National Vulvodynia Association

NVA News

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Recent Recommendations for the Treatment of Vulvodynia

This article is based on the treatment findings in Goldstein A, Pukall C, Brown C, Bergeron S, Stein A, Kellogg-Spadt S. Vulvodynia: Assessment and Treatment. J Sex Med 2016;13:572-90.

Six vulvodynia specialists from varied disciplines reviewed all of the published studies on the assessment and treatment of vulvodynia. In their article, published in the Journal of Sexual Medicine, levels of evidence were assigned to different types of treatment, depending on whether researchers had used a rigorous scientific method in collecting and analyzing outcome data. For example, results from randomized controlled clinical trials constituted the highest level of evidence. Unfortunately, there have been very few of these trials on treatments for vulvodynia. After reviewing all the evidence, the group reached consensus on treatment recommendations, which are presented in this article.

Introduction

Many vulvodynia specialists prefer to start treatment with the least invasive measures, such as vulvar self-care, pelvic floor muscle therapy and psychological intervention. Depending on a patient's response to these measures, oral and/or topical medication may then be prescribed. For women with provoked vestibulodynia (PVD), surgery is considered only when more conservative treatments fail to produce sufficient pain relief. Currently, most specialists advocate a multimodal approach, e.g., medication and pelvic floor therapy, the components of which are determined after months of trial and error with different

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Oral Medication Use in the Treatment of Vulvodynia

By Phyllis Mate, NVA co-founder

For many years, doctors have prescribed tricyclic antidepressants and anticonvulsants for women with vulvodynia. Marilyn McKay, M.D., was among the first to report that many of her patients with generalized vulvodynia (formerly, dysesthetic vulvodynia) experienced pain relief with a low dose of amitriptyline, which was used to treat other chronic pain conditions. Subsequently, low-dose tricyclic antidepressants became a common first-line treatment for women with generalized vulvodynia and provoked vestibulodynia, although a considerable number of women have experienced undesirable side effects.

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treatments. A multimodal approach has been widely used in the treatment of other chronic pain conditions, but has been relatively absent in the treatment algorithms in the vulvodynia literature.

Non-Medical Treatment

Over the years, research has shown that people with various chronic pain conditions can benefit from non-medical treatments, such as physical therapy, acupuncture and psychological therapy.

Pelvic Floor Physical Therapy

Women with vulvodynia often exhibit tenderness and hyperactivity of the pelvic floor muscles, which tighten and shorten in response to pain. Pelvic floor physical therapy for vulvodynia includes pelvic and core stabilization techniques, connective tissue and neural mobilization, internal and external trigger point release, and biofeedback. The initial goal of therapy is to reduce tender points and tissue restrictions. Subsequently, therapy can focus on restoring normal muscle length and relieving painful sexual intercourse.

Pelvic floor physical therapists are skilled in manual techniques, such as myofascial trigger point release and connective tissue manipulation. In addition to relieving restrictions in muscles, tissue and nerves, these techniques improve circulation in areas of decreased blood flow. Combined with external connective tissue release, internal release of myofascial trigger points in the pelvic floor muscles is essential to rehabilitate the pelvic floor and reduce pain with sexual intercourse. With this therapy, women are also able to sit more comfortably and have improved bladder and bowel function. In addition to manual techniques, neuromuscular re-education, e.g., biofeedback, helps women learn to relax overactive muscles.

Another critical aspect of pelvic floor and sexual rehabilitation is stretching and strengthening exercises. First, the physical therapist assists the patient with the stretching of muscles in the back, abdomen and legs. Once trigger points and connective tissue restrictions have been released, the therapist will teach specific strengthening exercises to address muscle weaknesses. As part of this rehabilitation, the physical therapist will design an individualized home-based program. This program typically includes breathing and relaxation methods, stretching exercises, guided imagery, and bladder and bowel retraining. Additionally, vaginal dilators may be recommended to desensitize areas of the vulva and vagina, and facilitate sexual intercourse. The use of these methods instills confidence in the patient, who is now in charge of her own well-being.

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NVA 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.

The NVA is not a medical authority and strongly recommends that you consult your own health care provider regarding any course of treatment or medication.

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Early randomized studies demonstrated the efficacy of electromyographic biofeedback in relieving chronic vulvar pain. Recent studies have found evidence that comprehensive pelvic floor therapy, including biofeedback, is effective in reducing pain during intercourse in PVD patients. One study found that 75 percent of vulvodynia patients reported improvement in pain after 10 sessions of physical therapy and electrical stimulation, biofeedback, and a home program with stretching exercises. The researcher concluded that pelvic floor therapy is safe and effective in relieving vulvar pain and painful intercourse. Although large prospective studies are needed, pelvic floor therapy appears to be effective in women with vulvodynia.

Psychological Interventions

The use of psychological interventions is common in the treatment of chronic pain sufferers who deal with varying degrees of emotional distress. Cognitive-behavior therapy (CBT), which teaches how to modify your thoughts, emotions and behavior, is the most commonly used and studied psychological intervention. One study comparing CBT, biofeedback and vestibulectomy in women with PVD found that vestibulectomy was the most effective in decreasing pain during intercourse, and that CBT and biofeedback were also effective to a lesser extent. At the 2.5 year follow-up, however, pain ratings were not significantly different in women in the CBT and vestibulectomy groups. Another study, comparing the efficacy of CBT to topical cortisone cream, found that women in the CBT group experienced greater pain relief than those who used the cream. At the study's conclusion, women in the CBT group also displayed less pain catastrophizing and were more satisfied with their treatment.

Studies of non-CBT individual or group therapy with vulvodynia patients have also shown positive results. Since psychological interventions are non-invasive and appear to be effective, they are recommended in the management of women with vulvodynia.

Alternative Treatments

In recent years, alternative treatments have become more popular in the treatment of chronic pain conditions. There are, however, little data on their efficacy in treating vulvodynia. Recently, the first controlled study using acupuncture in vulvodynia patients was published. Compared to a wait-list control group, subjects treated with acupuncture reported less vulvar pain and less painful intercourse. Acupuncture appears promising, but more research is needed to draw any conclusion on its efficacy for women with vulvodynia. More studies are needed on all alternative treatments, therefore, they are *not* currently recommended for the treatment of vulvodynia.

Multimodal Approach

Two uncontrolled studies have evaluated the efficacy of a multimodal approach in the treatment of women with vulvodynia. One pilot study used a combination of group CBT, physical therapy and regular medical appointments. Study participants reported an increase in knowledge and more tools for managing their pain, as well as improved psychological well-being. A multimodal approach in the treatment of vulvodynia is recommended, although research is essential to determine its efficacy and which components are the most effective.

Medical Options

Numerous medical treatments are prescribed for vulvodynia, but their efficacy is unknown because most studies have not included a control group. For many years, doctors have prescribed lidocaine, a topical anesthetic, for temporary relief before sexual intercourse. Some doctors speculated that daily use of lidocaine might actually lessen vulvar pain on a long-term basis. The only controlled study on the efficacy of lidocaine for long-term vulvar pain relief found that it was

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no more effective than a placebo. Thus, it is not a recommended treatment for vulvodynia.

There has been some interest in using botulinum toxin A (Botox) to treat vulvodynia because it inhibits the release of glutamate and substance P from nociceptors (pain receptors). The only controlled study using Botox injections to treat women with vulvodynia found it was no more effective than a placebo. Two uncontrolled studies, however, found it provided significant pain relief in vulvodynia patients. (In 2015, NVA funded a two-year controlled study of Botox.) Although Botox is not currently recommended as a first-line treatment, it may be considered as a second-line treatment for PVD until further evidence is available.

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SUMMARY OF TREATMENT RECOMMENDATIONS

1. Pelvic floor physical therapy is recommended for the management of vulvodynia.
2. Psychological intervention, especially cognitive-behavior therapy, is recommended for the management of vulvodynia.
3. There are not enough data to make an overall recommendation regarding alternative treatments for the management of vulvodynia at this time, but acupuncture appears to be promising.
4. A multidisciplinary treatment approach is useful in the management of vulvodynia; however, further studies are necessary to determine the efficacy of this approach and which treatments are most important.
5. Lidocaine is not recommended as a *long-term* treatment for provoked vestibulodynia (PVD).
6. Capsaicin is not recommended as a first-line treatment for PVD, but can be considered if other treatments fail.
7. Botulinum toxin A (Botox) is not recommended as a first-line treatment for PVD; however, it may be considered as a second-line treatment for PVD until further clinical trials are conducted.
8. Due to the lack of efficacy of low-dose topical corticosteroids and the potential side effects of high-potency corticosteroids, they are not recommended for the management of PVD.
9. Given the modest efficacy of the small non-controlled trials and lack of randomized controlled trials (RCTs) using interferon alone, it is not a recommended first-line treatment for the management of PVD.
10. Although the results of very small RCTs are promising, larger studies are needed before anti-inflammatory agents can be recommended for the treatment of PVD.
11. Although there is some promising evidence, further studies are needed before hormonal treatments can be recommended for the treatment of PVD.
12. Based on the results of recent RCTs, tricyclic antidepressant medication is not recommended for PVD.
13. At this time, anticonvulsant medication is not recommended for the treatment of PVD, but the results of a multicenter RCT investigating the efficacy of gabapentin will be published soon.
14. Vestibulectomy is recommended as a treatment option for PVD after less invasive measures have been unsuccessful.

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Anti-inflammatory Agents

Researchers have analyzed biopsies of vestibular tissue from women with PVD and noted the presence of pro-inflammatory cytokines, such as interleukin-beta. Specifically, there are elevated tissue levels of interleukin-beta in the hymenal area of PVD patients. Assuming there is an inflammatory component to the condition, many doctors have prescribed anti-inflammatory medication, e.g., topical corticosteroids, for these patients. Data from multiple studies investigating the efficacy of topical corticosteroids in PVD patients have found that they are minimally effective. Some clinicians inject a combination of lidocaine and a corticosteroid under the mucosa of the vulvar vestibule, but it is unclear whether this treatment is effective because no controlled studies of these injections have been done.

Researchers have found an increase in mast cells (mediators of inflammatory responses) in the vestibule of women with PVD. Interferon, a mast cell inhibitor that also downregulates pro-inflammatory cytokines, is another anti-inflammatory agent that has been used to treat PVD. Its efficacy has been studied in one controlled trial, three case series and one case study. Most studies have found a modest improvement in symptoms with submucosal infiltrations of interferon in the vestibular tissue. Further studies are needed to determine whether interferon is an effective treatment for PVD, and it is *not* currently recommended as a first-line treatment.

The efficacy of other anti-inflammatory agents was investigated in two small controlled studies. A double-blinded placebo-controlled study of topical cromolyn found modest improvement in vestibular tenderness and painful sex in seven women with PVD. In a double-blinded placebo-controlled trial with 40 women, the group that received enoxaparin, a type of heparin, showed a greater decrease in vestibular sensitivity at the end of treatment and three months later. Seventy-five percent of women in the treatment group reported at least a 20 percent reduction in pain, compared to only 28 percent of the control group. Larger studies of anti-inflammatory treatments are needed to determine their efficacy in treating PVD.

Hormonal Treatments

A non-placebo-controlled study of 50 women who associated onset of PVD with taking combined oral contraceptives (estrogen and progesterone) found that a topical cream of estradiol .01% and testosterone 0.1% reduced pain scores from 7.5 to 2. Another study found that topical estradiol reduced vulvar pain sensitivity in menopausal women. Although these results are promising for specific subgroups, further studies are needed before hormonal treatments can be recommended for women with PVD.

Oral Medications

Many women with vulvodynia have taken one or more oral medications, such as tricyclic antidepressants and anticonvulsants, that are prescribed for other chronic pain conditions. There is little to no evidence in the literature, however, that these medications are an effective treatment for vulvodynia. There has only been one randomized, double-blind, placebo-controlled trial on the efficacy of an oral tricyclic antidepressant in PVD patients. In this trial, the researcher investigated the efficacy of desipramine (with and without lidocaine) in treating PVD and found it to be no more effective than a placebo. Based on the current lack of evidence supporting their use, tricyclic antidepressants are *not* recommended for the treatment of PVD.

Anticonvulsant medication has been recommended for the treatment of vulvodynia, but convincing evidence to support its use is lacking. Five years ago, NIH funded a multicenter randomized controlled trial on the efficacy of the anticonvulsant gabapentin (Neurontin) for treating PVD. The results of this study will be published in 2017. At this time, anticonvulsant medication is not recommended for women with PVD.

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Remembering Howard Glazer

The members of the NVA executive and medical advisory boards were deeply saddened to learn that Howard Glazer, Ph.D., a longtime NVA medical advisory board member, passed away this summer. We would like to extend our condolences to his family and friends.

Dr. Howard I. Glazer was a clinical psychologist in New York City with a professional practice focus on surface electromyographic feedback in the treatment of pelvic floor muscle dysfunctions and vulvovaginal pain syndromes. He was a clinical associate professor of psychology in the departments of psychiatry, and obstetrics and gynecology, at the Weill Medical College of Cornell University and an associate attending psychologist at New York Presbyterian Hospital. He also was a member of the International Society for the Study of Vulvovaginal Disease.

After graduating from the University of Toronto, Dr. Glazer completed a doctoral degree in neurophysiological psychology at the University of Texas at Austin. He did his postdoctoral training at Rockefeller University in New York City. His background combined neurophysiology/neurochemistry, learning theory, sex therapy, behavioral medicine and electromyography. Dr. Glazer provided individual clinical services, training workshops, and in-office specialty training, and was actively involved in several multi-disciplinary and multinational research projects.

Howard Glazer dedicated himself to helping women with vulvodynia and supported the NVA's efforts from its inception. He was generous with his time and a trusted advisor to our executive director. We will miss him very much.

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Surgery

Surgery, which is usually not performed before women with PVD have tried less invasive measures, has a success rate of 60 to 90 percent, depending on the study. Some preliminary studies have found that the success rate is higher in women with secondary, rather than primary, vestibulodynia. Further studies comparing the efficacy of surgery in these two subgroups are needed.

Given the overall success rate of surgery compared to other treatments, some doctors have questioned why it remains a last resort for PVD patients. One long-term study followed 66 women with severe PVD beginning at diagnosis and ending with successful treatment. Thirty-nine (39) women did not respond to conservative treatment and underwent posterior vestibulectomy, while 27 managed their symptoms with medication. Painful sexual intercourse decreased significantly in both groups, with almost 67 percent of the surgery group and 78 percent of the medication group reporting improvement on this measure. Long-term sexual well-being did not differ between the two groups and 89 percent of women in both groups were satisfied with their treatment. These results indicate that conservative measures might be preferred as a first-line treatment given the invasiveness and long recovery period of vestibulectomy.

Conclusion

Although there are many treatments prescribed for vulvodynia, there is inadequate evidence of their efficacy because few randomized controlled trials have been performed. The treatment recommendations above were based on a thorough review of the vulvodynia literature. In general, treatment begins with conservative measures, but advances to more invasive measures if symptoms are not well-controlled.

(Editor's note: To obtain the Journal of Sexual Medicine article, with a list of references, please contact Gigi Brecheen, NVA Administrator, at gigi@nva.org or 301-949-5114.)■

Pregnancy and Childbirth Experiences of Vulvodynia Patients

Vulvodynia affects females of all ages, with the highest incidence of symptom onset between the ages of 18 and 25. Thus, many women have symptoms of vulvodynia during their child-bearing years. In addition to coping with the pain, many women with vulvodynia have difficulty with or avoid sexual intercourse, lessening the likelihood of conception. Furthermore, doctors may strongly recommend that certain medications be discontinued prior to conception. If a woman thinks that a treatment is relieving her pain, the prospect of discontinuing it is cause for concern, especially if it took years to find a treatment that relieved the pain.

Given the above challenges, do women with vulvodynia delay pregnancy or consider artificial insemination? Researchers Nora Johnson, M.P.H., Eileen Harwood, Ph.D., and Ruby Nguyen, Ph.D., of the University of Minnesota School of Public Health, conducted a study to try to answer that very question. For their study, 18 women with vulvodynia who met certain criteria were interviewed. They had to be (i) English-speaking U.S. residents, (ii) aged 18 to 45 years, (iii) diagnosed with vulvodynia or symptomatic before pregnancy, and (iv) currently less than 15 weeks pregnant or six to 12 months post-partum. Interview questions were designed to obtain a comprehensive overview of thoughts, feelings and concerns about pregnancy and delivery from contemplation of pregnancy through the post-partum period. Specific experiences were assessed, including relationships with clinicians, controlling pain and decision-making about treatment, as well as concerns about pregnancy, childbirth and motherhood.

Characteristics of Participants

All 18 women were Caucasian, ranging in age from 26 to 40, with an average age of 32. Fifty percent had obtained a master's or doctoral degree and nearly all had received at least some college education. All but one participant had been diagnosed with vulvodynia by a health care provider. (One woman had symptoms consistent with a diagnosis of vulvodynia.) Two-thirds had secondary vulvodynia, chronic vulvar pain that begins after a period of pain-free intercourse and/or tampon use. All participants had been in a heterosexual relationship, and 17 of the 18 currently had a male partner. The vast majority (89 percent) were trying to get pregnant at the time they conceived. Eight were pregnant at the time of the interview; 10 were post-partum. For the majority (78 percent), the results were based on their first pregnancy.

Results

Pain Experiences and Anxiety

The experience of pain was unique. It varied in severity, frequency and duration, and often occurred without an identifiable trigger. Symptoms also varied over time.

> '"When I'm having a problem, it can last for several hours and be very severe, and then it disappears as quickly as it came. [After that,] I don't have any pain for days, weeks or months."'

Due to the unpredictability of pain, participants expressed considerable anxiety that the pain might reoccur. For some, anxiety resulted primarily from not understanding what triggered their pain.

> '"I felt like I didn't know how I was going to be from day-to-day. For me, the anxiety of not knowing if I was going to be in pain while I was pregnant was the worst part."'

Others identified what provoked their pain. For these individuals, the cause was usually sexual intercourse, about which they experienced considerable anxiety. This anxiety was unrelated to current pain intensity and resulted from worrying about what might trigger another episode.

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> '"I don't know how to explain it, other than I had excruciating pain for several months and then moderate pain for several months, and pain during and after sex. I don't know if I'll ever be able to have sex without fear of pain."'

Pain Management

Participants were remarkable in their ability to adapt to pain, but expressed concern about finding a way to work through the pain if it worsened during pregnancy. Many searched for information about vulvar pain and used that knowledge to develop a self-management strategy. Several changed the type of clothing they wore to skirts, dresses and loose-fitting pants and stopped using harsh or perfumed soap. Many used over-the-counter products, e.g., topical anesthetic, for pain relief. (Additional self-help tips can be found at www.nva.org/for-patients/self-help-tips/.) Some tried lying down more often, avoiding sexual intercourse and doing physical therapy or muscle-relaxing exercises to cope with pain; others tried a cognitive approach to manage, block, or avoid pain, e.g., practicing positive thoughts or using distraction. Although these methods did not alleviate pain completely, participants felt that these self-care approaches made them better-equipped to participate in their daily activities, including sexual intercourse.

> '"I always have pain with intercourse. In fact, even just manual stimulation or oral sex can cause discomfort, so I always try to use my mind to block out the pain."'

Experience with the Health Care System

Those who were unable to achieve adequate pain relief on their own sought medical care and their experiences were mixed. Some had neutral or positive experiences with health care providers, while others reported having to explain their symptoms to doctors who were dismissive of their complaints and did not offer any treatment options. Research confirms that there is a shortage of providers knowledgeable about treating vulvodynia and that many women are inaccurately diagnosed.

> '"I guess my biggest frustration was how dismissive doctors were. [They] would literally say that it's probably just in my head and maybe I should see a sex therapist."'

Seeking care from specialists was also problematic for participants due to the high cost of specialized treatments and the lack of insurance coverage. They also said that geographic relocation, e.g., attending out-of-town college or moving away for a new job, resulted in an interruption in care.

Timing of Pregnancy

Did vulvodynia affect plans to have children? For the most part, the answer was no. Most participants did not feel that their current pain was enough of a reason to delay childbearing plans.

> '"It's not like you're going to wake up and the pain is gone. 'Okay, now I can have a baby.' You have to deal with it and have the children that you want."'

Others waited until their pain improved and they felt ready to conceive.

> '"When I was burning three weeks out of the month (and not burning during my period), there was no way I would get pregnant. I was not going to do that to myself."'

A few women who were taking prescription pain medication were told to discontinue it prior to pregnancy. They did not report any difficulty terminating the medication. For others, treatment to reduce vulvar pain did play a role in pregnancy timing. Specifically, some stated that they would delay pregnancy if they had

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In Her Own Words

By Sister Mary Anne

In April 2013, I went to my primary care doctor with vulvar burning that both of us thought was a yeast infection. She treated me, but the pain got worse. I took various medications, e.g., Neurontin, Lyrica, and Tramadol, but I had adverse reactions to all of them, as well as to the topical creams.

Five months later, I made a desperate plea to my doctor, saying that I couldn't stand the pain any longer, and she immediately sent me to a gynecologist. She, too, suspected an infection, did a thorough vaginal exam and scheduled a D & C. Then I was sent to a nurse practitioner who specialized in gynecologic and bladder conditions. She was wonderful and knowledgeable, checked for infections, and recommended Aquaphor ointment for the burning. She even suspected shingles, so I took Valtrex. My nurse practitioner also prescribed a painkiller, a combination of hydrocodone and acetaminophen, and I continued Tramadol as needed. Eventually she prescribed Estradiol, a compounded cream, which helped somewhat. I continued to use Aquaphor after urination to relieve the burning sensation. I also applied ice packs after getting up to urinate during the night, which helped me get back to sleep.

By the summer of 2014, my doctors decided that I should go to the Mayo Clinic. I couldn't get an appointment until late October. One day in August I had so much pain I called the clinic crying, and they moved up my appointment to September. I saw a gynecologist, physical therapist and urologist, all of whom were very helpful. The gynecologist diagnosed me with vulvodynia, explaining that it was a chronic condition that could be managed but not cured. He also said it may have been the result of a fall earlier in my life. He gave me lidocaine to numb the area and a brochure to the National Vulvodynia Association (NVA). I read that the NVA was founded by five vulvodynia patients, called for more information and have been a member for the past two years. I appreciate receiving the newsletters that have articles by different specialists and present the latest research findings. I participated in one study and was surprised that it didn't have any questions for women who aren't sexually active.

For the past year, I've been doing pelvic floor therapy with a physical therapist in Louisville. I have found this treatment to be very helpful. I do the recommended exercises every day and use a TENS unit when the pain flares up. I also decided to try acupuncture. I go every other week, because I find that the treatment eases both pain and anxiety. Additionally, I go to a massage therapist twice a month and see a Reiki specialist who recommends vitamins, enzymes, and probiotics to aid digestion. I discovered that the Tramadol had caused severe constipation, so I stopped taking it. With the help of herbal teas and Colace, a stool softener, my bowel function is now fine.

I am no longer on prescription medications for vulvodynia. I take herbal medication that my acupuncturist developed to relieve the burning after urination. I drink it three times a day and it has eliminated pain between urinations and during the night. I do continue to use Aquaphor after each urination to minimize immediate burning. I am very grateful that all these healers have come into my life.■

Please Donate to the NVA

There are many ways that you can help us fulfill our mission. You can write a check or make a credit card donation in response to one of our fundraisers, or in honor of a significant event in your family. You can make a gift of an appreciated asset (stocks, bonds or even works of art), or you can donate an old car. Finally, you can make a bequest to the NVA in your will. If you need any further information, please contact Phyllis Mate at pmate@nva.org.

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found an effective treatment or needed more time for the treatment to work, especially if the pain was severe.

> '"Honestly, if I had gotten treatment when it was very severe, and the medicine had worked, and someone told me to stop the medicine, I would have just stayed on it and not gotten pregnant. That's how severe the pain was."'

Conception

The majority of women were still experiencing vulvar pain at the time they tried to conceive, causing a significant amount of anxiety and apprehension about whether they would become pregnant.

> '"It was a lot harder for me because having sex was so excruciating that I would cry. It was just frustrating to see other people get pregnant right away. We were trying to limit the amount of time and the frequency, so the irritation and burning wouldn't be so bad."'

Only two women in the study used ovulation sticks to increase the probability of conceiving.

Pain Associated with Pregnancy

Nearly everyone interviewed had experienced heightened anxiety about the pain that might occur during pregnancy. Some, however, were optimistic that pregnancy might cure, or at least improve, their vulvodynia. (No studies have been conducted to determine whether pregnancy or delivery has an effect of vulvodynia.) Some did find pain relief during pregnancy, but others experienced an increase in pain. This increase in pain was especially difficult for those who had discontinued successful treatment in order to become pregnant.

> '"I [was] wondering, like, 'oh no…is this how it's going to be after I give birth? Am I going to have to start all over?"'

Pain During Delivery and Post-partum

Regardless of pain levels during pregnancy, almost all participants were concerned about vulvar pain during childbirth. Several participants created a birth plan to minimize or avoid pain, e.g., one woman chose to have an epidural and another chose a Cesarean delivery.

> '"I'm going to request a Cesarean because, if I understand correctly, this condition can worsen through vaginal birth. I don't want it any worse than what it already is."'

Some tried to be optimistic, accepting that childbirth would be painful and hoping that a vaginal delivery might relieve their vulvodynia.

> '"I swear by that vaginal birth. I think it really helped [my symptoms]. You don't realize that you're clenching or that your muscles are tightening. Over a few years of vulvar pain that area gets tight and the stretch of getting a nine-pound baby through the vagina seems to really help. It hurt like crazy when the baby was [coming out], but I would do it all over again."'

Unfortunately, most women did not have a similar experience. The degree of post-partum vulvar pain was variable among participants. For some, the pain was the same as before the pregnancy.

> '"My husband and I have had intercourse since I delivered. It doesn't seem like it's any worse than what it was prior to the baby and the delivery. I was hoping for a miracle; but it looks like I'll have to keep working on it."'

Discussion

The interesting information revealed in this study adds to our understanding of reproductive decision-making among women with vulvodynia. It is clear

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ORAL MEDICATIONS

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In the early 2000s, Pfizer promoted its new anticonvulsant Neurontin (gabapentin) for treating neuropathic pain. Many doctors recommended it for vulvodynia patients who preferred its relatively mild side effects. Other oral medications that were used to treat vulvodynia were the selective serotonin norepinephrine reuptake inhibitors (SSNRIs), a newer class of antidepressants. These medications, such as Effexor and Cymbalta, were often prescribed for patients with neuropathic pain and depression. When the anticonvulsant Lyrica was FDA-approved for seizures, neuropathic pain and fibromyalgia, some doctors began prescribing it for vulvodynia patients, especially those who also had fibromyalgia.

Randomized Controlled Trials

The National Institutes of Health have funded only three randomized controlled trials on the efficacy of oral medications for vulvodynia; there have been two trials of tricyclic antidepressants and one of the anticonvulsant gabapentin. In a study by Candace Brown, Pharm.D., and colleagues, one group of women with vulvodynia took 10 - 20 mg of amitriptyline and another group used a self-management plan. There was no significant difference in pain relief between the two groups and Brown concluded that amitriptyline was ineffective for the treatment of vulvodynia. In a randomized, double-blind placebo-controlled trial, David Foster, M.D., and colleagues, compared the efficacy of desipramine (with or without lidocaine) to placebo in PVD patients and found that neither desipramine nor lidocaine was more effective than placebo for long-term pain relief. Results from a recent multicenter placebo-controlled study, evaluating the efficacy of gabapentin (Neurontin) in PVD patients, will be published in 2017 .

Is My Medication Effective?

Most women with vulvodynia are desperate for relief and will try almost any medication recommended by their doctors until they find an effective treatment. Knowing that a certain medication has been successful in treating other types of chronic pain, and that any treatment has a placebo effect, doctors typically speak positively about the efficacy of the medication they are prescribing. Consequently, the patient feels somewhat optimistic or hopeful that a particular medication will be effective.

Without scientific evidence of their efficacy, many women with generalized vulvodynia and PVD have been taking tricyclic antidepressants and/or anticonvulsants for 10 to 25 years. For the past two decades, when I have asked some of these women whether their medication relieves pain, the most common reply has been, "I think it helps, but I'm not sure." Some women have stayed on a medication for a very long time, not because they're confident that it's effective, but because they are afraid the pain might get worse if they stopped it. Consider the following example of a woman diagnosed with vulvodynia in the 1990s, who described her pain as "severe burning in the vulva." First she took 150 mg of the tricyclic desipramine for five months, which did not relieve the pain. Next, her doctor recommended two pudendal nerve blocks, which reduced the pain to a moderate level. After the blocks, she started the anticonvulsant Tegretol, which was used to treat neuropathic pain. Many years later, while she was still taking Tegretol, the pain became severe again. She tried 3600 mg of Neurontin, which didn't relieve the pain, followed by 150 mg of Effexor, also ineffective. Again, pudendal nerve blocks were administered and the pain subsided. Over 17 years, she had considered discontinuing Tegretol several times, because she had doubts about its effectiveness. She didn't stop it, because of her overwhelming fear that the pain might get worse without it. Three years ago, she finally summoned the courage to stop taking Tegretol and the pain remained the same.

Ideally, doctors should emphasize the importance of keeping a pain diary and establishing a baseline before you start a new medication. Keeping a pain diary isn't

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ORAL MEDICATIONS

(from page 11)

a difficult task, but it requires discipline. To keep it simple, you can rate the pain on a 0 to 5-point scale three times a day, (1 = little pain, 3 = moderate, 5 = severe) and describe what you were doing at the time. Many medications used for vulvodynia require weeks to achieve a therapeutic level, so you can even start a pain diary on the first day you take a new medication and use the first 10 days as a baseline.

A Dilemma for Women with PVD

A group of vulvodynia specialists recently reviewed the evidence on the effectiveness of all vulvodynia treatments. They concluded that tricyclic antidepressants are not effective for PVD and that there is insufficient evidence to recommend anticonvulsants for PVD, pending the results of future clinical trials (*see* Recent Recommendations, p. 5). What should these women do if they've been taking one or more of these medications for years or recently started one? I would suggest making an appointment with the doctor who prescribed the medication, especially if you haven't experienced any pain relief. If you have not been keeping a pain diary, start today and take it to your next appointment. It's a good starting point for discussing the effectiveness of the oral medication(s) you are taking and whether it's time to consider other options, such as pelvic floor muscle therapy or possibly surgery. Alternatively, if you're taking oral medication and think it's effective, you can stay the course and await the results of future clinical trials.

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PREGNANCY

(from page 10)

that pain-related experiences prior to pregnancy influenced decisions regarding childbearing. The women in this study appeared to reach an acceptable level of pain prior to pursuing a pregnancy. However, certain limitations to this study decrease our ability to extrapolate these results to the general population. First, the study didn't differentiate vulvodynia subtypes. Women with constant pain, as opposed to those with provoked pain, may make different decisions regarding childbearing. Also, partner support can impact decision-making and was not analyzed in this study. Lastly, the small sample size may bias the results.

Each woman with vulvodynia needs to make the best pregnancy and childbirth decisions for herself. For this reason, the National Vulvodynia Association developed a resource titled, *Vulvodynia, Pregnancy and Childbirth.* This booklet includes information on conception through the post-partum period. In addition to describing alternate methods of conception and childbirth options, it offers advice on minimizing vulvar pain during pregnancy. NVA members can access the booklet online at www.nva.org/shg.

Reference

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