

Classification and Treatment of Vulvodynia

By Stanley Marinoff, M.D.

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The word "vulvodynia" simply means vulvar pain. The root "vulv" refers to the vulva and "odynia" is derived from the Greek word for pain. Scrotodynia is the analogous condition in the male. (One must be careful to use the word vulvodynia, rather than vulvadynia, when doing a literature or Internet search.) Vulvodynia is a symptom which can have multiple causes. There is no

prevalence data available at the present time, so one can only guess at its magnitude. A rough estimation is that 7 percent of the female population experiences painful sexual intercourse of a chronic nature, with 2 percent to 3 percent of these women suffering from vulvodynia. The chronicity of the problem differentiates this entity from acute causes of vulvar pain such as bacterial or fungal infections.

Physical Examination

The patient often presents with intermittent or constant burning of the vulva, sometimes described as rawness or irritation. The first diagnostic step is a thorough physical and comprehensive history. While taking a

patient's history, I specifically listen for the nature, location and duration of the symptoms. Here we must differentiate vulvodynia from pruritus (itching) and determine the chronicity of the problem. The results of previous treatments and medications must be evaluated. It is not unusual for a patient to bring to the appointment a large assortment of medications that have been prescribed. It is important to take the time to review these medications and the positive or negative results they have produced. The patient's sexual history, especially changes in sexual practices or contraceptive methods, must be explored. Hygienic patterns also must be assessed. Many women feel "unclean" in this area and respond by

See CLASSIFICATION, page 3

NIH Holds Conference on Gender and Pain

Are women really from Venus and men from Mars? There is a growing body of evidence that the physiological and psychological make-up of men and women is quite different. Following this premise, an NIH conference this past April posed the question, "Do men and women experience pain differently?" Many researchers agreed that the answer is yes. Although this topic has vast importance in clinical settings, it has not been studied extensively. As we enter the new millennium and women's health care continues to receive more attention, health care providers are acknowledging the need to develop better treatment strategies for pain conditions prevalent in women. To achieve this goal, first we must learn how and why pain impacts women differently than it does men.

Specific Chronic Pain Syndromes

Ursula Wesselmann, M.D., of Johns Hopkins University, currently is investigating the mechanisms responsible for pelvic pain in women to ultimately learn how to treat these patients more effectively. She presented preliminary data from a study designed to determine whether chronic pain syndromes of the reproductive organs are unique to women.

See GENDER AND PAIN, page 8

LETTER FROM THE EXECUTIVE DIRECTOR

Dear Friend,

Since that summer afternoon in 1994 when four of us founded the NVA, the organization has grown dramatically. Today, our mailing list consists of 2,600 patients and health care professionals, and we continue to receive hundreds of inquiries every month from all over the United States and Canada. Our medical advisory board also continues to grow. The NVA welcomes Dr. Ursula Wesselmann, assistant professor of neurology at Johns Hopkins University Medical School, to its medical advisory board. Given her dedication to vulvodynia research, we are excited to have her with us.

We're also pleased to announce the addition of Chris Sanders and Kathy Polletto to the NVA's executive board. For the past two years, Kathy has helped to answer our mail and worked with Harriet O'Connor to expand our support network. Kathy will serve as assistant director of support services. Chris Sanders led a support group in Madison, Wisconsin, and is currently research assistant to Dr. Wesselmann at Johns Hopkins. Her article in the Winter 1998 *NVA News* revealed her personal commitment to helping women with vulvodynia. For this issue, Chris covered the Gender and Pain conference at the National Institutes of Health (*see page 1*).

I'd like to express my appreciation to Kate Lee for her comprehensive article on vulvar vestibulitis in the May/June 1998 issue of *Health* magazine. Unfortunately, the coverage of vulvodynia in *Cosmopolitan's* article on painful sexual intercourse (June 1998) was brief and inaccurate. Diane Ranaldi, the NVA's publicity director, has written a letter to *Cosmopolitan's* editor-in-chief requesting that the magazine revisit the subject. Earlier this year, I mentioned an upcoming t.v. show which contains a segment on vulvar vestibulitis. To date, the program has not aired. We do not yet have an air date for the show, but it is possible that the network will put it on the schedule with little advance notice. To be sure not to miss it, watch your t.v. listings for a show entitled *CBS: The Body Human*.

As you know, the NVA has support leaders throughout the United States and Canada. Many of these leaders work very hard to help the women in their area find health care professionals who are experienced in treating vulvodynia. I'd like to take this opportunity to thank Nancy McGoon, an outstanding leader from California, for developing numerous medical resources in the San Francisco area. (*You can read about Nancy's efforts on page 10.*)

By the fall, I expect to have more news regarding the National Institutes of Health's (NIH's) commitment to vulvodynia research. We're making progress on that front, but it may take a while longer for NIH to earmark funds for this purpose.

With best wishes for a healthy summer,



Phyllis Mate

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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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Classification

(from page 1)

excessive washing and douching, which may lead to a vicious cycle of irritation and burning.

A pertinent medical history of trauma or metabolic disorders, such as diabetes mellitus, may be the clue to the origin of vulvar pain. Additionally, there is a high incidence of relationship between vulvar pain and other disorders such as interstitial cystitis, fibromyalgia and irritable bowel syndrome. The cause of this commonality is not yet known.

During the physical examination, the entire vulva must be carefully inspected. Adequate lighting and magnification are essential. A colposcope (magnifying instrument) helps to identify genital warts and lesions that may be cancerous. Abnormal-looking tissue should be biopsied. However, biopsies are not generally indicated for areas that show only erythema (redness), because the finding will most likely be chronic inflammation.

In particular, the vestibule (tissue immediately surrounding the entrance to the vagina) must be evaluated. To localize specific areas of tenderness in the vestibule, I use a moistened cotton-tipped applicator stick. Vaginitis must be ruled out so appropriate cultures are obtained and wet mounts with both saline and potassium hydroxide are inspected.

CLASSIFYING VULVODYNIA

Because vulvar pain conditions are not all the same, I use a chart of objective findings to establish the diagnosis and develop a treatment strategy (see chart, next page).

Dermatoses

The first category consists of dermatologic problems such as inflammatory dermatoses, which typically present as itching. These are grouped as the "lichen," an unfortunate term since it brings to mind a picture of the plant form. The three types are lichen sclerosus, lichen planus and lichen simplex chronicus. One must be able to recognize these entities and refer the patient to a dermatologist or vulvologist for appropriate treatment. These are treatable diseases (see *Treating Lichen Sclerosus*, page 5).

Vulvar Vestibulitis Syndrome

The second subset is vulvar vestibulitis syndrome (VVS), a chronic condition with three diagnostic criteria:

1. severe pain on vestibular touch or attempted vaginal entry;
2. tenderness to pressure localized within the vulvar vestibule;
3. physical findings confined to vestibular erythema of various degrees.

The *sine qua non* of VVS is introital dyspareunia, pain in the vestibule upon pressure or penetration. Initial therapy consists of various conservative measures such as removal of irritants and treatment of concomitant infections and dermatoses. Rehabilitation of the pelvic floor muscles with biofeedback has been helpful in some patients. Interlesional alpha-interferon injections into the vestibule also have been somewhat successful; 30 percent to 40 percent of patients who receive these injec-

See *CLASSIFICATION*, page 4

Classification

(from page 3)

tions exhibit improvement in sexual function. If all nonsurgical methods fail to provide relief, surgery may be recommended. Outcome research on surgery patients has found that surgery leads to marked improvement in the ability to engage in sexual relations in 65 percent to 85 percent of cases. The key to this success is careful patient selection, i.e., patients with pure vulvar vestibulitis syndrome, rather than essential vulvodynia, experience the best results.

Essential Vulvodynia

Essential vulvodynia and pudendal neuralgia comprise the third category of vulvar pain syndromes. The difference between these two entities is ill-defined, but I separate them on the basis of whether definitive neurological findings can be demonstrated. In these cases, I prefer the term pudendal neuralgia. These individuals usually report a constant or intermittent burning in a diffuse pattern over the entire vulvar area. With pudendal neuralgia, the pain follows the distribution of the pudendal nerve, so the localization of the pain may include a combi-

nation of any of these areas: clitoris, vestibule, urethra, labia minora with or without labia majora, perineum with or without the peri-rectal area, the mons, upper thighs, and even the posterior thighs and legs. The symptoms become worse as the day progresses, especially when there are long periods of sitting.

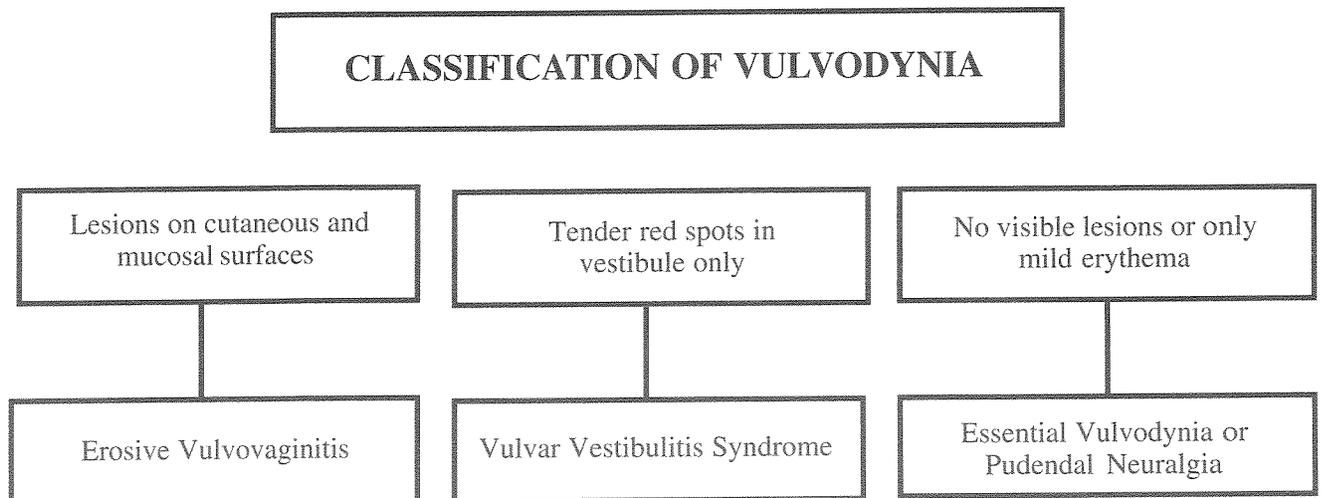
Because the vulva is an area with many sensory nerves, Reid (1995) first suggested that nerve sensitization might be involved in chronic vulvar irritation. To understand the neurological theory of vulvodynia, we must review the basic physiology of the burning sensation. The experience of burning pain involves nerves, mediators and perception. Pain receptors known as nociceptors are activated when there is tissue damage. These receptors normally transmit "pain" and "touch" sensations along unmyelinated C fibers (peripheral nerve fibers). Inflamed tissue contains biochemical mediators which activate the nociceptors, causing prolonged firing of the nerve fibers. (This sensitization of the nerve fibers explains why a sensation remains even after the original

stimulus has been removed.) The prolonged firing of the C fibers sensitizes neurons (nerve cells) in the dorsal horn, a part of the spinal cord. From the dorsal horn, neurons transmit the impulse to the brain stem and thalamus, where it is perceived as pain. In summary, the neurological theory says that sensitized peripheral nerves cause the brain to react similarly to "touch" and "pain" impulses, such that stimulation of either type will be perceived as pain.

The initiating factor of vulvodynia can be any event that causes irritation. Possible causal factors may be: chronic yeast infections or the many topical medications used in their treatment; herpes virus infection, resulting in a pseudo post-herpetic neuralgia syndrome; accidental trauma; prolonged stretching of the pudendal nerve due to childbirth; chemical or laser destruction of subclinical human papilloma virus (HPV); or certain metabolites in the urine.

Causes of pudendal neuralgia may include trauma, neoplasms (new be-

See CLASSIFICATION, page 6



Treating Lichen Sclerosus

By Libby Edwards, M.D.

Dr. Edwards is chief of dermatology at the Carolinas Medical Center in Charlotte, NC, and associate clinical professor of dermatology at Wake Forest University School of Medicine. She is Secretary-General of the International Society for the Study of Vulvovaginal Disease and a member of the NVA medical advisory board.

Lichen sclerosus is a skin disease that occurs most often on vulvar skin. Although lichen sclerosus was once believed to affect predominantly the vulva of postmenopausal women, this disease is found regularly among all age groups. The cause of lichen sclerosus is unproven, but it may be due to overactivity of the body's immune system (physiological responses which normally fight infection). Because its symptoms include vulvar itching or pain, lichen sclerosus must be eliminated as a possibility before a patient is diagnosed with vulvodynia. It is important to differentiate the two conditions because the treatment of lichen sclerosus is different from the treatment of vulvodynia.

Clinical Presentation

Lichen sclerosus probably begins asymptotically in most patients. By the time they are seen with classic symptoms of itching or pain, many women exhibit late signs of the disorder, including remarkable skin texture changes and scarring of the vulvar skin. Some women comfortably tolerate the disease until they develop a complicating event such as a yeast infection or thinning of vaginal skin after menopause, which produce additional unpleasant

symptoms. Itching, the most common symptom, can be mild or severe. Because vulvar skin is fragile, scratching can produce painful erosions. With resulting scarring and narrowing of the vaginal opening, pain with intercourse or an inability to engage in intercourse can occur.

In the early stages, lichen sclerosus usually presents as flat, white, well-circumscribed areas. Over time, these areas enlarge and coalesce, with the texture of the skin becoming crinkled, or, less often, waxy smooth. If treatment is not adequate, bleeding, ulceration and scarring of the vulva can occur in later stages of the disease. In rare cases, skin cancer can develop within a patch of lichen sclerosus. Even though the characteristic skin changes are very suggestive of the disease, a skin biopsy is frequently necessary to confirm the diagnosis.

Therapy

The management of patients with lichen sclerosus has become much easier in the past few years with the advent of extremely effective, ultrapotent topical corticosteroids (cortisone creams) such as clobetasol propionate. This medication is applied sparingly once or twice daily to all affected areas. Patients using ultrapotent cortisone creams daily should be monitored monthly because these medications can cause thinning and inflammation of the skin. At the same time, the physician needs to evaluate the degree of improvement, to decide when the frequency of application can be tapered.

With appropriate medication, most women experience dramatic relief

of itching or pain in about one week. However, patients should not abandon the regimen at this time, because recurrence is certain and scarring is likely. Most patients require three to five months of daily therapy to reach maximal improvement in the appearance of the skin. Thereafter, standardized long-term maintenance therapy involves the application of an ultrapotent corticosteroid about three times a week, rather than daily.

In severe cases of lichen sclerosus, with weeping from infection or sores from scratching, additional treatment to control infection and scratching for the first week or two often gives patients faster relief. This is especially important in prepubertal children and postmenopausal women not receiving estrogen, because their skin is naturally thinner and more fragile. Nighttime therapy with sedating doses of an antihistamine or tricyclic antidepressant medication helps to control scratching and hasten healing. An oral antibiotic (plus a yeast prevention regimen) during the first week of corticosteroid application also is recommended for women with especially severe symptoms.

Although testosterone cream was a time-honored therapy for lichen sclerosus, its effectiveness has not been substantiated by placebo-controlled, double-blind studies. Recent comparison studies have shown 2 percent testosterone cream and placebo to be equally effective, producing significant improvement in 66.6 percent and 75 percent of women, respectively.

See LICHEN SCLEROSUS, page 6

Lichen Sclerosus

(from page 5)

(Positive responses are likely due to the lubricating effect of the creams.) Another study comparing topical testosterone, placebo and the ultrapotent corticosteroid, clobetasol propionate, found the latter to be far superior in ameliorating symptoms. Given these results, there is no longer any place for topical testosterone in the treatment of vulvar dermatoses.

In the past, surgical therapies including cryotherapy (freezing off tissue), vulvectomy and carbon dioxide laser vaporization have been advocated for lichen sclerosus. Unfortunately, recurrence following these therapies is about 85 percent; thus, surgical removal of lichen sclerosus is rarely indicated. However, surgical intervention is required for patients who develop a secondary carcinoma and for those whose lichen sclerosus is well-controlled, but who experience scarring that results in sexual dysfunction.

Sometimes, patients with lichen sclerosus who are treated with an ultrapotent corticosteroid either fail to improve or experience a relapse following initial improvement. These women should be re-examined to be specifically evaluated for several events. First is the possibility of an ongoing bacterial or yeast infection. Second is the occurrence of an allergic contact dermatitis to the topical medication or its additives. Third is the possibility of a carcinoma, which would not respond to corticosteroid therapy. Finally, some patients who do not improve may have a different or additional diagnosis. For example, erosive lichen planus can produce similar white plaques and scarring, but this disease usually does not respond well to therapy.

Prognosis

Lichen sclerosus is not cured by corticosteroid therapy and the

disease gradually recurs in most patients when medication is discontinued. Based on anecdotal experience, however, once in remission the disease generally can be controlled with three applications per week of an ultrapotent corticosteroid.

Where to go for help

Lichen sclerosus is treated by both dermatologists and gynecologists. Ask your family physician for a referral. The American Academy of Dermatology and the American College of Obstetricians and Gynecologists also can provide referrals to physicians in your area.

(Editor's Note: For more information on lichen sclerosus, write to Harriet O'Connor at the National Vulvodynia Association. Be sure to include your name and address.) ■

Classification

(from page 4)

nign or malignant growths) of the spinal cord, infection, neurologic disorders and muscle spasm. Unfortunately, a specific initiating factor is not discovered in most cases, so the cause is termed idiopathic.

TREATMENT

The main treatment of both essential vulvodynia and pudendal neuralgia is the use of tricyclic antidepressants such as amitriptyline or desipramine. These norepinephrine re-uptake inhibitors previously have been shown to be effective in the management of neuropathic pain

conditions such as post-herpes zoster neuralgia and diabetic neuropathy. I start by prescribing the smallest dose and increase the dosage until improvement is noted or the patient complains of significant side effects. These drugs should not be discontinued abruptly as severe reactions can occur. The pure serotonin re-uptake inhibitors such as Prozac have not been found to be as useful in the treatment of neuropathic pain.

Other types of medications that occasionally are used to manage essential vulvodynia and pudendal

neuralgia are anticonvulsants such as carbamazepine (Tegretol) and phenytoin (Dilantin). These drugs are especially helpful in patients who experience shooting pains in addition to constant burning pain. Their method of action is to raise the threshold at which nerve transmission occurs. Monitoring of blood levels are necessary to assess whether the patient has reached a therapeutic level, and to check liver function and blood counts. Obtaining a detailed history of other medications being taken by the patient is

See CLASSIFICATION, page 7

Classification

(from page 6)

important, as drug interactions with anticonvulsants are common. Prophylaxis with acyclovir, 400 mg. twice a day, should be reserved for patients who have active herpes lesions associated with flare-ups of their symptoms. In these situations, acyclovir is given in addition to the tricyclic antidepressant or anticonvulsant.

In conjunction with medication, measures that reduce irritation of the sensitive vulvar mucosa (inner lining of the labia minora) are indicated. Loose fitting clothes, white cotton underwear, hypo-allergenic soaps, cold soaks, and the elimination of bubble bath and feminine deodorant sprays are helpful. I also recommend that a protective layer of an emollient-like plain petroleum or Crisco vegetable shortening be applied to the mucosa.

It should be noted that no single therapy works all the time in every patient. As mentioned earlier, **surgical procedures should primarily be limited to patients with vulvar vestibulitis syndrome.** On the other hand, medication is the treatment of choice for essential vulvodynia, but not for vulvar vestibulitis. Recent articles have suggested that pelvic floor adjustment with physical

therapy and biofeedback has helped some vulvar pain patients. Many alternative therapies have been tried with some success in some patients; for example, acupuncture and transepidermal nerve stimulation (TENS) have been used with varying results.

PSYCHOLOGICAL SUPPORT

Even though vulvar pain is a physical disorder, psychological support often is necessary to enable the patient to cope with what can be a severely disabling condition. In addition to its newsletter, the National Vulvodynia Association has organized a support network throughout the United States. Some patients also may benefit from professional counseling to deal with depression and interpersonal/sexual issues.

Any patient with chronic pain that interferes with normal functioning for more than three months is by definition depressed. I am always asked which came first, the chicken or the egg! A few psychological studies have shown that, in general, these patients do not differ significantly from control patients with regard to many psychological parameters. Given my personal experience with vulvar pain patients, once the diagnosis has

been made they are no different from my other patients. One factor that contributes to the frustration and depression initially exhibited by these patients is that they have been shifted from one physician to another, repeatedly misdiagnosed and treated for yeast infections which do not get any better.

SUMMARY

In conclusion, the key to vulvodynia treatment is early diagnosis. Potential therapies include:

1. Vigorously treating the initiating event.
2. Stabilizing the dorsal horn with tricyclic antidepressants and/or anticonvulsants.
3. Interrupting the mucosal pain loop with symptomatic treatment and removal of all irritants.
4. Breaking the deeper "pain loop" with biofeedback or physical therapy.
5. Providing emotional support and encouraging psychological counseling as needed.

Reference:

Reid, Richard, Flashlamp-excited dye laser therapy of idiopathic vulvodynia is safe and efficacious. *Am. J. Obstet. Gynecol.* 1995;172:1684-1701. ■

Help the NVA

Did you know that you can make a donation to the NVA using appreciated securities, including publicly traded or privately held stock and mutual funds? This method of giving allows donors to take a charitable deduction on their tax return for the full current value of appreciated securities held longer than one year. Because the NVA is a 501(c)(3) organization, donors do not have to pay the capital gains tax that would be due if these securities were sold under normal circumstances. For more information, contact the NVA's executive director, Phyllis Mate, at 301-299-0775.

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Gender and Pain

(from page 1)

To date, data on 39 women and 25 men indicate that both women and men suffer from chronic nonmalignant pain of the reproductive organs.

Dr. Wesselmann also is assessing whether pain medications prescribed for other chronic pain conditions are as effective in treating chronic pain of the reproductive organs. Interestingly, she has found that antidepressants, anticonvulsants, membrane stabilizing agents and opioids, which often provide satisfactory pain relief in men with chronic testicular pain, rarely are effective in women with chronic pelvic pain. She speculates that the reason for this might be that pelvic pain is a very complex syndrome that can involve any of the organs in the pelvic cavity. Dr. Wesselmann emphasized that further research is needed to develop more specific treatment strategies for women with chronic pelvic pain.

Richard Gracely, Ph.D., of the National Institutes of Health (NIH), presented data from a study designed to investigate whether vulvodynia is due to altered processing in the central nervous system and maintained by input from the vestibular glands. In this recent study, six vulvodynia patients had 0.1- 0.2 milliliters of lidocaine (without epinephrine) injected into the ducts of the Bartholin and Skene glands (lubricating glands near the vestibule). Using a numerical scale, patients were asked to rate the amount of pain they experienced after being touched in specific vulvar areas with a cotton-tipped swab. This procedure was performed at 5, 16, and 28 minutes after the lidocaine injection. The results showed a reduction in pain at 5 and 16 minutes, but not at 28 minutes. Perineal areas adjacent to the vestibule were tested

at the same time intervals and the pain ratings were analagous to those of the vestibule.

From these results, Dr. Gracely concluded that vulvodynia does indeed result from altered processing in the central nervous system and is maintained by input from the areas surrounding the openings of the vestibular glands. He hypothesized that a mild inflammation in the vestibular area can cause nerve fibers that normally transmit "touch" sensations to transmit "pain" sensations as well, increasing the input to the central nervous system and contributing to a vicious pain cycle. He suggested that therapies directed at the Bartholin and Skene glands may prove helpful in alleviating the amount of pain experienced by some vulvodynia patients.

Many other chronic pain syndromes that primarily affect women were addressed at the conference, including fibromyalgia, temporomandibular joint disorder (TMJ), and migraine headaches. Laurence Bradley, Ph.D., of the University of Alabama, reported interesting findings from a study on fibromyalgia. Although the disorder affects both men and women, 90 percent of fibromyalgia patients are female. Compared to healthy controls, women with fibromyalgia exhibited increased pain sensitivity, were superior at discriminating sensory stimuli, had higher cerebrospinal fluid levels of substance P (a neurotransmitter), and showed lower levels of brain activity in the caudate nucleus and thalamus (areas of the brain that influence systems affecting motor, emotional and cognitive behaviors). These abnormalities also exist in patients with

other neuropathic pain syndromes.

Contributing Factors

Linda LeResche, Sc.D., of the University of Washington, provided insight on how the epidemiological study of chronic pain syndromes sheds light on why men and women differ in pain perception. For example, a pain condition that is more prevalent in women, demonstrates a peak prevalence rate during the reproductive years, and declines with age (e.g., migraines) is likely to have a hormonally related cause. On the other hand, a pain condition that is equally prevalent in both sexes and increases with age is not likely to have a hormonal cause (e.g., joint pain). By studying the similarities and differences in men's and women's lives, as well as prevalence trends for different pain conditions, possible causes of pain conditions may become more apparent. Dr. LeResche discussed some specific factors that can influence women's experience of pain, such as the menstrual cycle, childbirth and menopause; differences between male and female perceptual styles and social roles also were addressed.

Several researchers have focused their attention on the effect of hormones on pain perception. Karen Berkeley, Ph.D., of Florida State University, and Maria Giamberardino, M.D., of the University of Chieti, Italy, examined the relationship between pain sensitivity and phases of the menstrual cycle. In one study, electrical stimulation was applied to three areas: the skin, directly below the skin, or muscle

See GENDER AND PAIN, page 9

Gender and Pain

(from page 8)

tissue. The overall result was that subjects experienced the least pain during the luteal phase of the cycle (between ovulation and premenstruation). Women who had dysmenorrhea (pain with menstruation) exhibited the same trend as women in general, but their reactions were accentuated. Alan Gintzler, Ph.D., of the State University of New York Health Science Center, reported that increased levels of estrogen and progesterone during pregnancy correlate with reduced levels of pain sensitivity during that period. Hormones may not be the only factor contributing to this effect, but they appear to play a significant role.

William Isenberg, M.D., Ph. D., of the University of California, San Francisco, conducted an illuminating study in which an inflammatory agent, prostaglandin E2, was injected into the skin of male and female rats. The initial result was that prostaglandin produced a greater increase in pain in the fe-

males than the males. In the second phase of the study, Dr. Isenberg gave testosterone to some female rats, resulting in reduced pain sensitivity comparable to that of the male rats. Finally, he gave estrogen to some male rats, causing them to react similarly to the female rats that were not given testosterone. From these results, he concluded that sex hormones contribute to basic biological differences in the structure of the male and female nervous systems.

Psychological/Behavioral Differences

It is widely acknowledged that there are differences in the perceptual styles and social roles of females and males. One study by Francis Keefe, Ph.D., of Ohio University, compared coping mechanisms and emotional behavior in women and men with arthritis pain. It was found that women used more pain coping strategies than men, and that men were more likely to exhibit negative mood as a result of pain. These find-

ings suggest that women may be better at controlling the emotional consequences associated with the experience of pain.

In another study, Dr. Keefe examined gender differences in the ability to judge a spouse's pain. Each participant had arthritis pain and was videotaped while engaging in a variety of daily activities. The participant then watched his/her self and rated the amount of pain she/he was feeling during the task. Subsequently, the participant's spouse viewed the same videotape and rated the amount of pain that his/her spouse was experiencing during the task. The two ratings were then compared. Results showed that women were much more accurate than men in evaluating their partner's pain. Dr. Keefe concluded that it is important to study gender differences in psychological and behavioral responses to pain, because this knowledge can help health care professionals to understand and treat individual patients with chronic pain.

Subjects Needed

Researchers at Johns Hopkins University currently are looking for volunteers to participate in a three to four-month study concerning changes in pain perception. You do not have to live near Johns Hopkins Hospital (Baltimore, MD) to be a subject in this study, i.e., correspondence can be done via mail or phone.

If you are between the ages of 18 and 45, currently menstruating, not pregnant and have been diagnosed with either vulvar vestibulitis syndrome or essential vulvodynia for at least six months, you are an appropriate candidate for this research. A control group comprised of women who do not suffer from chronic vulvar pain also is needed.

If you would like more information, please contact Chris Sanders at Blaustein Pain Center, Johns Hopkins Hospital, at 410-614-5775, or via e-mail at clsander@welchlink.welch.jhu.edu.

A somewhat different perspective was introduced by Dennis Turk, Ph.D., of the University of Washington. Based on his research, chronic pain patients should be classified according to psychological characteristics rather than gender. He presented results of a study in which chronic pain patients suffering from fibromyalgia were classified as dysfunctional, interpersonally distressed, or adaptive copers. The major finding was that the dysfunctional and interpersonally distressed patients reported higher levels of pain, disability and depression, compared to patients identified as adaptive copers. Dr. Turk

See GENDER AND PAIN, page 11

Becoming a Women's Health Activist

By Nancy McGoon

As any vulvodynia sufferer knows, a primary difficulty of the disorder is that it is relatively unknown and widely misunderstood within the medical community at large. Many patients wind up seeing multiple physicians who are at a loss to offer any real help. The secret to improving this seemingly hopeless situation lies in erasing the mystery and ignorance that surround the condition. Achieving this enormous task depends largely on the efforts of vulvodynia patients to help close the information gap however they can.

In my own search for effective treatment, I learned how difficult it is to diagnose vulvodynia and that ultimately, most cases are managed rather than cured. I made the decision to get involved in the management of my symptoms. Since I don't have a nursing background, I struggled with much of the technical medical terminology and asked a lot of questions. Surprisingly, I found that health care professionals who knew something about the condition were willing to answer my questions. Additionally, I appreciated the information and definitions provided by the NVA in its newsletters.

It was my gynecologist, Dr. David Galland, who first gave me the NVA brochure. I received lots of help from Dr. Galland and Linda Goldberg, the nurse practitioner in his office. At the same time I made contact with Harriet O'Connor at NVA headquarters, who put me in touch with Lorraine, my local contact leader. Together they gave me enough information to begin asking pertinent questions as my medical network began to expand. The more I learned about vulvodynia, the more control I felt I had over it. I must admit that some days that control seemed pretty slim; other days it was decidedly better.

Lorraine had a nursing background and was very helpful in educating me about the procedures and medications used to treat the disorder. As a long-time sufferer, she had first-hand knowledge of different treatments. As I watched her go through some difficult times, I decided to make some calls on her behalf to the University of California, San Francisco (UCSF), a teaching hospital near my home. After a flurry of phone calls and faxes, I made my first breakthrough—I contacted Drs. Bethan Powell and Sharon Lojun at the hospital. They faxed a study of their treatments to me.

That was my first success in receiving information from physicians. I sent a copy to Lorraine, and then closed the loop by forwarding the information to Harriet at NVA headquarters. This first experience made me realize that our challenge—as sufferers and as the ones who can help bring about a cure—is to find out what treatments are effective, and then pass on that knowledge to the NVA, so they can communicate it to other patients and the health care community. For me, the door opened a crack, and I knew what I had to do.

With the assistance of Drs. Powell and Lojun, I contacted other health care professionals with an interest in treating vulvodynia. First I found Dr. Jerome Weiss, a urologist who specializes in treating pelvic and vulvar pain, who in turn referred me to a noted dermatologist at UCSF, Dr. Richard Odom, an expert in the dermatological aspects of vulvodynia. I learned from Dr. Odom that Dr. Erika Klemperer had opened a gynecology/dermatology clinic devoted to vulvovaginal disorders. I was able to find and develop these resources by making a few phone calls and sending letters to their offices.

I hit paydirt again at the bookstore. Browsing through the health section, I came across the *Chronic Pain Control Workbook* edited by Ellen Catalano, M.A. and K.N. Hardin, Ph.D., from—you guessed it—

See *READER TO READER*, page 11

Reader To Reader

(from page 10)

UCSF. I knew that the NVA was contacting authors of medical and health books to convince them to include vulvodynia in future editions, so I sent the editors' names to Harriet. She spoke with the authors and they agreed to cover vulvodynia in the book's next edition. And so the information network continues to expand.

Every reader of this newsletter has valuable information to contribute. **YOU** can help lessen the ignorance surrounding this condition by just picking up the phone or dropping a note to your contact leader— tell her how you're doing, and what's working or what isn't. I'd like to encourage you to follow some of the tips at the end of this article. Think of yourself as the key to closing the information loop and helping medical researchers find a cure for vulvodynia — sooner, rather than later!

WHAT YOU CAN DO

1. Become involved in the NVA and get to know your local contact leader.
2. When you learn something about vulvodynia, pass it along: to your doctor or nurse practitioner, another vulvodynia patient, your contact leader, and/or NVA headquarters.
3. Find a doctor with experience treating vulvodynia, or find a physician who is willing to learn and work with you on this problem.
4. Ask the NVA for brochures and hand them out to internists, dermatologists, urologists, gynecologists and anesthesiologists. ■

Gender and Pain

(from page 9)

emphasized that not all patients with the same disorder have the same psychological make-up or respond similarly to their chronic pain state. He believes that individual characteristics should be taken into account for patients to receive optimal treatment.

Future Research

With the accelerating development of medical technology, many new avenues of exploration are opening up in pain research. For example, David Borsook, M.D., and his colleagues at Harvard University, employ functional magnetic resonance imaging (MRI) to measure changes in human brain activity. This technique can be used to compare brain regions before and after the application of painful stimuli, helping researchers to understand the transformation that occurs as a pain state changes from acute to chronic.

Another highly specialized technique, quantitative trait locus mapping, has been used to localize genes involved in pain perception in mice. Jeffrey Mogil, Ph.D., and his colleagues at the University of Illinois, have been able to localize genes involved in pain sensitivity and responsiveness to opioid analgesia. From this research, Dr. Mogil speculates that differences in pain perception between males and females may be the result of genetic differences, rather than sex hormones.

Another study by Christine Miaskowski, Ph.D., and her colleagues at the University of California, San Francisco, compared the effects of opioid analgesia on males and females suffering from postoperative pain. Most of the analgesics currently used for postoperative pain target specific opioid systems referred to as mu and

delta. Dr. Miaskowski compared male and female responses to kappa-opioid analgesia (e.g., Nalbuphine) and found that while men experienced little pain relief from this class of drugs, females experienced substantial relief. This discovery of a significant biological difference in opioid responsiveness of males and females may lead to improved analgesic treatment for both sexes in the years ahead.

Conclusion

From the overwhelming amount of information presented at this conference, it is apparent that the relationship between gender and pain is complex. It will take years of research to obtain the answers to the many questions now being asked. As scientists continue to assemble the pieces of the puzzle, better treatments will emerge, improving quality of life for millions of women and men with chronic pain conditions. ■

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