2013

- · Persistent pain is emotionally-driven
- (nociplastic) Chronic pain is mapped in the emotional brain areas of the neuromatrix (FMRI)
- Acute pain is nociceptive-driven
- Acute pain is mapped in the sensory areas of the brain neuromatrix (FMRI)
- Who has pain, a year after onset, is predicted by FMRIs and questionnaires:
  Use CSI with all patients

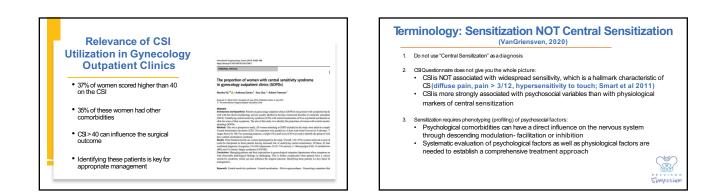
  - Screen psychosocial factors (SAD CLUFSS) Screen for sensory-motor dysregulation











## Pain System Hypersensitivity: So

What? (N = 1) 1. Central pain mechanisms can be recognised by screening for disproportionate pain, assessing the distribution of pain through patient pain drawing and using the Central Sensitivity Inventory questionnaire

- If central pain mechanisms are present, it predicts poor outcome following classical local treatments such as electrotherapy, manual therapy, motor control exercises and surgery (recommendations from Bergeron paper on Vulvodynia)
- Treatment of patients in whom central pain mechanisms are present should address the (lifestyle) factors that sustain the process of central sensitisation, including illness beliefs (pain education), stress, sleep, physical activity and diet.

Nijs et al (2019): Central Sensitisation: Another Label or Useful Diagnosis?

#### **Phenotyping Required**

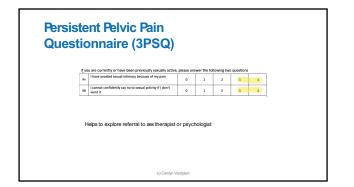
Psychosocial factors associated with pain and sexual function in women with Vulvodynia: A systematic review Claudia Chisari<sup>1</sup>, Mani emi<sup>1</sup>, Whitney Scott <sup>1</sup><sup>2</sup>, Rona Moss-Manis<sup>1</sup>,

lines a monor

Depression, anxiety, catastrophizing, pain-anxiety, pain acceptance, body-exposure anxiety, attention to sexual cues, partner hostility and solicitousness, self- efficacy and penetration cognitions are highlighted as potentially important treatment targets in PVD.

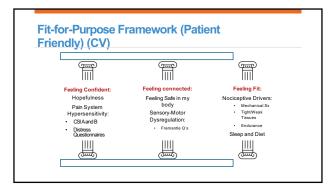


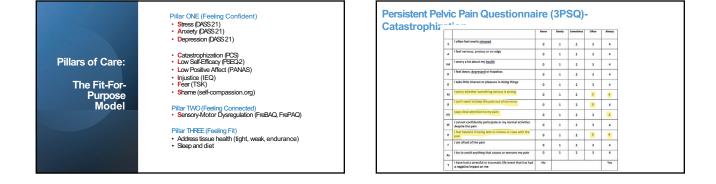
		Never	Rarely	Sometimes	Often	Aways
5	I often feel overly <u>stressed</u>	0	1	2	3	- 4
A	I feel nervous, anxious or on edge	0	1	2	3	4
на	I worry a lot about my health	0	1	2	з	- 4
D	I feel down, depressed or hopeless	٥	1	2	3	4
D	I take little interest or pleasure in doing things	0	1	2	3	4
м	I worry whether something serious is wrong	٥	1	2	3	4
R	I can't seem to keep the pain out of my mind	0	1	2	3	4
н	I pay close attention to my pain	٥	1	2	3	4
SE	I cannot confidently participate in my normal activities despite the pain	٥	1	2	3	4
н	I feel helpless in being able to reduce or cope with the pain	٥	1	2	3	4
۲	I am afraid of the pain	۰	3	2	3	4
Av	I try to avoid anything that causes or worsens my pain	0	1	2	3	4
т	I have had a stressful or traumatic life event that has had a negative impact on me	No				Yes

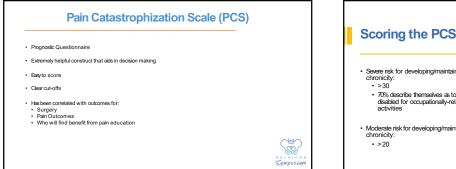


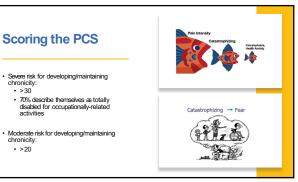












#### TARGETED RESEARCH- What does this look like for catastrophization?

JAMA Neurology | Original Investigation

Effect of Intensive Patient Education vs Placebo Patient Education on Outcomes in Patients With Acute Low Back Pain A Randomized Clinical Trial

Adrian C. Traeger, PhD; Hopin Lee, PhD, Markus Hübscher, PhD; Ian W. Skinner, PhD; G. Lorimer Moseley, PhD; Michael K. Nicholas, PhD; Nicholas Henrichke, PhD; Nathyn M. Belthauge, PhD; Flora M. Blyth, PhD; Chris J. Main, PhD; Jalla M. Hush, PhD; Sergier La, PhD; Janes H. McKaley, PhD;

The patients who did the best with pain education in acute pain were those who were catastrophizing Traeger et al, 2018

There is compelling evidence that pain education reduces pain, disability, catastrophization and improves physical performance in persistent pain Louw et al, 2012 (@uterity Workform

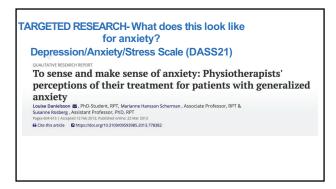
		Never	Rarely	Sometimes	Often	Aburry
\$	I often feel overly stressed	0	1	2	3	4
٨	I feel nervous, anxious or on edge	0	1	2	3	4
на	I worry a lot about my health	0	1	2	3	4
D	I feel down, <u>depressed</u> or hopeless	0	1	2	з	4
D	I take little interest or pleasure in doing things	۰	1	2	з	4
м	I worry whether something serious is wrong	0	1	2	3	4
R	I can't seem to keep the pain out of my mind	0	1	2	3	4
HV	I pay close attention to my pain	۰	1	2	3	4
st	I cannot confidently participate in my normal activities despite the pain	0	1	2	3	4
н	I feel helpless in being able to reduce or cope with the pain	٥	1	2	3	4
F	I am afraid of the pain	0	1	2	3	4
AN	I try to avoid anything that causes or worsens my pain	0	1	2	3	4
т	I have had a stressful or traumatic life event that has had a negative impact on me	No				Yes



Ariza-Mateos MJ, Cabrera-Martos I, Ortiz-Rubio A, Tomes-Sanchez I, Rodriguez-Torres J, Valenza MC. Effects of a patient-centered graded exposure intervention added to manual therapy for women with chronic polivic pain: a randomized controlled trial. Arch. Phys Med Rehabil 2019; 10:09–16

Study	Sample	PIPT intervention	Standard PT intervention	Outcomes	Summary results
Ariza-Mateos et al. <sup>3</sup>	40 terratie potients with chronic polvic pain Mean agri: 41,3 years	Craded approach theopy included approach theopy included manual heapy pain education, and exhip- based treatment focused on the patient's creat found the patient's creat found theory. Patients were exponed to take taxed on least to mast learni. Progressions were based on within-session changes in their. Patients parterned graded exposure for a single discriming association each week for 6 weeks. Patients in this grap able neolwid manual therapy similar to control graup.		Disability: ODI Pain interference: BPI Pain internaty: EPI measured at 6 woeks ant 31 months	There was a significant distintuous in and 3- month clashiply socres after graded exposure theragy. There was a significant difference in 3-month pairs, with lower poin scores after graded exposure theragy.

_						
		Never	Rarely	Sometimes	Often	Aberryn
5	I often feel overly <u>stressed</u>	0	1	2	3	- 4
A	I feel nervous, anxious or on edge	0	1	2	3	4
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Av	I try to avoid anything that causes or worsens my pain	0	1	2	3	4
т	I have had a stressful or traumatic life event that has had a negative impact on me	No				Yes



#### **Anxiety and Feeling Connected to** our Body Main Role: To sense and make sense of one's anxietv

- · The body is the arena of anxiety
- To get in touch with oneself (Turn towards the pain instead of away from it)
   To get down to earth with oneself (Body scan, grounding exercise)
- To make sense of bodily sensations (Pain Education: this is NOT dangerous)
   To gain trust in one's capability of handling anxiety (Worry journal)

(Danielsson et al, 2013)

#### **Persistent Pelvic Pain Questionnaire** (3PSQ)- D

		Never	Rarely	Sometimes	Often	Always
5	I often feel overly <u>stressed</u>	0	1	2	3	4
٨	I feel nervous, anxious or on edge	0	1	2	3	4
на	I worry a lot about my health	0	1	2	3	4
D	I feel down, depressed or hopeless	0	1	2	3	4
D	I take little interest or pleasure in doing things	0	1	2	3	4
м	I worry whether something serious is wrong	0	1	2	3	4
R	I can't seem to keep the pain out of my mind	0	1	2	3	4
HV	I pay close attention to my pain	0	1	2	3	4
SE	I cannot confidently participate in my normal activities despite the pain	0	1	2	3	4
н	I feel helpless in being able to reduce or cope with the pain	0	1	2	3	4
£.	I am afraid of the pain	0	1	2	3	4
AN	I try to avoid anything that causes or worsens my pain	0	1	2	3	4
т	I have had a stressful or traumatic life event that has had	No				Yes



Conclusion: Childhood adversity and depression are areas of interest during the clinical assessment of patients with LUTS. Early detection of these conditions might help to manage risk, aid in the prevention of LUTS, and facilitate trauma-informed care.

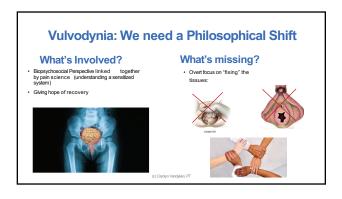
What can we do as PT's to address depression (low mood) in the clinic?

✓ Severe or Extremely Severe Depressed Mood
 • Referral to trauma-informed talk therapy

✓ Moderate Depressed Mood:

 Exercise (walking)
 Yoga/meditation
 Resistance Training

Characteristics of Persistent Pain-Pain is Like a Snowflake	How to Measure It	Treatment Considerations to Address Various Drivers
Central Sensitization	CSI- Central Sensitivity Inventory	Biopsychosocial Framework
Catastrophization	PCS-Pain Catastrophizing Scale	Reconceptualizing Pain-Education Meditation, Body scans
Self-Efficacy	PSEQ2- Self Efficacy Questionnaire	Minimize Passive Treatment; Lived Experiences of Change
Low Positive Affect	PANAS-Positive Affect/Negative Affect Scale	Gratitude Training, Mindfulness- Positive Affirmations
Sensori-Motor Smudging	Fre-BAQ-FreMantle Back and Knee Questionnaire	Body Mapping Exercises- Sensori-motor integration exercises
Depression	DASS-21- Depression, Anxiety, Stress Scale	Cardiovascular Exercise, CBT, Yoga, Resistance Exercise
Anxiety	DASS-21- Depression, Anxiety, Stress Scale	Cognitive Behavioral Therapy; WOEBOT, Worry Journals
Stress	DAS321- Depression, Anxiety, Stress Scale	Evoke the Relaxation Response-yoga, meditation, tai chi/qi gong, prayer
Fear	TSK-Tampa Scale of Kinesiophobia	Graded Exposure, Fear ladders, OFT





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Sexuality Counseling Approaches for Patients with Vulvodynia





#### Sexuality Counseling Approaches for Patients with Vulvodynia

Dr. Stephanie Buehler Licensed Psychologist, AASECT Certified Sex Therapist & Supervisor And ISSWSH International Fellow President, The Buehler Institute and LearnSexTherapy.com



#### About Me

- Co-created an integrated wellness center with an endocrinologist in 2001
   Joined Hose Hospital Women's Health
- Joined Hoag Hospital Women's Health Institute in 2015 with my office located in the pelvic floor PT clinic
- Author of What Every Mental Health Professional Needs to Know about Sex, 3<sup>rd</sup> Ed
- A decade providing continuing education The Buehler Institute and LearnSexTherapy.com

I have no financial disclosures

#### **Learning Objectives**

- $\bullet$  Describe the sexual and relational concerns of people with vulvodynia
- Use the sexological ecosystem to organize the patient's experience of vulvodynia and develop paths of inquiry
- Use cognitive behavioral therapy to educate the patient and address hopelessness, helplessness, and avoidance
- Use a brief solution-focused approach to help patients improve problem-solving skills and a more positive outlook
- Understanding the nature of sex therapy for more effective referrals

#### **Contributing Factors**

A complex diagnosis with many CFs

#### **Psychological Factors and Sexual Function**

- People with vulvodynia report many psychological issues
  - Depression: A lifelong predictor of long-term sexual pain Anxiety: Associated with hypervigilance, fear avoidance and pain catastrophizing
  - Trauma: Avoidance of seeking help for vulvodynia and the possibility
  - Negative body image: Shame about the body; feeling "broken" or undesirable

#### **Psychological Factors and Sexual** Function

- Psychological factors contribute to higher pain scores and determine lower scores on sexual function and sexual satisfaction
   Difficulty becoming sexually aroused · Lower sexual desire and infrequent or absent attempts at sexual
  - activity
  - Difficulty with orgasm or anorgasmia which impacts motivation for sex
- Depression can contribute to feelings of powerlessness and lack of self-efficacy in resolving sexual pain
   Remaining stuck and hopeless
  - Impacting relationship, and partner may also become hopeless

#### **Sexual Health Aspects of Vulvodynia**

- Negative attitude toward one's genitals which is associated with lower sexual function
- Not wanting body exposed during intercourse, leading to avoidance
  - Emotional vulnerability; may trigger a trauma response
  - Feeling ashamed of their own sexual arousal, or lack thereof Worried that their body is "broken" or unattractive

See Chrisari et al. (2020) and Niedenfuehr et al. (2023) in reference list

#### **Sexual Health Aspects of Vulvodynia**

- "Sexual contingent self-worth"
- The belief that one's value lies in ability to maintain a sexual relationship
  - "If I cannot have intercourse, I have no value."
  - "My partner will leave me for someone who can have penetration."
  - "Because I cannot have penetrative sex, I am infertile and broken."

#### **Sexual Aspects of Vulvodynia**

- Paying attention to negative sexual cues during intercourse · Focusing in on what is uncomfortable
  - Misinterpreting partner's behavior ("they only want me for sex")
  - Not attending to what is pleasurable
  - However, some women experience pleasure despite painful penetration as well
     lower pain catastrophizing and higher sexual function
- Approach/avoidance of sexual goals
   ""upper to be
  - "I want to have sex to feel close" vs. "I have sex to avoid losing my Partner"
     • Those with higher approach goals and lower avoidance goals had better sexual
    - function

#### **Relationship Factors**

- · Greater sexual communication associated with lower pain and better sexual functioning vs. avoidance • "If we don't talk about it, maybe the problem will go away."
- "Sexual communal motivation"
  - The extent to which someone can be responsive to a partner's sexual needs while still attending to their own
  - "I must make sure my partner is satisfied and ignore my own pleasure"

#### **Relationship Factors**

- Both partner solicitousness and hostility were associated with higher pain intensity
- Relationship intimacy regarding disclosure and empathy was associated with better sexual satisfaction
  - Open communication about vulvodynia
  - Sharing what is and isn't pleasurable about touch

#### **Relationship Factors**

- In heterosexual couples, both partners may be mystified by sexual pain, with many implications
- Not seeking out a diagnosis since pain with intercourse is "normal"
  Woman being blamed for misdiagnosis and/or partner not believing
- the diagnosis
- Avoidance of sexual communication and activity

See Myrtveit-Stensrud et al. (2023) in reference list.

#### **Relationship Factors**

#### • Feelings of guilt and shame

- "It's all my fault" we can't have sex
- Believing cause to be completely psychological
   "It's because I'm untight about say"
- "It's because I'm uptight about sex."
  "If I weren't so messed up in the head this wouldn't be happening."
- Having or developing a rigid belief system

#### **Cultural/Relational Factors**

- Many cultures put the emphasis on reproduction and function over pleasure
- Women receive the message that sex is a "duty," and they are responsible for their partner's happiness
- Painful sex is "normal," and a woman needs to grin and bear it
  Internalization of heteronormative script that penis-vagina intercourse is the only legitimate way to have sex
- Practice cultural humility and not make assumptions—explore beliefs of each partner about what sexual activity means to them

See Myrtveit-Stensrud et al. (2023) in reference list.

#### Fear-Avoidance and Catastrophizing

- Fear-avoidance: Wanting to avoid any stimuli that may lead to painful activity
  - Lack of opportunity to practice sexual skills and expand sexual repertoire
     Cleaves the emotional intimacy afforded by sexual activity.
  - Cleaves the emotional intimacy afforded by sexual activity
    Interferes with motivation to lessen pain intensity
- Catastrophizing: Maximizing pain; belief that pain will never improve, and that life will never get any better
- Both contribute to low sexual function, sexual satisfaction, low self-efficacy relationship satisfaction

#### Sexuality Counseling Approaches

Practical Ways to Improve Self-Efficacy and Treatment Outcome

#### **Overview**

- Multiple review articles conclude that there is no one well-researched treatment-psychological or physical-for vulvodynia
- Anecdotally, an ecosystemic approach may help develop rapport and facilitate a collaborative relationship
- CBT may be helpful in disrupting negative thoughts and beliefs about the nature of pain, sexuality, and self-worth
- Solution-focused approach can help with "stuckness"

#### **Sexological Ecosystemic** Approach

With a nod to Dr. Uri Bronfenbrenner

#### **Microsystem**

Microsystem: Individual attributes (biological, physical, psychological); family of origin; close extended family
 What messages did you receive about sex from family?

- More specifically, what messages did you receive about being a woman regarding sexuality?
- What messages did you receive about your genitals, or your body in
- general? What did you learn about physical pain, either through your own
- experience or observation
- Did you receive any messages, or witness anything, regarding pregnancy and labor and delivery?
- What happened in your family when members were faced with a problem? hler. S. (2021, 2024)

#### Mesosystem

- Interactions between and among systems-couple's relationship; healthcare; workplace (work/life balance)
- What experiences have you had in seeking a diagnosis?
- How is this affecting your relationship?
- Does your partner understand the diagnosis?
  Are you able to communicate about your sex life?
  How much responsibility are you taking for the impact of vulvodynia?
  Is work creating stress or does your work schedule make it difficult to take care of yourself?

#### Macrosystem

- Systems that have significant influence-the media, religious organization, community and peers
  - Where did you learn what sex is "supposed to" be like?
  - Have your peers given you misinformation about sex?
  - How has your religious upbringing impacted your ideas about sex? Is there something in your religious belief system that has been helpful?

#### **Exosystem**

- · Systems that have indirect but significant influence-culture, legal system, myths and beliefs-the ethos
  - What is your culture's outlook on sexuality?
  - What is your culture's outlook on pain, especially sexual pain?
  - What myths do you hold about how women are "supposed to" act in the bedroom?
  - · What beliefs do you hold about the healthcare system and its ability to help?

#### **Chronosystem**

- The impact of time on the individual and subsystems
  - I hear what you learned about sex from your family. Now that you are an adult, what do you believe about sex?
  - How did you imagine it would be to have a sexual relationship when you became an adult?
  - . What do you imagine about your sex life and the quality of intimacy in the future?

#### **Case Example: Janice**

- Janice grew up in a household that was restrictive about sex. Although Janice was not abused, her mother told her she was abused and that, "Men only want one thing" and "Don't be surprised if sex hurts."
- When sex was painful, Janice told herself to grin and bear it. Eventually she shut down, leaving her partner sullen and angry at times.
- She was dismissed by several healthcare providers or given unhelpful suggestions to "just relax."
- Both she and her husband believed that they would never have children.
- PT felt like a last hope-but Janice wasn't very hopeful.

#### **Further Thoughts**

- It's okay to pick and choose areas of exploration
- Not all questions will fit all patients
- You can create questions based on the patient population or your own clinical experience
- Answers can determine if a referral to a psychotherapist who does sex therapy is appropriate

#### **Cognitive Behavioral Therapy**

A health psychology approach

#### CBT

- Cognitive behavioral therapy may include educating the patient; recommending actions to take; and addressing thought distortions
  - Compared to mindfulness, CBT was especially effective for women with primary vulvodynia
  - Women with secondary vulvodynia seemed to receive additional benefit if mindfulness training was included (Brotto et al., 2020)
    - Mindfulness training has been found to help cope with multiple chronic pain conditions
    - Also associated with improvement in sexual function

#### **Begin with Education**

- If possible, include partner
- What is know and unknown about vulvodynia
- What causes pain and what may make it better or worse
- Anatomy, for both patient and partner
- Sexual response
  - How arousal helps prepare the body for penetration, if part of the desire goal
  - What creates a pleasurable experience and perhaps orgasm
  - Why lubrication or HRT may be needed
  - · What other types of sex--as well as sex positions--can be practiced

#### Add New Behaviors

- Plan and schedule for appointments and treatment compliance
- Techniques for down-regulating the nervous system Diaphragmatic breathing
  - Yoga
  - Art, music, movement therapy
  - Mindfulness or movement meditation
- Communication with partner
- Support from family member(s), friend(s)

#### **Create Positive Self-Talk**

- Addressing negative sexual thoughts and distortions
  - "I am broken sexually," "I will never be able to have intercourse," "I have no value as a person if I cannot have sex" Empathize with and accept the patient's feelings
    - Ask if they are willing to see how their thoughts might be influencing their feelings and behaviors
    - Give an example, such as, if someone doesn't believe they can improve their game score they will likely give up and stop trying

#### **Black & White Thinking**

#### • Identity black and white thinking

- · Using words like "never," "always," "impossible," "I can't"
- Rephrasing statements to include future possibilities
  - "Today it is true I have never been able to have intercourse, but it may be possible in the future."
     "I haven't enjoyed sex yet, but if PT helps then maybe it can happen."
  - · "Even though I think I am always in pain, I can notice moments that are pain free."
  - "I have never noticed feeling pleasure during sex, but if I pay a little attention, it's possible that something might feel good."

#### Shoulds and Musts

- Identify "should" and "must" statements
  - "I must be able to have intercourse to get pregnant"
  - "It is possible to have intercourse with an unable to have intercourse."
    "It should have sex with my partner if they need it."
    "I may not be able to have intercourse, but I will ask my partner if they are open to other sexual activity."
  - "We must have penis-vagina intercourse to have sex."
  - "I can acknowledge that there are other ways of having sex. It may take time and experimentation, but we might even have fun learning."

#### **Personalization and Generalization**

- Personalization is the belief that one is responsible for all things
  - "I brought this condition on myself by being prudish about sex." "No one is completely sure why vulvodynia happens. Maybe there are other things to consider."
- · Generalization is taking one instance and applying it to
- everything. "Sex was uncomfortable before my period, so I'm going to give up
  - "Sex wats operher."
     "Sex was uncomfortable before my period, but I'm not sure if it is always uncomfortable then. I can keep a log and note down where I am in my cycle to better understand what is going on."

#### **Solution-Focused Counseling**

Emphasis on the possible future vs. the unsolvable past

#### **Solution-Focused Counseling**

#### The Miracle Question

- Creating curiosity about the future and what is possible; motivating someone to attain their possible future.
  - "I'm going to ask you what might be a strange question. What if you
    woke up tomorrow and you no longer had vulvodynia, or it was
    greatly improved. What would be happening?"
  - "What steps can be created to help you have that kind of experience in the future?"

#### **Solution-Focused Counseling**

#### The Exception Question

- Increasing awareness and using one's knowledge or wisdom to problem-solve and more forward
  - Has there ever been a time when intercourse was pain free?
  - Has there ever been a time when intercourse was painful, but your partner was supportive? Has there been a time when you felt pleasure and pain?
  - If patient is not forthcoming with an exception, suggest that perhaps they will experience something different in the future.

#### **Solution-Focused Counseling**

#### The Scaling Question

- What is your pain level today? And what might improve it from a "7" to a "5"? What could I be doing to help? What can you be doing to help yourself?
- You said you used your dilators one time this past two weeks. How might we work together to find ways to move that from one time to three times in three weeks?

#### **About Sex Therapy**

What is a sex therapist?

#### How Can Sex Therapy Help?

- A sex therapist is a licensed psychotherapist trained to use "talk therapy" to treat all kinds of common, and uncommon, sexual complaints
- Sex therapy never includes sex or physical contact
- Sex therapy may be brief, from 1-6 sessions, to intensive • Brief for newly emerged, mild to moderate issues
  - Intensive for long-standing issues and trauma
- Sex therapists may use different modalities, but the "secret sauce" is a blend of confidentiality and having time to explore thoughts and feelings that create barriers to resolution

#### Sex and Couples Therapy

• Generally important for the partner to be included in sex therapy for the treatment of vulvodynia and sexual pain

- Partner may feel frustration, anger, depression, rejection, confusion-even if on the surface they seem fine
- They may not understand vulvodynia nor its treatment
- They may not have realistic expectations about treatment
- Diminish blame and finger-pointing about the problem
- Improve communication about sex
- · For heterosexual couples, explore heteronormative sexual scripts
- Introduce or re-introduce sensuality and sexual exploration



Take-aways to put into practice

#### **Clinical Pearls**

- The sexological ecosystem can give insight into the individual and systemic contributing factors, creating paths of exploration and opportunity to address unhelpful beliefs and areas that need healing.
- The psychological, sexual, and relational aspects of vulvodynia are complex, but identifying and working with just 2-3 negative thought patterns may help a patient become unstuck. Educating both the patient and the partner can help to de-mystify vulvodynia and help the partner become part of the treatment team.

- the partner become part of the treatment team. When possible, exploring the possibility of sexual activity outside of intercourse may be helpful when there is fear-avoidance. This may include thinking about heteronormative sexual scripts. Many women are socialized to believe that sex is a duty or that they are defined as being "useful" by how they fulfill their partner's sexual needs. Provided the partner is truly supportive, emphagize that sexuality is only one part of their identity and existence. Improving self-worth and self-esteem can increase self-efficacy and move PT forward.

#### **Clinical Pearls**

- Depressed mood, anxiety, and trauma can be addressed by a general therapist, but also sex therapists who are licensed psychotherapists who treat a broad range of problems.
- Solution-focused questions can be especially helpful when someone with vulvodynia appears to be "stuck" in treatment.
- When asking questions, acknowledge feelings and respond with empathy before attempting counseling interventions.

#### Thank you kindly.

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**Practical Considerations** & Treatment for the Pelvic Rehab Provider

Nicole Cozean PT, DPT, WCS Jessica Reale, PT, DPT, WCS









#### **About Nicole**

- Doctor of Physical Therapy; (DPT) from Chapman University Board-Certified Pelvic Health Specialist (WCS)
- boaro-Lertine 7 evic Realth Specialist (WCS)
   Founder of PelvicSanity, a cash-based pelvic rehab clinic in Orange County, California
   Founder of Pelvic PT Rising, an online education and mentorship platform for pelvic health professionals
   Author of The Interstitial Cystitis Solution (2014)

- Only pelvic floor PT to sit on ICA Board of Directors (2016-2023) 2023) • Named The ICN Physical Therapist of the Year (2017) • Named Chapman University DPT Alumnae of the Year (2012) • Host of The Pelvic PT Rising Podcast with husband and business partner, Jesse Cozean

- Guest lecturer at Chapman University and CSULB and more
   Co-Founder of PelviCon



#### **About Jessica**

- Doctor of Physical Therapy (DPT) from Duke University
   Board-Certified Specialist (WCS) in pelvic health
   Founder of Southern Pelvic Health
   o Cash-based pelvic PT practice in Atlanta, GA
   Educator in pelvic health coursework, participating in the
   training of thousands of physical therapists and other health
   care providers across the world
   Co-author, "The Role of Physical Therapy in Sexual
   Dustinction in Men and Wonzen".
- Dysfunction in Men and Women" Sexual Medicine Reviews Co-founder of PelviCon
- Co-founder of Pelvic Floor University
   Founder, Pelvic Pro Collective
   Guest lecturer at Mercer University, Emory University,
   Georgia State University and the University of South Carolina, and more.

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• No relevant financial disclosures



- Following this presentation, participants will:
- $\cdot$  Recognize the role of pelvic floor rehabilitation in the care of patients with vulvodynia
- · Identify key strategies to optimize the rehab examination and build a treatment plan
- · Identify key strategies to optimize pelvic health rehabilitation interventions



#### Pelvic Floor Rehabilitation for Vulvodynia

- Pelvic floor muscle dysfunction is common
   Neuville et al. (2024) found that in 132 patients with provoked vestibulodynia, 91% had pelvic floor muscle dysfunction.
- + Pelvic floor rehabilitation is an important component in

  - Pelvic floor renabilitation is an important component in multidisciplinary care
    10- week multidisciplinary program (medical, psychology, physical therapy) found 53% improvement in dyspareunia (Brotto et al., 2015)
    Multicenter RCT found topical lidocaine + physical therapy superior to lidocaine alone (79% very much or much improved vs. 39%) (Morin et al., 2021) Sumposiu

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#### Pelvic Floor Rehabilitation for Vulvodynia

#### ACOG Committee Opinion #673: Persistent Vulvar Pain

"Women with vulvodynia should be assessed for pelvic floor dysfunction. Biofeedback and physical therapy, including pelvic floor physical therapy, can be used to treat localized and generalized vulvar pain." (Wexler et al., 2016)



#### Effectiveness of Rehab for Vulvodynia

- A 2022 review of 10 studies found that "... PFPT seems to be efficacious in patients with chronic prostatitis, chronic pelvic pain syndrome, vulvodynia, and dyspareunia." (van Reijn-Baggen et al., 2022)
- A 2017 systematic review examining physical therapy modalities for provoked vestibulodynia stated, "...modalities such as biofeedback, dilators, electrical stimulation, education, multimodal physical therapy, and multidisciplinary approaches were effective for decreasing pain during intercourse and improving sexual function." (Morin, Carrol & Bergeron, 2017)



## Tips for Optimizing the Rehab Examination

Patients have been through varying journeys prior to their rehab evaluation

Intentionality during the evaluation can strongly impact the course of treatment



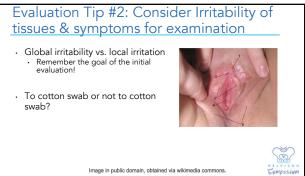
"An average museum visitor spends 17 seconds looking at a work of art. Physicians spend 8 seconds listening to patients before interrupting. How long do we spend singularly looking at our patients, using all senses, being fully present?"

~ Dr. Martin Hueker (2018)



Sumpo:





#### Evaluation Tip #3: This is a patient with pelvic pain

- · How do we evaluate people with pelvic pain?Examine the whole person, not just the
- vulva. Consider:
- · Movement assessment-full body
- approachSpinal mobility, hips, feet, etc. · External and/or internal assessment of
- pelvis & pelvic floor muscles
- ADLs, body mechanics, preferred exercise, etc.

- Viscerosomatic convergence Multidisciplinary care Role of bladder & bowel dysfunction,

## S

#### Evaluation Tip #3: This is a patient with pelvic pain

- Femoroacetabular impingement, labral tears and hip dysplasia correlated with vulvodynia and sexual dysfunction Niedentiehr & Stevens (2023) review- Surgery improved vulvodynia, clitorodynia and scrotal pain.
- High rate of vulvodynia & dyspareunia amongst individuals with Ehlers Danlos or hypermobility spectrum disorders (Glayzer et al., 2021)

Common Comorbidities

 Irritable Bowel Syndrome, Interstitial Cystitis/Painful Bladder Syndrome, Fibromyalgia (Reed et al., 2012)

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#### Evaluation Tip #4: Consider other key members of the patient care team

- · Does the patient have adequate medical care? pain management?
  - · Build your network!
- · For non-rehab providers: Has the patient had appropriate pelvic rehab?
  - Is the provider well-trained in pain?
  - Failed physical/occupational therapy? or just failed with 1 provider?





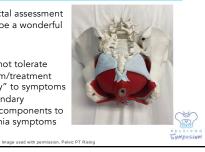
#### Practical Strategies for **Rehab Treatment**

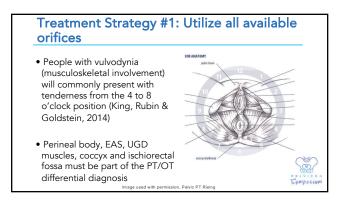
include the orthopedic contributors, internal and external tissues of the pelvic floor & nervous system

strategies is important for optimal pelvic health and wellness

#### Treatment Strategy #1: Utilize all available orifices

- In general, transrectal assessment and treatment can be a wonderful tool for:
  - People who cannot tolerate transvaginal exam/treatment
  - Finding the "why" to symptoms • Addressing secondary
  - bowel/GI/rectal components to primary vulvodynia symptoms





## Treatment Strategy # 2: Consider the entirety of the pelvic floor

- First, consider timing for pelvic floor direct interventions
  Direct reproduction of vulvodynia symptoms is NOT
- necessary to indicate need for treatment to the pelvic floorPatients may present with symptoms at the vulva and vestibule but we must consider the autonomic nervous
- system's role in perpetuating tension/tightness in the entire pelvic floor • Also consider pelvic floor muscle dysfunction and vulvar
- referral patterns



#### Treatment Strategy # 2: Consider the entirety of the pelvic floor • Jantos et al. (2015) examined 82

- patients with vulvodynia and IC/BPS. Significant pain with palpation identified at:
- External: urethra, vestibule
   Internal: levator ani, other pelvic floor
- Internal: levator ani, other pelvic floo muscles, paraurethral
- Palpation of paraurethral structures led to referred symptoms at abdomen, low back, suprapubic, buttock, medial thigh and intense urgency symptoms – all decreased following intervention.



## Treatment Strategy # 3: Treat pain with respect, not fear

- Nervous system guided approach to treatment is necessary
- Patients with vulvodynia have been shown to (Pukall et al. 2016)
  - Have increased neural activity is response to painful vestibular stimulation in areas of the brain that
  - involve pain modulation • Have augmented sensory processing

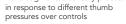


Image used with permission, Pelvic PT Ris

### Treatment Strategy # 3: Treat pain with respect, not fear

- Having vulvodynia symptoms even if severe is not an automatic disqualifier to transvaginal or external vulvar work
- Each individual's entire patient experience must be taken into account when determining how and when to implement direct strategies of treatment
- Flare management and communication with patient around flares is key
- Flares should not be a surprise to the patient
  Communication on mitigation strategies and proposed mechanism as to why is imperative



## Treatment Strategy #4: Be Intentional in Use of Treatment Adjuncts Dilators/Trainers Wands TTNS TTNS Ubdicants & Moisturizers Lubricants & Moisturizers Topical lidocaine or compounds prior to or after manual therapy Self-massage tools (balls, cups, etc) Cold pack/Heat SI Belts Cushions



## Treatment Strategy # 5: Don't be afraid to 'journey' with your patient.

- Vulvodynia is a chronic pelvic pain condition with multiple contributing factors
- Pain may have been present for a long timeMultiple systems may be involved
- Having vulvar pain is likely to be comorbid with other psychosocial factors that can make healing more complex
- Plan of care length can vary greatly and may be long



## Treatment Strategy # 5: Don't be afraid to 'journey' with your patient.

 Patient education on realistic expectations based on their specific contributing factors, longevity and severity of pain, social support and nervous system state is imperative.



#### Conclusion

- $\cdot$  Treat the person, not just the vulva/pelvic floor
- · Be creative with use of adjunctive treatments
- Multidisciplinary care is key.
- Other providers: Remember pelvic floor rehabilitation providers are practitioners not treatments.

