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NVA News

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Self-Misdiagnosis of Vaginal Infections

An Interview With Daron G. Ferris, M.D.

Dr. Ferris is a professor in the family medicine and obstetrics and gynecology departments at the Medical College of Georgia in Augusta. He currently serves as the president of the American Society for Colposcopy and Cervical Pathology.

NVA: How frequently are vaginal yeast and bacterial infections diagnosed by health care providers in the United States?

DF: Vaginitis is one of the leading problems encountered by healthcare providers in the United States, resulting in about 10 million office visits to gynecologists per year. Because of the availability of over-the-counter (OTC) medications for treating vulvovaginal Candida (also referred to as yeast), Bacterial Vaginosis is now the leading type of vaginal infection diagnosed by clinicians, followed by Candida and Trichomonas vaginitis.

NVA: How accurate are health care providers in their diagnosis of these infections?

DF: Unfortunately, clinicians accurately diagnose yeast infections only 50 percent of the time using microscopy, as compared to a yeast culture. Because some yeast is present as a tiny round spore, it is extremely difficult for a clinician to diagnose this type of infection using a microscope. Although cultures are significantly more sensitive in detecting yeast infections, the increased cost of this test and delay in diagnosis minimize its use in complicated cases. However, the vast majority of infections can be diagnosed in the office by simply using a strip of pH paper, performing a saline wet prep and potassium hydroxide microscopic examination, plus considering the patient's history and findings seen during the pelvic examination.

NVA: Can these infections become recurrent or chronic?

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Classifying Vulvar Vestibulitis as a Pain Disorder

By Caroline F. Pukall, Ph.D., Alina Kao, Ph.D. Candidate, Yitzchak Binik, Ph.D.

Dr. Pukall is an assistant professor of psychology at Queen's University in Kingston, Ontario. Ms. Kao is a doctoral candidate in the psychology department at McGill University, and Dr. Binik is a professor of psychology at McGill University and the director of the Sex and Couple Therapy Service at the Royal Victoria Hospital in Montreal, Quebec.

Vulvodynia affects an estimated 16 percent of women in the general population and the majority of these women are thought to suffer from the subtype known as vulvar vestibulitis syndrome (Harlow and Stewart, 2003). The pain of vulvar vestibulitis syndrome (VVS) is localized, occurring at the entrance of the vagina (the vulvar vestibule) in response to contact or pressure. The pain is typically described as "burning" and "sharp" and can occur in response to both sexual and non-sexual activities. Most health care providers quite reasonably search for a physical cause for this pain. Unfortunately, no simple physical cause has yet been found. As a result, some women are referred to

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DF: Yes, most certainly. Recurrent Vulvovaginal Candida (RVVC) is defined as four or more attacks of symptomatic Candida Vaginitis in a 12-month period. Recurrent Bacterial Vaginosis and RVVC are more common than the general population would expect. In fact, at large vaginitis referral centers, they are the most frequently occurring disorders exhibited by patients. However, in the average clinician's office, these chronic diagnoses tend to be overlooked.

NVA: How many women in the United States suffer from chronic vaginal infection?

DF: Because such data are not routinely collected, it is impossible to estimate how many women suffer from chronic vaginal infections. Nevertheless, the experience of many clinicians suggests that chronic or recurrent vaginal infections are not unusual. One expert estimates that RVVC affects approximately 5 percent of the population.

NVA: Do most women accurately self-diagnose yeast and bacterial infections?

DF: Because of the availability of OTC medications to treat vulvovaginal Candida, many women self-diagnose and treat without seeing a healthcare provider. Millions of dollars are spent each year by women who are treating a self-diagnosed condition. Unfortunately, most women are unable to reliably tell when they have a yeast infection.

NVA: Do women often misuse OTC products to treat suspected yeast infections?

DF: In my experience, misuse of OTC medications is a common practice. Many women present to the clinic after trying two or three courses of the same medication for yeast, or several different products, before finally seeking a professional evaluation. In fact, a clinical trial that we conducted a few years ago demonstrated that two-thirds of women who purchased OTC yeast medication for self-diagnosed vulvovaginal Candida did not have a yeast infection. In our study, 33 percent of women were confirmed to have yeast infections, 19 percent had bacterial vaginosis, 21 percent had multiple types of vaginitis, 14 percent did not have an infection and 11 percent had other diagnoses, which included various vulvar conditions. It was noted that women with a previous clinically based diagnosis of yeast infection were no more accurate in their diagnoses than women without a prior clinical diagnosis of yeast infection. (In approving OTC medications for yeast infections, the FDA assumed that having had prior yeast infections would enable women to appropriately use these products.) Furthermore, women who reported that they read the package label were no more likely to have a yeast infection than were women who did not read the label.

NVA: What are the repercussions of misusing OTC medications to treat suspected vulvovaginal infection?

DF: First of all, self-misdiagnosis and treatment may delay the correct diagnosis of a more serious

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The National Vulvodynia Association is an educational, nonprofit organization founded to disseminate information on treatment options for vulvodynia. The NVA recommends that you consult your own health care practitioner to determine which course of treatment or medication is appropriate for you.

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condition. In the trial above, one woman purchased medication for a presumed yeast infection only to eventually discover that she had a pelvic inflammatory infection that required hospitalization and intravenous antibiotics. Generally, misdiagnosis does not lead to such serious repercussions. In addition to delaying treatment of more serious conditions, over-the-counter agents may minimize symptoms of different types of vaginitis, making them harder to diagnose. Furthermore, there is a risk of an allergic or contact dermatitis in reaction to the OTC product.

NVA: What are the classic signs and symptoms of Bacterial Vaginosis, Candida and Trichomonas?

DF: Approximately 50 percent of women with Bacterial Vaginosis do not realize that they have it. The remaining 50 percent may notice an odor, particularly noted at the time of menstruation and after sexual intercourse, if not using a condom. Some may notice an off-white, thin vaginal discharge with minimal itching or irritation. In contrast, Candida is likely to cause intense itching of the vulvar region, swelling or redness of the vulva, but generally no odor is noted. Women may also notice a thick white vaginal discharge. By contrast, Trichomonas may produce a thin, watery, yellow vaginal discharge, as well as itching in some women.

NVA: If a woman is experiencing abnormal vulvovaginal symptoms, what would you recommend?

DF: If it's the first occurrence of vulvovaginal disease or infection, she should visit her healthcare provider. In the case of recurrent vulvovaginal Candida, once a clinician confirms the infection and educates the patient about her condition, then perhaps in the future the patient may be able to self-diagnose and treat it. However, before beginning self-diagnosis and treatment, I strongly recommend that when the second infection occurs and is presumed to be caused by yeast, the patient be evaluated by a clinician again (to determine whether she does have the ability to render the proper diagnosis). After the confirmation test, a decision should be made between the patient and clinician regarding the patient's ability to self-diagnose and use OTC products in the future. If a woman is pregnant, has fever, pelvic pain or other systemic symptoms, she should always see her healthcare provider first.

NVA: Many women with vulvodynia are repeatedly misdiagnosed with yeast infections. If a woman suspects that there is more going on than a yeast or bacterial infection, what would you recommend?

DF: Well, certainly a woman with pain in the vulvar area should consult a knowledgeable healthcare provider. Vulvodynia is frequently misdiagnosed and occasionally vulvovaginal yeast mimics vulvodynia.

NVA: What questions should a woman ask her healthcare provider to determine whether she has been correctly diagnosed and been prescribed appropriate treatment?

DF: Telephone diagnoses should be avoided unless the circumstances prohibit the patient from presenting for a proper examination. A proper assessment should consist of a detailed history, a short pelvic examination and finally a laboratory examination of clinical specimens. Accurate diagnoses can be rendered only after all three of these important steps. Clearly, if a woman notices that her healthcare provider has chosen not to perform a comprehensive evaluation, then she should question the rationale of that healthcare provider. For women with vulvodynia, it is reasonable to query the clinician as to whether the symptoms may represent vulvodynia instead of a yeast infection or other condition. Many healthcare providers are not familiar with vulvodynia or its management, and raising the question itself may generate additional investigation by the clinician.

NVA: Do you have any other advice/recommendations for women who are experiencing abnormal vulvovaginal symptoms?

DF: In summary, most causes of vaginitis can be easily diagnosed by healthcare providers using proper protocol. However, the various skills and training of a clinician may impact his/her ability to render an

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accurate diagnosis. Women should know that being diagnosed and treated on the phone is risky. It is estimated that only 10 percent of women who are evaluated on the phone receive appropriate treatment. Although it is an inconvenience to visit your healthcare provider, proper care requires collection of important historical data, examination for various signs of different vulvovaginal conditions, and then appropriate laboratory testing. A careful balance must be achieved between self-diagnosis and treatment, and clinician-conducted assessment.

References:

Ferris DG, Dekle C, Litaker MS. Women's use of over-the-counter antifungal medications for gynecologic symptoms. *J Fam Pract* (1996) 42:595-600.

Ferris DG, Nyirjesy P, Sobel JD, Soper D, Pavletic A, Litaker MS. Over-the-counter antifungal misuse associated with patient-diagnosed vulvovaginal candidiasis. *Obstet Gynecol* (2002) 99:419-25.■

VVS

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mental health professionals to be assessed for possible psychological causes of the pain, rather than being treated for the psychological and sexual effects of the pain.

One reason this happens is that dyspareunia, the distinguishing characteristic of VVS, is currently classified in the Diagnostic and Statistical Manual of Mental Disorders (DSM) as a sexual dysfunction rather than as a pain disorder. The DSM defines dyspareunia as a "recurrent and persistent genital pain associated with sexual intercourse" (p. 556). This definition is based on the observation that VVS typically interferes with sexual intercourse; difficulty with sexual intercourse because of the pain is often the main concern of women with VVS seeking clinical attention. Unfortunately, this focus on interference with intercourse has drawn attention away from the major symptom of a woman with dyspareunia, i.e., the pain. To reinforce this point, the DSM explicitly excludes dyspareunia from the category of Pain Disorder. Aside from this exclusion, dyspareunia meets all the criteria for Pain Disorder, including the following: "pain in one or more anatomical sites [that] is the predominant focus of the clinical presentation and is of sufficient severity to warrant clinical attention" and "the pain causes significant distress or impairment in social, occupations, or other important areas of functioning" (p. 503). This leads us to ask, isn't sexuality an important area of functioning?

The DSM also indicates that there are two types of pain: sexual and non-sexual. Many chronic pain conditions, e.g., low back pain and fibromyalgia, interfere with and disrupt sexual functioning, but are not considered sexual dysfunctions. In addition, the genital pain experienced by women with dyspareunia is not limited to sexual activity, i.e., many women with VVS also experience pain during tampon insertion and gynecological examinations. This finding removes the pain of dyspareunia from a purely sexual context.

Our research group has adopted a pain perspective of dyspareunia that views the pain as a multidimensional experience, including both physical and psychological factors. While adopting this approach necessitates that pain is the major focus of assessment and treatment, psychosocial, psychological, behavioral, and sexual factors are given great importance because they play a crucial role in the disability resulting from the pain, as well as in pain perception and control. This article focuses on research supporting a pain conceptualization of VVS.

Empirical Evidence

There has been considerable recent research on pain-related processes in VVS. Recent studies indicate that there are abnormalities in the vestibules of women with VVS consistent with altered sensory

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The Evolution of Vulvodynia Terminology: Clarifying the Issue

By Chris Veasley and Stanley Marinoff, M.D.

Chris Veasley is director of research and professional programs for the NVA and Dr. Stanley Marinoff is a member of the NVA's medical advisory board.

Evolution of the Term *Vulvodynia*

Although the medical community didn't begin to address vulvodynia as a condition warranting serious attention until the late 1980s, the symptoms were first mentioned in the medical literature in 1880. Eight years later, Alexander J.C. Skene, M.D., described *hyperaesthesia of the vulva* in a medical textbook on the diseases of women. He wrote, "This disease... is characterized by a supersensitiveness of the vulva. Pruritus [itching] is absent, and on examination of the parts affected, no redness or other external manifestation of the disease is visible. When, however, the examining finger comes in contact with the hyperaesthetic part, the patient complains of pain, which is sometimes so great as to cause her to cry out. Sexual intercourse is equally painful, and becomes in aggravated cases impossible." In 1928, Howard Kelly, M. D., further described "exquisitely sensitive deep-red spots in the mucosa of the hymenal ring as a fruitful source of dyspareunia."

After Kelly's publication, no mention of the condition appeared in medical texts for five decades. During this time, the medical community, and society in general, paid little attention to female conditions and topics involving sexuality. Then, at the 1975 World Congress of the International Society for the Study of Vulvovaginal Disease (ISSVD), Dr. Esther Weisfogel urged members to investigate a problem that she called "the burning vulva syndrome." In response to her request, in 1982 the Society surveyed their membership about the condition and then held a seminar to discuss the issue.

As a result of this discussion, the ISSVD proposed the term v*ulvodynia* as a global term to describe pain of the vulva, specifically defining it as, "chronic vulvar discomfort, especially that characterized by the patient's complaint of burning (and sometimes stinging, irritation or rawness)." They further stated that vulvodynia was a symptom rather than a diagnosis and that it might have multiple causes. It was recommended that the term *burning vulva syndrome* be used to describe cases of vulvodynia in which no physical cause was found or that persisted despite appropriate treatment for associated physical findings. Then, at the 1985 World Congress, Dr. Peter Lynch suggested that the term *burning vulva syndrome* be replaced by the term *vulvodynia,* "only for cases which lack a demonstrable etiology." He noted that the term *vulvodynia* would be analogous to *glossodynia*, a term used to describe chronic, idiopathic pain in the tongue. Consequently, the term *burning vulva syndrome* disappeared from the medical literature.

Vulvodynia Subsets

In the late 1970s, Dr. Marilynne McKay evaluated 52 patients and was the first to delineate five distinct subsets of *vulvodynia.* These subsets were: (1) vulvar dermatoses, (2) cyclic candidiasis, (3) squamous papillomatosis, (4) vulvar vestibulitis and (5) essential vulvodynia ("essential" means without a known cause). McKay further stated that these subsets might occur alone, simultaneously or sequentially, and that treatment for one type might affect the onset of another. After 1985, when the term *vulvodynia* replaced *burning vulva syndrome,* it became synonymous with chronic, idiopathic (without known cause) vulvar pain, thereby excluding three of the five subsets: vulvar dermatoses, cyclic candidiasis and squamous papillomatosis. The only two subsets described by McKay that remained within the new definition of *vulvodynia* were the idiopathic conditions, i.e., *essential vulvodynia* and *vulvar vestibulitis syndrome.*

Essential (Dysesthetic) Vulvodynia

In her 1988 publication on vulvodynia, McKay suggested that essential vulvodynia could be considered a dysesthesia, since a single nerve is causing localized discomfort, such as in postherpetic neuralgia and

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Terminology

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glossodynia. She noted that essential vulvodynia patients show no significant, visible changes on physical examination and complain of unremitting burning localized to the vulva. In 1992, she suggested that the term *dysesthetic vulvodynia* replace *essential vulvodynia*, because the word *dysesthetic* refers to "nonspecific burning with a neurologic basis."

Vulvar Vestibulitis or Vestibulodynia

In 1987, Eduard Friedrich, Jr., coined the term *vulvar vestibulitis syndrome* to describe women who present with, "(1) severe pain on vestibular touch or attempted vaginal entry, (2) tenderness to pressure localized with the vulvar vestibule and (3) physical findings confined to vestibular erythema of various degrees. The classic patient with pure vulvar vestibulitis syndrome does not have symptoms unless the area is touched or manipulated, for example, when sexual relations are attempted. The patient only experiences burning or discomfort when pressure is applied to the vulva.

In 1997, Dr. Jacob Bornstein introduced the term *vestibulodynia* to describe a subset of women diagnosed with vulvar vestibulitis, who presented with a combination of constant vulvar pain of vestibular origin and dyspareunia, or painful intercourse. He proposed that vestibulodynia might be a severe subset of vestibulitis, or a novel syndrome involving a combination of vestibulitis and constant, spontaneous vulvodynia.

In 1999, the ISSVD suggested that the term *vestibulodynia* replace *vulvar vestibulitis,* because the suffix "-itis" indicates the presence of inflammation and an inflammatory etiology had not been proven. In addition, subsequent research by the ISSVD Vulvar Pain Terminology Committee determined that *vestibulitis* could not be located in the International Classification of Disease (ICD-9) manual.

Current ISSVD Classification

Despite ISSVD's efforts to define vulvodynia, a great deal of confusion has existed in the medical community regarding its diagnosis. At the 1999 and 2001 ISSVD World Congresses, some members proposed that the term *vulvar dysesthesia* replace *vulvodynia* and provisional terminology was put in place. However, it was not widely accepted by the medical community because the definition of dysesthesia includes sensations other than pain. Following the 2001 ISSVD World Congress, the Vulvar Pain Terminology Committee was asked to review nomenclature and diagnostic manuals, such as the International Classification of Disease (ICD-9) manual. The committee also corresponded with other organizations involved in studying the nomenclature of pain disorders. They found both *vulvodynia* and *"pain, vulva"* referenced in the ICD-9 manual under code 625.9 (unspecified pain and other symptoms associated with female genital organs), whereas *vulvar dysesthesia* could not be located in either the index or the text of the manual. *Dysesthesia* was mentioned only in code 782.0 and referred to skin, but not mucous membrane. It was characterized as a disturbance of skin sensation, e.g. numbness, tingling, burning or prickling, and it did not refer to genital organs.

Therefore, at the ISSVD 2003 World Congress, the committee discouraged the use of the term *vulvar dysesthesia* and proposed reinstatement of *vulvodynia,* which is referenced in the ICD-9 manual and easily recognized by both the medical and patient communities. *Vulvodynia* was officially defined as, "vulvar discomfort, most often described as burning pain, occurring in the absence of a relevant specific infectious, inflammatory, neoplastic or neurologic disorder."

In the years preceding the 2003 Congress, the ISSVD membership had debated whether the subsets of vulvodynia should be classified by location (generalized vs. localized) or stimulus (provoked vs. unprovoked). In 2003, they decided to classify subsets first, by location, and second, by stimulus, with the following categories: 1) *generalized vulvodynia* (replaces dysesthetic vulvodynia), defined as the involvement of the whole vulva and 2) *localized vulvodynia,* defined as involvement of a portion, or component of the vulva, such as the vestibule, clitoris, hemivulva, or other specified site (*see Table*). Both localized and generalized vulvodynia can be further categorized as provoked (sexual contact, non-sexual contact or both), unprovoked (spontaneous) or mixed (provoked and unprovoked). Furthermore, *provoked vestibulodynia* (formerly vestibulitis) was newly defined as introital dyspareunia associated with discomfort on vestibular

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ISSVD Classification of Vulvar Pain (2003)

Vulvar Pain Related to a Specific Disorder
1) Infectious (e.g., candidiasis, herpes, etc.)
2) Inflammatory (e.g., erosive lichen planus, immunobullous disease, etc.)
3) Neoplastic (e.g., Paget's disease, squamous cell carcinoma, etc.)
4) Neurologic (e.g., herpetic and postherpetic neuralgia, etc.)

Vulvodynia (defined as vulvar discomfort, most often described as burning pain, occurring in the absence of a relevant specific infectious, inflammatory, neoplastic or neurologic disorder)
1) Generalized (involvement of the whole vulva)
    a. Provoked (sexual contact, nonsexual contact, or both)
    b. Unprovoked (spontaneous)
    c. Mixed (provoked and unprovoked)
2) Localized - involvement of a portion, or component, of the vulva (vestibulodynia, clitorodynia, hemivulvodynia, etc.)
    a. Provoked (sexual contact, nonsexual contact, or both)*
    b. Unprovoked (spontaneous)
    c. Mixed (provoked and unprovoked)

*Provoked vestibulodynia was formerly referred to as vulvar vestibulitis.

contact. (Pain in response to any type of contact, e.g., clothing, tampon insertion, cotton tip test, finger tip pressure, etc., are also included in this definition.)

Conclusion

A precise classification scheme for vulvodynia and its subsets ensures that the clinical and scientific communities will uniformly diagnose and reference these conditions, and is critical to furthering research in the field. It is our hope that the current terminology will be considered useful and accepted within the greater medical community, because uniformity in the classification of vulvodynia is essential for discovering its causes and developing effective treatments.

References:

Bornstein, J., Zarfati, D., Goldshmid, N., Stolar, Z., Lahat, N. and Abramovici, H., Vestibulodynia - a subset of vulvar vestibulitis or a novel syndrome. *Am J Obstet Gynecol* (1997) 177:1439-1443.

Freidrich, Jr., E.G., Vulvar vestibulitis syndrome. *J Reprod Med* (1987) 32:110-114.

Kelly, H.A., Dyspareunia. In: H.A. Kelly, *Gynecology.* D. Appleton & Co., New York (1928), pp. 235-239.

Lynch, P.J., Vulvodynia: a syndrome of unexplained vulvar pain, psychologic disability and sexual dysfunction: The 1985 ISSVD Presidential Address. *J Reprod Med* (1986) 31: 773-780.

McKay, M., Burning vulva syndrome: report of the ISSVD task force. *J Reprod Med* (1984) 29:457.

McKay, M., Vulvar vestibulitis and vestibular papillomatosis: Report of the ISSVD committee on vulvodynia. *J Reprod Med* (1991) 36: 413-415.

McKay, M., Subsets of vulvodynia. *J Reprod Med* (1988) 33:695-698.

McKay, M., Vulvodynia: Diagnostic patterns. *Dermatologic Clinics* (1992) 10: 423-433.

Skene, A.J.C., Diseases of the external organs of generation. In: *Treatise on the Diseases of Women.* D. Appleton and Co., New York (1888) p.77-99.

VVS

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processing, a characteristic often seen in patients with other chronic pain conditions. There is a heightened innervation of intraepithelial nerve fibers, an increase in blood flow and erythema (redness), the presence of calcitonin gene-related peptide (a peptide that exists in pain nerves), and an increase in vanilloid receptor-1 expression (a receptor present in pain fibers). These tissue properties should lead to an increased sensitivity in response to vestibular pressure, consistent with the clinical picture of provoked pain in women with VVS. Taking a cotton-swab, for example, and touching different areas of the vestibule in a non-affected woman is perceivable but not painful, but the same stimulation to the vestibule of a VVS sufferer is excruciatingly painful. In the pain literature, a painful response to something that is normally not painful is termed "allodynia." Allodynia is characteristic of many chronic pain syndromes, such as neuropathic pain.

Evidence of allodynia in women with VVS comes from a study conducted by our research team (Pukall et al., 2002). First, we developed a set of disposable nylon filaments based on those typically used for sensory measurement in neurology patients. Then, in conjunction with a computer program developed to calculate thresholds, we determined both tactile and pain thresholds in four vestibular areas (i.e., 1, 3, 6, and 9 o'clock around the entrance to the vagina) and over the labia minora in women with VVS and a control group of age-and contraceptive-matched women.

We found that women with VVS were more sensitive to pain around the vestibule and over the labia minora as compared with non-affected women. This finding was not surprising since vulvar pain is the major part of the clinical presentation of VVS. What was unexpected was the finding that women with VVS were also more sensitive to touch in these areas, suggesting that there is a significant shift in terms of their sensitivity to non-painful stimulation as well. The difference in sensitivity was striking; the point at which women with VVS reported pain was at the same level at which control women first reported feeling touch (i.e., evidence of allodynia), and women with VVS were capable of perceiving non-painful stimulation at levels that were imperceptible to non-affected women. In addition, the phenomenon of higher sensitivity to touch and pain was not limited to the vulvar vestibule; women with VVS reported higher sensitivity to touch and pain in several non-genital areas of the body (e.g., forearm). That is not to say that women with VVS suffer from spontaneously experienced chronic pain all over their bodies – their primary complaint is the vestibular pain and that is where the biggest difference in sensitivity is found. What this indicates is that women with VVS may have a more generalized sensory abnormality than researchers initially believed.

Although the idea of a generalized sensory abnormality in women with VVS is just beginning to be studied, controlled studies support it. VVS patients are more sensitive to non-genital touch, pain, and pressure, and report more pain-related complaints than non-affected women. Reports consistent with these findings have been found in patients with other pain syndromes, such as arthritis and migraine, and support the importance of the pain component in VVS. In addition, these findings have been linked to a possible genetic contribution in VVS; women with VVS have a genetic profile that has been associated with a severe and prolonged pro-inflammatory immune response (Witkin et al., 2002) that has been associated with a generalized increase in sensitivity.

Further evidence supporting a generalized increase in sensitivity has recently been documented in our laboratory using functional magnetic resonance imaging (fMRI), a brain imaging technique that measures the amount of neural activity in response to external stimulation. While subjects' brains were being scanned, we used a vulvalgesiometer, a mechanical device with a cotton-swab tip that exerts standardized pressures, to apply mild and moderate pressure to the posterior portion of the vestibule in women with VVS and non-affected women. We compared regions of neural activity between both groups and found that women with VVS showed more significant activations than control women, especially in the insular and prefrontal cortices. These brain areas are important in pain

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Vulvodynia Highlighted at National Meeting

In May 2004, the 52nd annual meeting of the American College of Obstetricians and Gynecologists (ACOG) took place in Philadelphia. More than 3,700 health care providers specializing in the treatment of obstetrics and gynecology attended, seeking information from leaders in the field.

The NVA was one of only a few nonprofit organizations that could afford an exhibit booth at this important conference, thanks to the generosity of longtime supporter Mona Schlossberg. Staff members Christin Veasley and Phyllis Mate spoke with hundreds of health care providers who visited the NVA's booth. Two NVA members from the Philadelphia area, Loretta Sernekos and Susan Beckman, also volunteered their time to answer health care providers' questions and distribute patient guides and professional education materials. (Thank you, Loretta and Susan!)

Exhibiting at the conference were more than 350 pharmaceutical and medical device companies showcasing their products. A few of the pharmaceutical companies had previously contacted NVA, expressing an interest in developing novel treatments for vulvodynia. During the conference, Christin Veasley met with research and development representatives from these companies to discuss their current research projects and potential treatments.

As part of the proceedings, vulvovaginal specialists Hope Haefner, M.D., director of the University of Michigan Center for Vulvar Diseases, David Scott Miller, M.D., director of gynecologic oncology at the University of Texas Southwestern Medical Center, and dermatologist Lynette Margesson, M.D., adjunct assistant professor of obstetrics, gynecology and medicine at Dartmouth Medical School gave an eight-hour course on recent developments in the field of benign vulvar and vaginal disorders. The course covered vulvar cancer, vulvar dermatoses, vaginitis and vulvodynia.

Haefner began her vulvodynia presentation with a summary of the new terminology that was adopted last year by the International Society for the Study of Vulvovaginal Disease (see *Terminology* on page 5). She commented that there are conditions other than vulvodynia that can have a vulvar pain component, such as herpes, endometriosis and carcinoma. Haefner reviewed possible causes of vulvodynia, including inflammatory mechanisms, genetic/immune factors and neuropathy, and closed her presentation with a description of current treatments for vulvar pain patients.

In addition to clinical workshops, ACOG hosts an annual film festival that presents films dealing with gynecologic and obstetric issues. A patient education film created by Dr. Dilek Avci entitled, "Finding Answers about Vulvodynia," won second prize at this year's meeting. Dr. Avci works with NIH vulvodynia grant recipient Gloria Bachmann, MD, associate dean of women's health and professor of obstetrics and gynecology at Robert Wood Johnson Medical School. The film is directed at women who are waiting for an annual gynecological examination in their health care provider's office and covers all aspects of vulvodynia, including how to perform a pelvic exam on a woman experiencing vulvar pain. Bachmann is hopeful that, "by allowing women to view this film before they visit with their provider, they will have a better understanding of the condition and how to approach the topic during their examination." The 17-minute film will be made available for purchase from ACOG in August 2004 ($55 for ACOG members and $85 for non-members, plus S&H) and can be ordered by contacting ACOG's distribution center at 800-762-2264 (please reference item #AVL-178). ■

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Thank You

We gratefully acknowledge the services of Dawn Danby who so ably illustrated the article entitled, "Pudendal Nerve Block in the Treatment of Vulvodynia" in the Spring 2004 *NVA News*. We sincerely apologize for the omission.

VVS

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processing and in the phenomenon of allodynia. These results suggest that women with VVS exhibit an augmentation of genital sensory processing and reinforce the importance of the pain component in VVS.

In addition to our pain conceptualization of VVS, we also emphasize the importance of psychosocial factors in the maintenance and/or exacerbation of the pain. Factors such as psychological distress, anxiety, depression, pain hypervigilance (an increase in attention towards painful stimuli), and pain catastrophization (a negative, exaggerated response to pain) have been found in women with VVS; they have also been found in other chronic pain patients. Although it is impossible to tell whether people with these characteristics are more likely to develop a pain syndrome or whether they develop as a result of having a pain syndrome, these factors can be successfully targeted concurrently with pain management therapy.

In terms of sexual functioning, it is not surprising that women with VVS report lower frequency of intercourse; lower levels of sexual desire, arousal, and pleasure; and less orgasmic success than non-affected women. Disturbance of sexual function also occurs in other chronic pain patients, although sexual functioning has not been studied extensively in this population. It is interesting to note that even after successful treatment of VVS, these women do not return to a normal level of sexual functioning (Bergeron et al., 2001), supporting the notion that multiple components, in addition to the pain, must be addressed in treatment.

Improving Treatment for Women with VVS

From a clinical psychologist's perspective, conceptualizing VVS solely as a sexual dysfunction limits the range of treatments to be considered. Typically, women with VVS undergo a "serial unidisciplinary" treatment strategy beginning with medical interventions; if these interventions are unsuccessful, psychotherapy/sex therapy sometimes is recommended; if therapy fails, surgery often follows.

Conceptualizing VVS using the chronic pain model is quite different. The typical starting point for treatment is multidisciplinary, and consistent with this approach, multiple modalities of treatment are often used simultaneously. Pain control is the major goal and all appropriate methods are attempted whether they are linked to the presumed pain mechanism or not. Applying the pain model to VVS expands the range of treatments that can be considered and encourages a multidisciplinary approach. For example, in addition to medical intervention, it would be reasonable to consider pelvic floor physical therapy, acupuncture, and hypnosis. It might also be appropriate to add cognitive behavioral therapy to the treatment regimen.

A previously published randomized treatment outcome study from our research group (Bergeron et al., 2001) compared the relative efficacy of vestibulectomy, pelvic floor biofeedback, and group cognitive-behavioral pain management for the treatment of VVS. Women suffering from VVS were randomly assigned to one of these treatments after a 6-week baseline period and were followed for a period of 2.5 years post-treatment. The major outcome variables were measures of pain and sexual

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New Patient Self-Help Guide

The NVA, through a grant from Purdue Pharma, L.P., has published a patient guide, *I Have Vulvodynia...What Do I Need to Know?* This comprehensive guide is free to all current NVA members if ordered as an e-book (PDF file) by sending an e-mail to gigi@nva.org. (Put "patient guide" on subject line and include your full name in the e-mail). For a printed copy, please send a $6 check or money order to NVA Patient Guide, PO Box 4491, Silver Spring, MD 20914-4491. Health care providers may review the guide prior to purchasing copies by e-mailing chris@nva.org.

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functioning. All treatment groups benefited from significant improvements, which were maintained at follow-up: vestibulectomy resulted in an average pain reduction of approximately 70 percent, while group cognitive-behavioral pain management and pelvic floor biofeedback resulted in pain reductions of approximately 40 percent. All groups improved equally and significantly on measures of sexual functioning; however, post-treatment levels on these measures (for example, intercourse frequency) did not approximate population norms. These data suggest that it is possible to reduce the pain of VVS through different treatment modalities, all of which were administered by different professionals and which presumably work through different therapeutic mechanisms. Our conclusion is that the study's results support a multidisciplinary, pain-oriented approach to the treatment of VVS.

Conclusion

We suggest that vulvodynia be evaluated from a pain perspective, with an emphasis on physical, psychological, relational, sexual, behavioral, and cognitive consequences. This approach will aid in the application of pain-related treatments to vulvodynia. Given the physiological, cognitive, affective, and interpersonal complexity of genital pain, it is likely that no one 'cure' will be found. Thus, we propose a multi-modal treatment approach for all types of vulvodynia, tailored to each patient, and including a careful assessment of various aspects of the individual's pain experience. Although pain reduction is an important goal, sexual functioning should also be addressed simultaneously through individual or couple therapy, since it has been shown that pain reduction does not necessarily restore sexual functioning.

Selected References

Bergeron, S., Binik, Y.M., Khalifé, S., Pagidas, K., & Glazer, H. (2001). A randomized comparison of group cognitive-behavioral therapy, surface electromyographic biofeedback, and vestibulectomy in the treatment of dyspareunia resulting from vulvar vestibulitis. *Pain*, 91, 297-306.

Danielsson, I., Sjöberg, I., & Wikman, M. (2000). Vulvar vestibulitis: Medical, psychosexual and psychosocial aspects, a case-control study. *Acta Obstetrica Gynecologica Scandinavica*, 79, 872–878.

Granot, M., Friedman, M., Yarnitsky, D., & Zimmer, E.Z. (2002). Enhancement of the perception of systemic pain in women with vulvar vestibulitis. *British Journal of Obstetrics and Gynecology*, 109, 863-866.

Harlow, B.L., & Stewart, E.G. (2003). A population-based assessment of chronic unexplained vulvar pain: Have we underestimated the prevalence of vulvodynia? *Journal of the American Medical Women Association*, 58, 82-88.

Pukall, C.F., Binik, Y.M., Khalifé, S., Amsel, R., & Abbott, F.V. (2002). Vestibular tactile and pain thresholds in women with vulvar vestibulitis syndrome. *Pain*, 96, 163-175.

Pukall C.F., Binik Y.M., & Khalifé S. (2004). A new instrument for pain assessment in vulvar vestibulitis syndrome. *Journal of Sex and Marital Therapy*, 30, 69-78.

Pukall, C.F., Payne, K.A., Kao, A., Khalifé, S., & Binik, Y.M. (in press). Dyspareunia. In: R. Balon & R.T. Segraves (eds). Handbook of Sexual Dysfunction. New York: Marcel Dekker Inc.

Pukall, C.F., Strigo, I.A., Binik, Y.M., Amsel, R., Khalifé, S., & Bushnell, M.C. (submitted). Neural correlates of painful genital touch in women with vulvar vestibulitis syndrome.

Witkin, S.S., Gerber, S., & Ledger, W.J. (2002). Influence of interleukin-1 receptor antagonist gene polymorphism on disease. *Clinical & Infectious Disease*, 34, 204-209.

(Editor's note: For purposes of this publication, we removed the authors' footnotes from the text. If you would like to receive the article as an e-mail attachment with its footnotes and all references included, please e-mail chris@nva.org.) ■

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