

What We Want Every Provider to Know

Michelle B.

Disclosures

- None

Objectives

1

Engage with personal stories of patients treated by sexual medicine specialists

2

Explain the importance of specialty training in sexual medicine

3

Provide patient perspectives on the expectations versus reality of sexual medicine and the role of provider-patient communication

Michelle's Story

- Incorrect diagnoses:
 - Nothing. "It's all in your head"
 - Repressed sexual abuse
- Correct diagnoses:
 - Pelvic floor muscle dysfunction
 - Vaginal septum
 - Congenital neuroproliferative vestibulodynia
 - Clitorodynia/Clitoral adhesions
 - Recurrent infections
 - Vulvovaginal erosive lichen planus
 - Epilepsy*

*Ref:

- 1) Markoula S. et al, "Reproductive health in patients with epilepsy", *Epilepsy&Behavior* 113 (2020) 107563 <https://doi.org/10.1016/j.yebeh.2020.107563>
- 2) Li S. et. al, "Research Progress on the effect of epilepsy and antiseizure medications on PCOS through HPO axis", *2021 Frontiers in Endocrinology*, Vol 12 Article 767854
- 3) Reimers, A. "New antiepileptic drugs and women", *Seizure* 23 (2014) 585–591

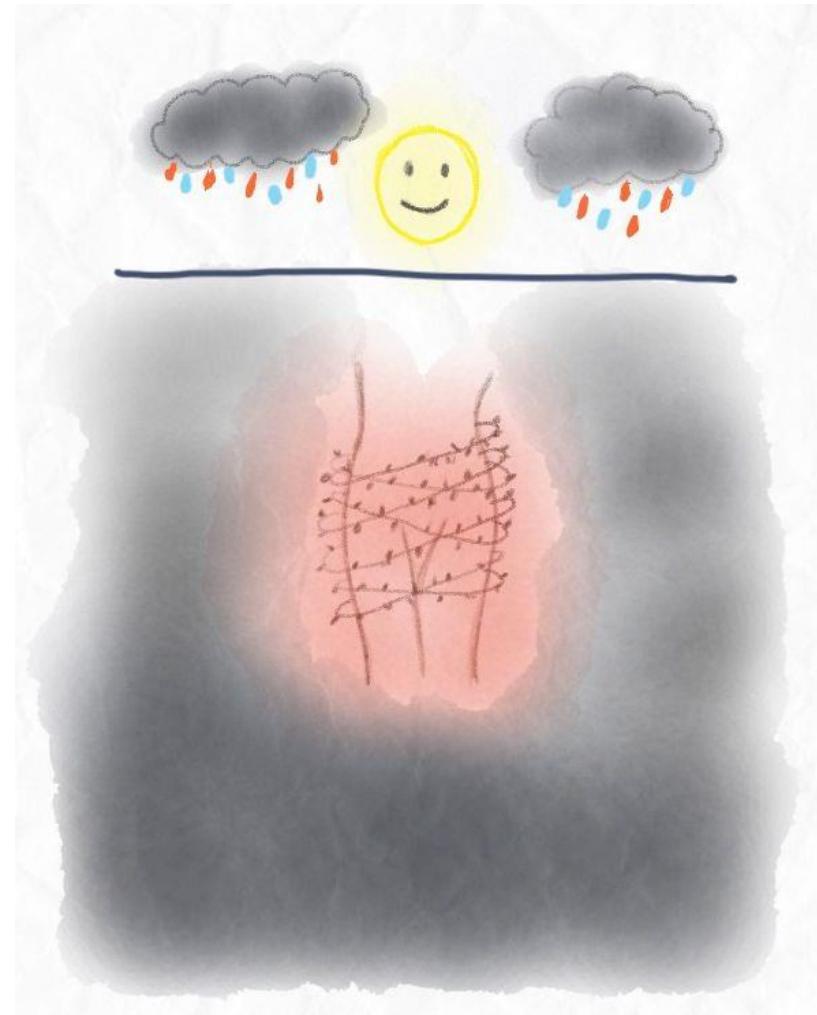


Michelle B.

What should providers know
about the patient experience?

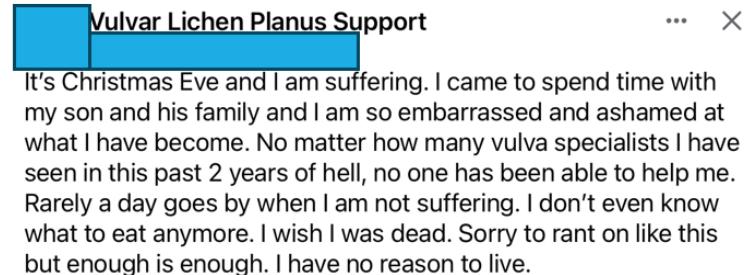
This journey is difficult.

- Sexual dysfunction and chronic pain affects all aspects of life.
- Isolation
- Patients don't always look sick.
- FSD is more than infertility.
- Having a diagnosis is important.
- Rare vs. rarely diagnosed
- Navigating insurance/ Providers not accepting insurance



In addition to pain, patients experience...

- Medical Trauma
- Helplessness
- Hopelessness
- Fear
- Anger
- Shame
- Relationship failures
- Distrust of providers after failed treatments and dismissals



Vulvar Lichen Planus Support ... X

It's Christmas Eve and I am suffering. I came to spend time with my son and his family and I am so embarrassed and ashamed at what I have become. No matter how many vulva specialists I have seen in this past 2 years of hell, no one has been able to help me. Rarely a day goes by when I am not suffering. I don't even know what to eat anymore. I wish I was dead. Sorry to rant on like this but enough is enough. I have no reason to live.

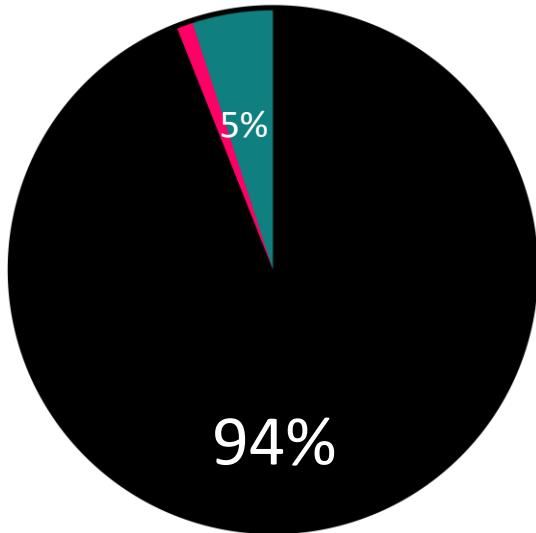
So to recap:

I am officially post-menopausal and unofficially diagnosing myself with vaginismus with a side of vulvodynia. I am using 1/2 - 1g of estrogen cream vaginally once a day. I have added a 5mg dissolvable DHEA tablet to the cream. I take 25mg of DHEA orally every day. With some care and in a relatively short period of time I am now able to insert an average-sized dildo into my vagina and have a good time.

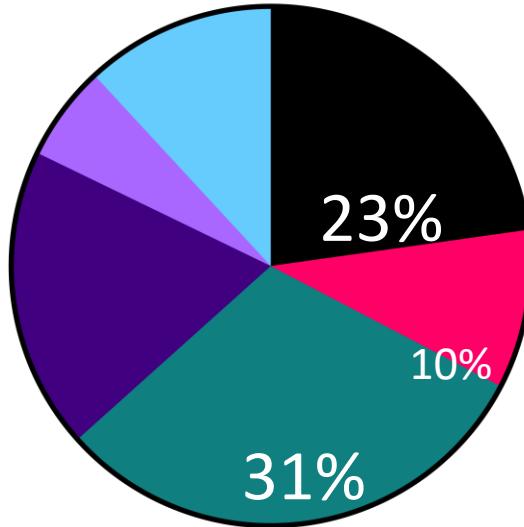
And the takeaway: Medical care for women's sexual health especially post-menopause BLOWS and I'll never stop being angry about it. Because here's another fun fact - I also haven't had a pap smear this whole time because of the pain.

Providers & good information about FSD are difficult to find:

**Patient Search Terms
(Poll Results)**



**Website Keywords
(Average)**



- Symptoms
- Non-medical Terms
- Medical Terms
- Anatomy
- Provider & Society Names
- Other

What can you do to best help
your patients?

Be a good listener



Listen!

Get a thorough history
Review records



Believe the patient



Learn & practice responses that don't dismiss the abnormal

Be trustworthy

Recognize that most patients will not initially trust you

Have discussions with your patients while they are dressed

Ask for consent

Follow through



Doctor: "Don't confuse your Google search with my 6 years of medical school".

Patient: "Don't confuse the one-hour lecture you had on my condition with my 20 years of living with it".



Be honest

Don't oversell

Say "we don't know"
and/or "I don't know"

Share the data we do have

Discuss treatment options and ideas

Don't underestimate the patient

The Vulvodynia Support Group 14m ·

I'm beginning to think all OB/GYNs are the same... like yeah some will claim to know more about Vulvodynia than others but really the one I saw didn't know any more than my "regular" OB/GYN.

Like Comment Send

3

All comments

You know what? I'm going to save my money. No more "specialists". If I do see one, it will be online. I've had like 50 pelvic exams the last year and they all told me the same thing anyway. No reason why I can't just deal with my issues through telemedicine.

9m Like Reply 1

Here's what's wild. Im a nurse, I work in the system , and I was not heard. What chance does that possibly give everyone else???. If the gyne would have commented on my "loss of architecture" I would have told him that nothing has changed. I've always had next to nothing for labia minora. If he would have told me he was suspecting LS, I would have requested a biopsy. Thankfully, my new doctor got me to a new gyne, who did a biopsy. Turns out it was chronic dermatitis.

Be knowledgeable

- You are here - thank you!
- Diagnose accurately
 - Know what tests to perform
 - Know how to interpret results
 - Understand the strengths & weaknesses of test results and symptoms
- Know when to refer
- Seek training on unconscious bias

via No Nonsense
Neurodivergent

OMG I'm Autistic AF
@OMGImAutisticAF

“Why do you need a label?”
Bc there is comfort in knowing
you are a normal zebra, not a
strange horse. Bc you can't find
community w other zebras if you
don't know you belong. And bc
it is impossible for a zebra to be
happy or healthy spending its life
feeling like a failed horse

11:58 a.m. · 29 Aug. 22

Be trauma conscious

Chronic pain is traumatic

Not being believed is traumatic

Medical care is traumatic

Get involved...



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Who should you be following?

- SexMed Advocate
 - DiscoverSexMed
 - Tight Lipped
 - The Orgasm Lab
 - Healthy Hooha (Aimee Cloutier)
 - The Broken Brown Egg
 - Unraveled Self (Kristen Loop)
 - Vulval Pain Society
 - Vulval Cancer UK Awareness
 - NVA
-
- Education/Data Resources
 - Prosayla by ISSWSH
 - Dr. Jill Krapf
 - Dr. Rachel Rubin
 - Dr. Ashley Winter
 - AED Pregnancy Registry
 - JustAsk Podcast

Connect with us!



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