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NVA News

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Why So Many Women Hide Their Sexual Pain

By Sari Cooper, CST, LCSW

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When the topic is female sex-related pain, omission is a common form of communication. Most people, including medical professionals, are uncomfortable discussing or simply hearing about female genital pain. (Sometimes, the word gynecology alone is enough to get the men in the room to leave.) It's 2022 and we're still in a situation in which eight to 16 percent of the female population suffers from chronic vulvar pain, but many suffer in silence. It's difficult for an adult to cope with it, but imagine being a 14 year old girl who's suffering from vulvar pain, doesn't understand why and is too embarrassed to ask her pediatrician.

Vulvodynia and vaginismus are two conditions that cause vulvar pain, but there are others, such as lichen sclerosus. Many women have been misdiagnosed with infections or told nothing is wrong medically before they finally receive a diagnose of vulvodynia, i.e., vulvar pain without a precise identifiable cause. In vaginismus, it is the involuntary contraction of the vaginal musculature that causes pain. Some women with vaginismus have never been able to insert a tampon or engage in sex without pain (primary vaginismus) and others have been pain-free for a period of time, but no longer (secondary vaginismus). Clearly, both vulvodynia and vaginismus make sexual intercourse painful or impossible. The common medical term for painful sexual intercourse has been dyspareunia, but the current diagnostic manual classifies painful sexual intercouse as genito-pelvic penetration pain disorder (GPPPD).

Women's Sexual Pain Shows Up in the Medical Realm

One epidemiological study (2003) found that only 60% of women with vulvodynia seek medical help, and among those, 40% never receive a diagnosis. The lack of support from the medical community contributes to feelings of invalidation and stigmatization often experienced by women with vulvodynia. When it comes to pain specific to female anatomy, diagnosis veers off-course, e.g., doctors suspect menopause, PMS or depression. In fact, many of the women seeking help from sex therapists are younger than 40 and not perimenopausal or postmenopausal.

Primary care doctors may suspect disorders located in other parts of a woman's body, and not understand that the primary pain is located in the genitals. This gap in the assessment process leaves women with the wrong diagnosis and still in pain, with the additional psychological distress and loneliness of being misunderstood or dismissed. Many women with genital pain think that silence is better than being disbelieved.

“There's virtually no vulvovaginal training for clinicians,” gynecologist Elizabeth Stewart, M.D., told the audience in a vulvovaginal disorders session for internal medicine doctors. Due to the lack of training on women's sexual health in medical school and residencies, doctors can be stymied when women present with genital pain. Stewart criticizes the tendency to rely on

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patients' assessments of their vulvar symptoms, stating, "When clinicians rely on a patient's self-diagnosis instead of doing an exam and cultures, inappropriate treatments are often prescribed."

Gynecologist Chris Creatura and I recorded an online webinar titled, “How to Help Women with Sexual Pain and Low Desire”. Chris explained to gynecologists that when they examine a woman with vulvovaginal symptoms, many diagnoses must be considered. There isn't a single cause for vulvar pain, so infection, allergy, skin disease, systemic disease or cancer (or a combination of a few factors) can be the cause.

Sexual Pain Affects Partners and Relationships

Similar to how the subject of sexual pain gets shut down, minimized, or avoided in medical appointments, some women keep the reality of sexual pain from their partners, even when it’s a longtime partner or spouse. They remain silent to feel more accepted by the partner and out of fear of rejection and shame. Recent research findings posted by sexuality writer Michael Castleman indicate that this behavior is a reaction to a patriarchal society that prioritizes men’s sexual pleasure over women’s desire and pleasure. Women report not telling partners about their pain because they feel “they should subordinate their erotic pleasure to their men's."

Male partners of women who suffer from sexual pain are deeply affected by their partner’s experience. In a recent *Journal of Pain* study of women with vulvodynia and their partners, women experienced greater pain when they also felt pain-related shame, and their partners experienced distress because they felt guilt for causing their partner’s pain. On days they had sexual activity, both partners reported greater levels of sexual distress. The authors of the study state: “Qualitative studies show many women who experience vulvar pain feel inadequate, are apprehensive to speak about their pain, and fear that their condition spells the end of their romantic relationship.”

Sex Therapists Can Help Women and Their Partners

As a sex therapist, I consider the reach and power of a woman’s genital pain and the impact on her partner and their relationship. It is critical for a sex therapist to first validate and empathize with the woman since most women have been made to feel embarrassed or that they are hypochondriacs. To uncover the source, experience, and history of the pain, the sex therapist conducts a thorough sexual status and history assessment. It is also essential that the therapist do an assessment of the partner. (Our practice offers two recorded webinars on interventions for therapists, sex therapists, pelvic floor physical therapists, and doctors.)

Typically, when a woman is in a committed sexual relationship (in the cases provided here, the partner is male, though this is not always the case), the vulvar pain has an effect on the partner’s sexual functioning. Male partners, feeling guilty for causing pain during penetrative

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NVA E-News

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The National Vulvodynia Association is a nonprofit organization that strives to improve women's quality of life through education, research funding, support and advocacy.

NVA Funds Vaginal Microbiome Study

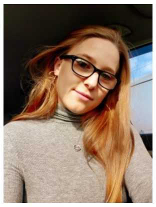
After two decades of research comparing vulvar tissue in women with vestibulodynia versus controls, researchers have made progress, but haven't determined the precise cause of vulvodynia. This has led some researchers to start investigating the microorganisms that colonize the vagina, i.e., the vaginal microbiome. (Each body site constitutes a habitat of trillions of organisms known as the microbiome. For example, much has been written about the effect that the gut microbiome has on your overall health.)

Early studies on the vaginal microbiome have only tested a small number of subjects, so unsurprisingly, the findings have been inconsistent. For example, one study found an increase in Gardnerella among women with vestibulodynia, but others didn't. All these studies concluded that further research and larger sample sizes are essential.

In September, the NVA executive board, in consultation with our medical review committee, voted unanimously to fund a larger study of the vaginal microbiome. We awarded $30,000 to investigator Gary Ventolini, M.D., of Texas Tech Health Science Center. His commitment to vulvodynia research is impressive and we should have results from this study in fall 2023.■

In Her Own Words

By Tiffany Roche



Three years ago, I was just finishing my second year of university. It was a very exciting time for me. I was entering the fourth year of a relationship and looking forward to my future. However, nothing could have prepared me for what happened next.

I began to suffer with excruciating pain in the most private part of my body and after two years of endless appointments and treatments that failed, I was diagnosed with vulvodynia. I believe that when discussing vulvodynia, we should be raw, real, and honest. Vulvodynia slowly took over my life. I lost my passion for studying, I lost my day-to-day happiness and positive outlook on life, I lost the relationship with my partner, and most importantly, I felt like I was losing myself.

When you're diagnosed with vulvodynia, they may explain the physical pain you will suffer, i.e., the burning, stinging, throbbing, and aching, but they often forget to mention the emotional pain you'll go through. A condition like this can make you feel incredibly alone; I know I did. That was until I found the NVA website and realized just how many incredible women were out there. I began to feel less alone and confident enough to speak out. I surrounded myself with support and used my voice to get the help I needed.

There were days when I couldn't imagine a pain-free life and days when I couldn't even get out of bed. However, with the right help, emotionally and physically, I was able to fight this condition every single day. I found tips to relieve some of the pain so that I could get back to doing the things that brought me joy. I found a way to communicate with my partner and we were able to continue a healthy, happy, and intimate relationship. Most importantly, I found a knowledgeable doctor and the right treatment plan, which I can happily say, has completely changed my life.

I am no longer in constant pain, I can wear pants, I can do the activities I want to do, and I am myself again. Of course, as with any chronic pain condition, I have occasional flare-ups, but they are manageable and remind me to be grateful for the pain-free days.

After struggling with this debilitating condition for three years, I became more passionate about advocating for women's health and taboo topics. I started my own blog, where I share my story, tips, advice, and both the good and bad days. I created a blog where you can go for a giggle, cry, a moment of relief or just a place to keep learning about conditions like these. Take a look at https://thedreadedvword.wixsite.com/website if you think it would benefit you.

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vaginal sex, may experience erectile dysfunction, uncontrolled ejaculation, or low desire. It is important for women to seek help not only on their own but with their partner as well.

The discussion above provides a strong case for therapists to work with *both* partners in sex therapy. In this type of therapy, it is critical for sex therapists to:

1. Provide sex education about vulvodynia to both partners so they understand that this is a medical condition and no one's fault.
2. Refer the woman suffering from pain to a well-trained sexual health medical professional able to diagnose and treat vulvodynia and GPPPD.
3. Explain how the entire couple's relationship has been impacted by the disorder.
4. Urge the couple to use therapy to address both partners' feelings of shame and anxiety, explain that their reactions are understandable, and give them hope that these conditions can be treated.
5. Outline a treatment plan to work on the pain treatment and their communication and sexual alternatives while the Vulvodynia is being treated.
6. Teach them mindfulness techniques that induce relaxation and help them focus on giving and receiving sexual pleasure. There is a whole body of research and a recent book written by Lori Brotto, Ph.D., showing the benefits of *Mindfulness-Based Stress Reduction* for women suffering from sexual pain.
7. Advocate and support women as they work with allied health care professionals.

Creating a Holistic Medical Team

In the second of our sexual pain webinars titled "The Collaborative Clinical Care Model Between Therapists and Pelvic Floor Physical Therapists," (co-hosted with physical therapist Amy Stein), we presented the case of a client experiencing severe genital pain. She described feeling like a freak amongst her sexually active college peers. Another woman attributed the breakup with her boyfriend to her pain during sex and the resulting lack of sex. In another example, a high-achieving professional woman worried she would lose her supportive fiancé when he started graduate school. In almost every case, these women felt extremely isolated, embarrassed, and anxious.

Silence and shame about one's pain creates a vicious cycle of intimacy breakdown that can be fixed by having a knowledgeable supportive professional team and working on communication about intimacy. Sex therapists are trained to coordinate care among multiple providers and to encourage women to speak about their sexual pain with their medical providers and partners.

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(Editor's Note: We are encouraged to see more mainstream publications publishing articles on painful sex and overcoming the stigma associated with it. This article was adapted from a *Psychology Today* publication. The link to the original article is: www.psychologytoday.com/us/blog/sex-esteem/202010/why-so-many-women-hide-their-sexual-pain.)■

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Spring Research Summit

NVA Board members Dr. Susan Kellogg-Spadt and Phyllis Mate, plus representatives from organizations including the International Pelvic Pain Society and International Society for the Study of Women's Sexual Health, have been appointed to the steering committee for the early 2023 novel treatment research summit. The meeting facilitator is vulvodynia expert Andrew Goldstein, M.D., and the chairperson will be scientist Paul Yong, M.D. Renowned vulvodynia experts serving on the joint working committee include Jacob Bornstein, M.D., Nina Bohm-Starke, M.D., and David Foster, M.D.

This summit is designed to bring together a select group of researchers who have demonstrated expertise or have original ideas for developing novel vulvodynia treatments. We are deliberately keeping the number of participants under 40 to maximize discussion and encourage research collaborations among participants.

Many vulvodynia experts, as well as women suffering from vulvodynia, have expressed frustration with the inadequacy of current treatments. Thus, the NVA has committed to Dr. Goldstein that we will fund the most promising studies recommended at the summit. Please join us in this effort to relieve pain for millions of women with vulvodynia by making a research donation online at www.nva.org/donate.■

CBT Module Coming in 2023

University of Michigan researchers are currently testing the effectiveness of NVA's online cognitive behavior therapy (CBT) module for women with vulvodynia. This research will determine if any changes are necessary before the program is released. NVA funded the development of the CBT module, because research has shown that CBT improves quality of life for people living with chronic pain. It has also shown that people experience less pain after they learn to use CBT techniques.

For those who are unfamiliar, CBT capitalizes on the mind-body connection that scientists have been studying for 30-plus years. CBT is more specific than simply 'think positive.' First you need to assess which thoughts intensify pain and trigger anxiety/depression, and then you have to replace them with thoughts that are calming and pain-relieving. In laypersons' terms, what you say to yourself can actually modify brain connections, reducing anxiety, depression and pain.

In my 3-month experience learning CBT, the biggest challenge was abandoning catastrophic thinking and developing phrases that were positive. The therapist made suggestions, but sometimes I had to modify her wording to make a phrase resonate for me. She encouraged using the present tense ("I feel fine" instead of "I will feel fine"), but that didn't ring true for me. Instead I've used, "I'm getting better" and "I feel calmer." Learning to stop catastrophic thinking was incredibly helpful for me. For especially anxiety-provoking days, e.g., long plane trips, I focus on how I can make it easier beforehand and then use deep breathing and visual imagery (imagine I'm driving down the California coast) while I'm traveling.

These techniques I've described can be learned without a therapist. If you want to read more about CBT, visit https://my.clevelandclinic.org/health/treatments/21208-cognitive-behavioral-therapy-cbt. We will let you know as soon as the CBT module for women with vulvodynia is online.■

NVA Referral List Available Online

NVA maintains the most extensive list of health care providers skilled in the diagnosis and treatment of vulvodynia. If you need a doctor, nurse practitioner, physical therapist or sex therapist, visit our website at: www.nva.org/providers.

Please help us keep this list up-to-date by letting us know if you've had a positive (or negative) experience with a particular provider. If you receive successful treatment from someone who is not on our referral list or if you discover that a provider has moved or retired, please email their name and contact information to lisa@nva.org.

IN HER OWN WORDS

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If I could give my 19-year-old self advice, it would be to seek help straight-away. Yes, it may be embarrassing to admit, but being in intense pain for years is absolutely worth an uncomfortable 10-minute chat. For those who are still suffering badly, keep going. There is an end in sight, but you need perseverance to reach it. Be your own advocate. And for the women, like me, who have come through the worst of it and can breathe a sigh of relief, embrace your new lease on life, do everything you hoped to do and never forget how strong you are. Nobody deserves to live in pain.

By Megan O.

My story ends with a happy marriage, the birth of a beautiful baby, and no more vulvar pain! I believe that you can find a happy ending too.

My dream was to find love and be a mother, but for many years that dream was unreachable. As a teenager, I couldn't even insert a tampon. I didn't understand how other girls could do it and that made me self-conscious. Finally, when I was 19 years old, I told an ob-gyn about my problem. She discovered I had a vaginal septum, a thin wall of skin vertically separating the inside of my vagina down the middle. I needed surgery to remove the septum.

The surgery was successful and I was instructed to use a huge dilator for 5 to 10 minutes every day to ensure that the sutured walls of the vagina healed properly. It was extremely painful. I had never been able to use a tampon, let alone a huge dilator. And, although there was no more septum, the inside of my vagina was very sore from surgery.

A couple of years later, I fell in love. I didn't consummate the relationship when we were dating. I told him it was a moral choice to wait until I found my life-partner. After he "put a ring on it" I tried to consummate the relationship, but it was so painful! I often had to ask him to stop because I would feel severe burning, or a sharp, stabbing pain.

The first ob-gyn I saw about this condition told me to use more lubricant and said I shouldn't feel pressured to have sex if I wasn't in the mood. I knew my desire for my husband was not the problem. The second ob-gyn was more understanding and prescribed a numbing cream. That didn't help at all. The third ob-gyn referred me to a pelvic floor physical therapist and pelvic pain doctor. I spent hours researching solutions to this condition and was overwhelmed by all the terms, i.e., vulvodynia, vestibulodynia, vaginismus. I was scared that the treatment options included anti-convulsants, anti-depressants, Botox, vestibulectomy, etc.

I went to a physical therapist, and she spent an hour using what I call "magic fingers" to hit pressure points on my pelvic muscles and make the pain in that area go away. It was amazing! However, it was only a temporary fix. She told me to use dilators – starting with the smallest size – until I no longer felt pain inserting it, and then to move to the next size. The dilators did help, but I still had burning at the vaginal opening.

The dilators made intercourse tolerable and if I could make it past the initial burn, it was okay. We decided to conceive a baby. After the second month of trying, I got pregnant! As the due date approached, I feared that childbirth would be more painful for me than for the average woman. With an epidural, that worry went right out the window. I was able to have a vaginal birth and delivered my baby with no tearing (lucky me!). After waiting eight weeks post-birth, I nervously tried to have intercourse with my husband again and the pain had practically vanished! Now it's four months later and I finally find intimacy enjoyable!

I highly recommend pelvic floor physical therapy to women with this condition. Please don't accept that you have to suffer through sex. Every woman deserves a patient partner and a gradual physical therapy program that, little by little, helps you reach your goal. This is a real problem and there are real solutions out there. Don't give up!■

The NVA staff wishes you a safe and happy Thanksgiving and holiday season!