N National
V Vulvodynia
A Association

NVA News

Volume V, Issue II

Summer 1999

A Modern Approach to Vulvodynia Therapy

By Jessica Thomason, M.D.

Jessica Thomason, MD, FACOG is a Clinical Professor of Obstetrics and Gynecology, University of Wisconsin Medical School, Madison, Wisconsin, and Director of WomenNow Health Care, Milwaukee, Wisconsin.

Overview and Prevalence

Vulvodynia is defined as chronic vulvar discomfort with a duration of at least 3 months. This discomfort can be expressed as pain, burning, itching, dyspareunia (painful sexual intercourse), stinging, rawness, or irritation of a constant or intermittent nature. The prevalence rate is not well-established, but an article by Martha Goetsch, M.D., (American Journal of Obstetrics and Gynecology, 1991) reported the prevalence rate of Vulvar Vestibulitis Syndrome to be 15 percent in her general gynecologic private practice. Early results from a survey by the National Vulvodynia Association found the mean age of women with vulvodynia to be 43. Age ranges have been reported from 11-75 years.

Classification

Vulvodynia can be classified as primary, meaning the pain has been present since first sexual experience or tampon use, or as secondary, beginning after first tampon use or first sexual experience. It can also be classified as pure, occurring only with touch (such as with sexual intercourse, riding a bicycle, during wiping of the perineum after voiding) or as mixed, occurring both with touch and at other times (e.g., spontaneously when one is sitting). It can be organic, i.e., have an identifiable cause, or idiopathic, meaning it does not have an identifiable cause.

There are several classification schemes for dyspareunia (painful sexual intercourse). For example, it can be classified according to type and severity. The type can be superficial, located only at the opening of the vagina, or deep, located deep within the vaginal cavity, or both.

(See VULVODYNIA, page 4)

Multidimensional Assessment of Vulvodynia

By Robin M. Masheb, Ph.D

Robin M. Masheb, Ph.D., is an Associate Research Scientist and Assistant Clinical Professor in the Department of Psychiatry at the Yale University School of Medicine, New Haven, Connecticut.

Most treatment studies of vulvodynia have taken a unidimensional approach, focusing exclusively on the measurement of pain as the criteria for success or failure. This is the approach taken with acute pain, i.e., pain that lasts less than 6 months. Yet studies of vulvodynia report an average duration of pain greater than 6 months, indicating that vulvodynia is predominantly a chronic pain condition. The purpose of the present study was to conduct a multidimensional assessment of vulvodynia patients by comparing a sample of women with vulvodynia to a group of healthy women without chronic pain.

(See ASSESSMENT, page 3)

LETTERS TO THE EDITOR

Dear NVA,
As requested in the recent issue of the NVA Newsletter, I would like to relate my experience in treating vulvovestibulitis with Aldara. I have used this medication in both HPV positive and HPV negative patients. Unlike my experience with 5-FU cream, which has resulted in about a 20-25% response rate, Aldara thus far has been completely unsuccessful in alleviating the symptoms of any of my patients. It does cause significant redness and inflammation which, on occasion, exacerbates their symptoms.

Please let me know if the experience of others is different. My series of patients is small (less than 10), however I have a large number of patients with vulvovestibulitis who do respond to other forms of treatment. I currently use Zovirax, 5-FU, Triamcinolone injections, Alferon injections, estrogen application, and vestibulectomy. In our clinic, we have a greater than 90% success rate and rarely have to resort to vestibulectomy.

I have enclosed some information about our International Pelvic Pain Society which has many common members with your association. We meet twice per year and have had at least one lecturer on vulvodynia at each of our Pelvic Pain symposia. Your newsletter is helpful to us and we appreciate your hard work.

Sincerely,
C. Paul Perry, M.D.
You can contact The International Pelvic Pain Society at 800-624-9676, or visit its Web site at www.pelvicpain.org.

Dear NVA,
I have enclosed another donation to the NVA. I look forward to the newsletters and appreciate the quality of the articles, and the information on grants that are being approved for research.

I am hoping that NVA might be able to generate more articles this coming year on subjects related to psychological, emotional and relationship aspects of living with vulvar pain. This has been a highly frustrating year for me. I had a long period that was relatively symptom-free, then two horrible months, then three great weeks (didn't even take acidophilus), now symptoms again. I think many of us end up with classic feelings of powerless and learned helplessness.

At a recent stress lecture at work, it dawned on me that all the burnout features being identified were actually how I experience trying to cope with vulvodynia every day. The bottom line is: nothing I do seems to matter. I can analyze every day, every behavior, every food consumed, and never find a pattern. I can distinguish nothing unique about a good week that makes it different from a bad week. What I think works, does not consistently work, so maybe it wasn't actually working at all. It leaves one with feelings of utter resignation that are depressing and despairing. It's hard to keep up that positive thinking when you feel so totally out of control of what is happening, and what you can do to impact it. My relationship with my husband is strained. Practically every "encounter" becomes a to-do or not-to-do matter, because I either hurt, or will hurt. Sometimes I don't want to be close in any way, because that is merely a trigger for the anguish over making the decision for sexual intimacy. I don't even want to "share" what is going on, because it is a drag to have a relationship structured around my physical state of being, even with a partner who wants to be understanding. Often, I just shut down. This gets no easier with duration, I am running out of ideas, and my doctor has nothing new to offer.

I think I must speak for other women, and if there is anyone that you can share this with, you have my full permission. A segment on any of these varied issues, in every newsletter, would be greatly appreciated. I am grateful to have this forum, where I can just ramble on without having to censor the details. We have a small NVA group here, and we keep in touch, but I am always looking for more. Thanks for anything you can do.

Sincerely,
Carolyn Piper
1529 Silandro
Las Vegas, NV 89117

Dear Carolyn,
We know that many others can relate to the feelings that you have expressed and we appreciate your suggestion. We will

(See LETTERS, page 10)

Assessment

(from page 1)

Multidimensional Assessment

State-of-the-art assessments of chronic pain conditions such as low back pain and arthritis focus on improved functioning as well as pain reduction. Functioning typically encompasses two broad areas: physical disability and psychological well-being. Pain measures may include the severity of the pain, as well as the frequency and duration of pain episodes. Assessment of a chronic pain disorder that includes pain symptoms, physical disabilities and psychological well-being is known as a multidimensional chronic pain assessment. This provides a comprehensive way to measure chronic pain and the changes that may occur as a consequence of treatment. For example, a woman who has had surgery as a treatment for vulvodynia may report a signficant reduction in pain, but her capacity to engage in pleasurable sexual relations may not have improved.

NVA News
National Vulvodynia Association
P.O. Box 4491
Silver Spring, Md. 20914-4491
(301) 299-0775
FAX: (301) 299-3999
www.nva.org

The *NVA News* is published three times per year.

Editor:
Phyllis Mate

Layout:
Andrea Hall

Contributors:
Harriet O'Connor
Chris Sanders
Eleanor Brosius

The Present Study

A multidimensional chronic pain assessment using self-report measures from the literature on other chronic pain syndromes was conducted. The survey compared a group of women with vulvodynia to a group of healthy women without chronic pain. In addition to asking subjects to answer questions on pain, physical disability and psychological well-being, measures of marital and sexual functioning were included because they also appear to be areas of impairment in women with vulvodynia.

Vulvodynia subjects were recruited from support group members of the National Vulvodynia Association and from the patient population of two New York City gynecologists who specialize in the treatment of vulvodynia. These subjects were self-identified, i.e., they reported having vulvar pain for a period of six months or longer. It was decided that the cost and time involved in obtaining a physician's confirmation of the diagnosis was not warranted because of the lack of a diagnostic test for the disorder and confusion in the literature about vulvodynia subtypes. Control group subjects did not have vulvodynia or any other chronic pain condition, and were either friends of the vulvodynia subjects or healthy patients from the gynecologists' practices.

Subject Characteristics

The total number of vulvodynia subjects was 57 and the total number of control subjects was 74. The vulvodynia and control conditions (groups) were well-matched for age (43.9 years and 42.1 years respectively) and socioeconomic status. The overall sample was 87.8 percent Caucasian, 5.3 percent Black, 3.1 percent Hispanic, and 3.1 percent Asian. The vulvodynia condition contained a higher percentage of Caucasians (94.7 percent) than the control condition (82.4 percent). However, the vulvodynia and control conditions were well-matched for marital status (59.6 percent and 55.4 percent married, respectively) and education (52.6 percent and 56.2 percent having at least a four-year college degree). The vulvodynia condition had a lower percentage of individuals engaged in full-time employ-

(See ASSESSMENT page 8)

Vulvodynia

(from page 1)

Dyspareunia can also be classified according to its severity. In Type 1, sexual intercourse causes discomfort but does not prevent intercourse from occurring; in Type 2, the pain frequently prevents intercourse; and in Type 3, intercourse is completely prevented because of pain.

Nervous Input to the Vulva

To understand vulvodynia, it is important to review the anatomy of the nerve supply in the pelvis. The vulva receives nervous input from three major nerves: the pudendal, ilioinguinal, and genitofemoral. The pudendal nerve originates from the S2-S4 region of the spinal cord and has three branches: the inferior hemorrhoidal (rectal) nerve, the perineal nerve, and the dorsal nerve of the clitoris. It functions to transmit sensory signals to the genitalia and perineum and also supplies motor function to the pelvic floor and external sphincters of the urethra and rectum. Both the ilioinguinal and genitofemoral nerves originate in the L1-L2 area of the spinal cord; they have sensory functions, but not motor functions. The ilioinguinal nerve transmits sensory signals to the inguinal (groin) area, symphysis (mons pubis) and anterior vulva. The genitofemoral nerve transmits sensory signals to the anterior vulva and the labia majora.

Types of Neuropathic Pain

Many physicians have conceptualized vulvodynia as neuropathic (nerve) pain, which can be classified as one of the following three types. Allodynia is the term used to describe a painful response to a stimulus that does not ordinarily cause pain; for example, touching a healthy person's arm with a feather does not normally cause a painful sensation, but if such touch was perceived as painful, the sensation would be classified as allopathic pain. Hyperalgesia describes an exaggerated pain reaction to a stimulus that is normally painful. Dysesthesia is the perception of an unpleasant and abnormal sensation produced by a non-noxious stimulus. Women with vulvodynia may experience all three types of neuropathic pain, but many pain specialists consider vulvodynia to be primarily an allodynia.

Nociceptors are receptors that transmit pain caused by injury to body tissue. There are many types of nociceptive damage which can cause vulvar pain. Nociceptive damage can result from neurologic compression, either from a stretch injury, transection (cutting) of a nerve, or infection of a nerve. It also can occur from pelvic floor descent, i.e, prolapse of the pelvic floor with stretching of the pudendal nerve through "Alcock's canal." (Alcock's canal is an area where the pudendal nerve runs very near to the hipbone.)

Vulvar pain also can result from damage to nerves from tumors, cysts or surgery; soft tissue injury from an episiotomy or vaginal delivery; laser ablation of the vulvar skin; a car accident; a straddle injury; vaginal atrophy caused by a lack of estrogen; chronic skin irritation from application of medications such as steroids or Aldara; and infective agents such as viruses, e.g., HPV. Furthermore, vaginal surgery can increase the risk of pudendal nerve injury.

DIAGNOSIS

A variety of factors need to be considered to make an accurate diagnosis of vulvodynia. Initially, it is important to take a careful medical history. In particular, one should look for an initiating factor such as surgery, childbirth, or change of sexual partner. Other factors to explore are a relationship between vulvodynia and the menstrual cycle; urethral symptoms; other medical conditions; any medications used (past or present); any family history (other female family members who have experienced similar symptoms); the use of menstrual pads or pantyliners; trauma to the perineum from excessive exercising or bicycle riding; and contraception use.

Physical Examination

There are multiple aspects of the gynecologic examination. To minimize pain on the patient's first visit, the use of an intravaginal speculum may not be necessary. Since pain is usually located on the vulva, a careful, thorough examination of this area may be all that is required initially to localize the pain. To start, it is important to evaluate the following: the size and shape of the clitoris, the clitoral hood and labia minora; possible inflammation of the Bartholin glands and minor vestibular glands

(See VULVODYNIA, page 5)

Vulvodynia

(from page 4)

(using the Q-tip test); and Fox Fordyce spots (normal anatomic spots on the labia minora). The labia should be examined for lesions, the perianal area should be checked for whiteness and/or fissuring, and the general color of the genital and anal skin should be noted. Next, a neurological examination should be carried out, evaluating reflexes in the vaginal and rectal areas, as well as allodynia.

During the internal examination of the vagina, the pelvic muscles should be palpated. Areas surrounding the vulva should be evaluated for pain including any coccygeal (tailbone) pain, mons pubis (area around the pubic bone) pain, upper inner thigh pain, pyriformis (pelvic floor muscle) pain, and sciatic pain. Any pelvic prolapse should also be noted. Colposcopic examination should be performed in some cases to rule out conditions such as condylomatous vaginitis, lichenoid vaginitis, lichen planus, and other dermatologic conditions. If there are any suspicious lesions, a biopsy should be performed to confirm the diagnosis.

Laboratory Testing

In some cases, an array of laboratory tests are also necessary. These include potassium hydroxide and normal saline wet mounts for microscopic examination of vaginal secretions. This evaluation also can be done with the vulvar skin and perianally, if needed. Laboratory tests should be performed to rule out metabolic diseases such as hypothyroidism, hyperthyroidism, glucose intolerance, and autoimmune diseases. In order to rule out menopause or premature ovarian failure, blood levels of certain hormones such as serum estradiol and follicule stimulating hormone should be measured.

Multidisciplinary Approach

Ideally, the evaluation and treatment of vulvodynia should involve a multidisciplinary approach. A neurological examination, including an EMG of the pelvis, should be completed. A gastroenterologist may be needed to examine sphincter integrity and check for intestinal inflammatory disease. A dermatologist should evaluate if the pain is resulting from any dermatoses. To manage pain medications and evaluate trigger points, an anesthesiologist may be needed. If the patient exhibits depression, a referral to a psychiatrist may be appropriate. A physical therapist skilled in the use of biofeedback may be needed for a biofeedback evaluation of the pelvic floor musculature. In certain cases in which the patient has undergone prior vulvar surgery, a consultation with a plastic surgeon may be indicated if major skin grafting is required at subsequent surgery. Finally, a referral to a vulvar disease specialist may be appropriate.

TREATMENT

Once the initial work-up and all necessary referral visits have been completed, it is important to treat any underlying conditions found during the course of the examinations. Some of these underlying conditions are infections: if yeast is found, antifungals are prescribed; if bacterial vaginosis is found, antibacterials are prescribed; for herpes simplex, antivirals are used; for human papillomavirus, ablative therapy (application of certain topical biochemicals) is performed; if there's a Bartholin gland abscess, the gland should be excised.

All possible trauma to the area should be avoided including wearing tight clothing, excessive exercising, and motorcycle or bicycle riding. The physician should repair vaginal prolapses and revise scars created during previous surgeries, vaginal deliveries, or pelvic floor injury.

Any medications or vaginal products that might be causing an allergic reaction should be discontinued including anesthetics, topical antibiotics, antifungals, antiseptics, corticosteroids, and spermicides. All materials that come in contact with the vulvar region such as condoms, latex, rubber, and pantyliners, as well as over-the-counter personal hygiene products which may contain additives that are irritating to the vulva should be avoided. Substances that sting upon application, e.g., soaps, alcohol, douches, and gentian violet, should also be avoided.

In some cases, vulvar symptoms may be the result of dermatological disorders such as lichen sclerosus, eczema, atrophic vulvitis, or contact dermatitis. Some other dermatological conditions to be ruled out are Candida vulvitis, lichen simplex, Herpes simplex and Crohn's disease of

(See VULVODYNIA, page 6)

Vulvodynia

(from page 5)

the vulva. Vaginal or vulvar atrophy due to perimenopause, menopause, or prolonged breast feeding can be treated with hormone therapy. Similarly, one should treat any underlying metabolic diseases such as Crohn's, Sjogren's syndrome, and Systemic Lupus Erythematosus to see if vulvar symptoms are eliminated.

Patients with chronic vulvar pain which does not result from an underlying disease and does not have an identifiable cause are treated with an "antineuralgic" medication. The classic approach is to prescribe a tricyclic antidepressant such as Elavil, beginning with doses as low as 5 or 10 mg. daily to minimize side effects. Typically, doses are gradually increased to a maximum of 50-100mg. The difficulty with prescribing Elavil is that many patients discontinue the drug because of its sedating side effect. Tricyclic antidepressants with a better side effect profile include desipramine and nortriptyline.

The selective serotonin reuptake inhibitors such as Zoloft and Paxil also may be prescribed. These medications have had most benefit in chronic pain syndromes such as fibromyalgia. They can be useful because they have a less sedating effect than the tricyclics. Alternately, or in conjunction with an antidepressant, anticonvulsants such as Tegretol, Depakote, or Neurontin may be prescribed for pain relief.

Topical anesthetic agents that may provide short-term relief include Xylocaine (lidocaine), Hurricaine (benzocaine), and Zonalon (topical doxepin). In some cases, a referral to a pelvic floor dysfunction therapist for biofeedback training may be indicated. Finally, if the patient has Vulvar Vestibulitis Syndrome, surgery may be recommended.

An important part of treatment is helping the patient to develop realistic outcome goals. In general, the shorter the duration of the syndrome, the better the outcome. The patient needs to develop positive coping mechanisms to control the pain such as exercise, distraction techniques, and active participation in managing the pain.

VULVAR VESTIBULITIS

Etiology

The etiology of Vulvar Vestibulitis Syndrome (VVS) is often idiopathic, i.e., without identifiable cause. Dyspareunia at the entrance to the vagina is the defining characteristic of this condition. Sometimes it occurs secondary to dermatological conditions such as lichen sclerosus or desquamative vaginitis. Frequently, the initiating factor in VVS appears to be a history of serial antibiotic use for urinary tract infections, acne, sinus infections, or vaginitis, or the use of highly progestational agents such as certain birth control medications. Symptoms always intensify from the use of pantyliners or menstrual pads. VVS involves inflammation of the Bartholin glands and/or the minor vestibular glands at the base of the hymen.

Therapy

Treatment begins by instructing the patient to stop attempts at intravaginal penetration and inviting the husband/partner to the patient's next examination. Topical estrogen such as Estrace cream should be applied to gland openings to relieve symptoms of burning and reduce inflammation. The use of topical and intravaginal steroids also may be beneficial.

Some of the commonly used treatments for VVS do not appear to have a high success rate. One of the popular alternative methods, the low-oxalate diet plus calcium citrate, does not work for most VVS patients. Likewise, oral corticosteroids are ineffective. Interferon injections, a fairly common medical treatment, also has not been successful in many cases. Another treatment sometimes used, the superficial lasering of the vestibular gland openings, has actually made symptoms worse in many patients.

For most patients with VVS, surgery appears to have the highest success rate, especially if the condition has been of short duration. Of 127 vestibulectomies performed at WomenNow Health care, 108 women were evaluated five years after surgery. "Success" was defined as the ability to engage in sexual intercourse without pain and with normal frequency. "Improved" was defined as the ability to engage in intercourse with occasional discomfort during or afterwards; the experienced discomfort, however, did not inhibit frequency of episodes.

Seventy-five percent of patients were determined to be a success post-surgically, eighteen percent were

(See VULVODYNIA, page 10)

Vulvodynia in the Media

Vulvodynia Topic of National Broadcast

On July 26th, vulvodynia was discussed live on the network radio program *Sex and Relationships,* one of Renaissance radio's top 10 shows. This program reaches as many as 10 million listeners in the Southwest and in the Boston/Cape Cod and Rhode Island region.

On his weekly broadcast, psychologist Dr. Robert K. Madsen, the show's host, interviewed Marjorie Veiga, the Washington, DC area NVA support group leader. Ms. Veiga disclosed all aspects of vulvodynia, including possible causes, multiple treatments, and its impact on quality of life. Listeners called in with questions and were directed to call the NVA or visit its Web site for more information.

Our thanks to NVA Executive Board member Katie Axley for leading us to this opportunity to foster public awareness. Through these types of shows, we are able to reach countless numbers of women who realize for the first time that they are not alone. ■

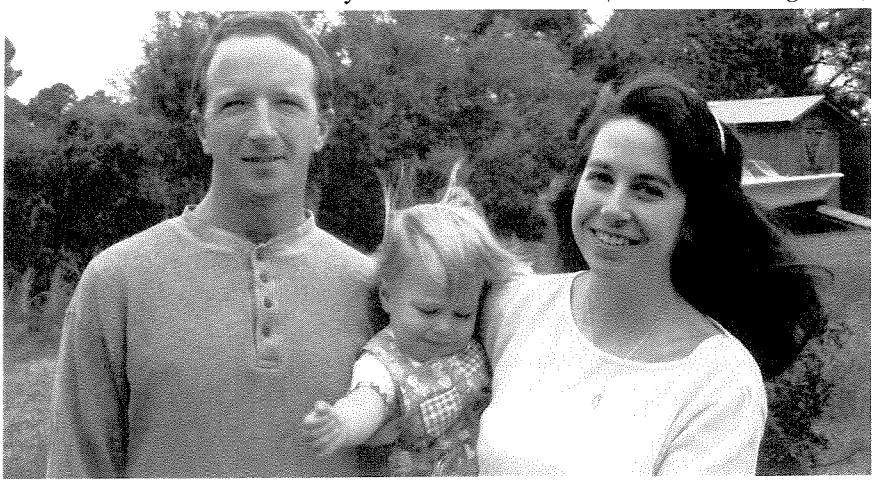
CBS Special Showcases NVA Support Leader

Two years ago, a television producer contacted the NVA, expressing an interest in featuring a vulvodynia story on a TV special on reproduction and sexuality. (See www.bodyhuman2000.com) The program's theme was "medical miracles" and he wanted to tell the story of a woman suffering from vulvodynia who had been treated and cured. After making several phone calls, the NVA contacted Janet Roberts (pictured below with her husband), one of our support leaders in North Carolina. She spoke with the producer, discussed it with her husband, and agreed to participate. Janet gave the producer a comprehensive overview of vulvodynia and recounted her own successful treatment for vulvar vestibulitis.

Janet was originally diagnosed by her local gynecologist, who referred her to John Steege, M.D., a vulvodynia specialist at the University of North Carolina Hospital, Chapel Hill. After a thorough evaluation of her history and physical examination, Dr. Steege recommended a vestibulectomy, a surgical procedure often used in the treatment of vulvar vestibulitis. Three months after the surgery, Janet and her husband Ted were able to regain the intimacy that they had lost. A year and a half later, Janet became pregnant, and it was during this time that she and Ted were filmed for the CBS special. The producer and cameraman spent three days with the Roberts and Dr. Steege, taking 10 hours of film which would eventually be condensed into only 10 minutes of air time.

During the 10 hours of filming, Janet and Dr. Steege spoke about other types of vulvodynia which had different symptoms and treatments than Janet's condition. For example, Dr. Steege described patients with dysesthetic vulvodynia who have constant vulvar burning and are typically managed with medication. All this material was edited out of the show's final version which only

(See CBS, Page 11)



Moving?

Please send your change of address to the NVA:
P.O. Box 4491
Silver Spring, MD
20914-4491

Newsletters are sent by bulk mail and are not forwarded by the USPS.

Assessment

(from page 3)

ment (47.4 percent) compared to the control condition (68.9 percent).

The average age of onset of vulvar pain for the vulvodynia condition was 35 years, 9 months. The average length of time with vulvodynia was 7 years, 7 months. Frequency of pain was 4.86 days per week. Duration of pain was difficult to assess because some vulvodynia subjects reported constant pain and others intermittent. Intensity of pain on a 7-point scale ranged from an average of 1.98 (least intense this week), to 4.54 (most intense this week). Fifty-six percent reported gradual onset of pain, and 44 percent reported acute onset of pain. Eleven percent reported that someone in their family expressed similar complaints. Ninety-six percent of vulvodynia subjects reported that pain interfered with sexual activity, compared to only 10 percent of controls. Furthermore, 89 percent of vulvodynia subjects reported some degree of pain with sexual intercourse compared to 24 percent of controls.

Physical Functioning

Findings from the study revealed that women with vulvodynia exhibited poorer physical functioning than controls in areas ranging from basic activities such as chores, walking, and sitting, to working and social activities. Three types of disability scales were completed by both the vulvodynia and control conditions. The Physical Functioning scale asked participants whether their physical health interfered with activities such as carrying groceries, climbing stairs, walking more than a mile, sitting for more than an hour, etc. Fourteen items were rated on a 7-point scale from 0 (Limited a Lot) to 6 (Not Limited at All). The vulvodynia condition scored significantly lower than the control condition, indicating that women with vulvodynia were more limited in basic physical activities.

The Physical Role Limitation scale asked participants the extent to which, during the prior month, they needed to cut down on, or had difficulty performing, work or activities because of their physical health or pain. The vulvodynia condition reported greater difficulties performing work or activities than the control condition.

The Social Functioning scale measured participation in conversations with family, friends and coworkers, as well as activities such as going to movies, parties, and business meetings. Even engaging in social functions was more difficult for vulvodynia subjects; they reported to a greater extent than controls that their physical health or pain interfered with social activities.

Emotional Well-Being

The Negative Mood scale asked participants to rate their mood and levels of irritability and anxiety during the prior week. On this scale, vulvodynia subjects reported more negative mood than controls. However, when vulvodynia subjects were asked about a range of moods on the General Mental Health scale, they scored the same as control subjects. (The General Mental Health scale has four positive moods such as happy and calm, and five negative moods). These somewhat contradictory results suggest that women with vulvodynia may experience more negative moods, but not necessarily fewer positive moods.

The Emotional Role Limitation scale, similar to the Physical Role Limitation scale, asked participants how much, during the prior month, they needed to cut down on, or had difficulty performing, work or activities. This time, however, participants were asked the extent to which they attributed these limitations to negative emotions such as feeling depressed or anxious. Vulvodynia subjects reported being more limited in work and activities than control subjects, not only because of their physical health and pain, but also because of negative emotions such as anxiety and depression.

Sexual Functioning

The Sexual Activity and Sexual Satisfaction measures were only completed by subjects who: (1) had a sex partner, and (2) had engaged in sexual activity during the prior month. Seventy-five percent of vulvodynia subjects and eighty-two percent of control subjects fulfilled the above criteria.

The Sexual Activity measure assessed how often per month subjects felt a desire for, became aroused by, achieved orgasms from, and engaged

(See ASSESSMENT page 9)

Assessment

(from page 8)

in a range of sexual behavior from kissing to sexual intercourse. No differences in sexual activity were found between vulvodynia and control subjects. The Sexual Satisfaction measure assessed how pleasurable sexual activity was and how satisfied the subject felt. Interestingly, the vulvodynia subjects reported greater sexual satisfaction than control subjects.

In summary, fewer women with vulvodynia (as compared to controls) are engaging in sexual activity, but for those who are, sexual activity and sexual satisfaction is comparable to or better than that experienced by control subjects. One problem with these findings is that these sexual functioning measures are not specifically designed for chronic pain conditions, and may not be sensitive enough to differentiate individuals with chronic pain from healthy individuals.

The Marital Satisfaction survey was completed only by subjects in a relationship. This survey assesses a range of areas including the extent to which partners agree on handling finances, family and friends, sexual relations, and interests. Compared to control subjects, women with vulvodynia reported greater marital dissatisfaction, according to this survey.

Study Limitations

A number of limitations to the current study should be noted. First, the present study relied primarily on results from support group members, a select sample of women with vulvodynia. Secondly, confirmation of the diagnosis by a physician was not required. Finally, while this study assessed a range of domains, only one mode of assessment, i.e, self-report measures, was utilized. Future treatment studies would be greatly improved by assessing outcome with standardized multidimensional measures.

Conclusion

The chronic pain literature has highlighted the importance of multidimensional assessment of chronic pain patients. The present study employed this comprehensive approach with a sample of vulvodynia patients. In comparison to healthy control subjects who did not have chronic pain, women suffering from vulvodynia demonstrated greater physical disabilities (due to both the pain and its emotional consequences), more negative mood, and greater marital dissatisfaction. To gain further insight into the consequences of living with chronic vulvar pain, it is recommended that future studies of vulvodynia patients utilize a multidimensional assessment approach.■

NVA Represented at Nurse Practitioners Conference

On June 3rd, Jane Elmer, the NVA contact leader in Plain, Wisconsin, and Christin Sanders, a member of the NVA executive board, represented the National Vulvodynia Association at the 27th Annual Conference for Nurse Practitioners in Women's Health in Lake Geneva, Wisconsin.

Women's health topics addressed at the conference included HIV, vulvodynia, urinary incontinence, menstrual headache, polycystic ovary syndrome, contraception, and endometrial biopsy.

Jessica Thomason, M.D., director of WomenNow Health Care, Milwaukee, Wisconsin (see article on page 1), was in charge of the vulvodynia section of the conference. Two hundred and fifty nurse practitioners attended her lecture on vulvodynia and participated in a workshop on how to perform vulvar biopsies.

The NVA is committed to spreading awareness of vulvodynia at future conferences of gynecologists, dermatologists, and other health care professionals. If you are willing to represent the NVA at conferences that are held in your city, please contact Chris Sanders at csanders@bme.jhu.edu or at 410-614-5775. ■

Vulvodynia

(from page 6)

improved and three percent were failures. No patient's symptoms worsened as a result of surgery. Complete removal of both the major and minor vestibular glands was critical to success of the procedure. Fifteen percent of patients subsequently became pregnant. Eight percent required a second procedure such as a skin graft at the perineal body posteriorly, removal of a suture granuloma, or, in one case, a second surgery to remove a gland that wasn't removed during the first procedure.

SUMMARY

Chronic vulvar pain, whether intermittent or constant, can be a debilitating symptom that deserves appropriate work-up and disease specific therapy. As the millenium draws to a close, it is unwarranted and unjustified that a woman should have to live with the fear of suffering from such pain or being told that it's "all in your head."

There is hope associated with treating this disorder, and vulvodynia patients need to be directed toward health care providers who are interested, dedicated and competent in helping them. In particular, surgery for Vulvar Vestibulitis Syndrome should no longer be considered a last effort, because there is excellent data reported from various investigators nationwide showing high success rates with this form of therapy. Such surgery does not have to be cosmetically disfiguring and can help to restore normal sexual function between loving couples. ■

Letters

(from page 2)

do our best to include articles or forums on emotional and relationship issues in future newsletters.

Dear NVA,
Hopefully my experience will help the many others whom your good articles and demographics indicate have tried anti-yeast treatments. I too thought I had yeast infections which exacerbated my vulvodynia.

What I discovered was that the white, non-odorous secretions which appeared to be yeast products indicated cytolytic vaginosis. This is a condition reversed by baking soda douches – and exacerbated by the vinegar douches and other applications I was using to combat the yeast infection I thought was the problem!

Cytolytic vaginosis is characterized by overly-acidic secretions which cause painful inflammation of the vestibule. My physician diagnosed my condition correctly, but could not figure out the cause. If anyone has had experience reversing the underlying cause of excess acidity (or with other remedies), please write to me.

Meanwhile, those with suspected yeast infections might want to have a culture for cytolytic vaginosis and/or see if douching with several teaspoons of baking soda in a quart of water improves their condition.

Sincerely,
Barbara Herzog
5050 Lowell St. NW
Washington, D.C. 20016

Dear Barbara,
Thank you for your letter about cytolytic vaginosis. You are correct that this can be one of the problems that women experience. I think all vulvodynia sufferers would do better if their condition was reviewed periodically. A diagnosis can change, become more complicated, or a secondary condition may appear.

Cytolytic vaginosis is a condition in which the overgrowth of lactobacilli destroys epithelial cells and produces an excess of irritating acids. Cyclical, recurrent symptoms typically appear during the luteal phase of a woman's menstrual cycle. The symptoms include vulvar burning, itching, painful urination and entry pain with intercourse. The symptoms usually increase until the onset of menses. This raises the vaginal pH and thereby often provides relief of symptoms. This pattern can repeat for months.

The normal pH of vaginal secretions is 4.0 which is acidic (pH 7 is neutral; above is alkaline, below is acidic). As you mentioned, the initial treatment of cytolytic vaginosis is baking soda in water (an alkaline solution), which is used to make the vaginal secretions less acidic.

Thanks for your help in drawing attention to this problem. Most women don't know that they should have the pH of their vaginal secretions measured frequently— preferably at every visit to their gynecologist or nurse practitioner. ■

CBS

(from page 7)

depicted Janet's surgical "cure." Unfortunately, this gave most viewers the impression that surgery is the only treatment for vulvodynia.

It is, of course, impossible to cover all aspects of vulvodynia in a 10 minute television segment. In spite of the fact that it only portrayed one vulvodynia treatment, the NVA is thrilled that Janet had the opportunity to tell her personal story on this network television presentation of "Medical Miracles." The Roberts' willingness to open up a private part of their lives on national television was courageous and will help thousands of women facing similar ordeals. A few months after the filming ended, Janet and Ted Roberts produced their own miracle, Margaret Coe Roberts, born January 1, 1998. ■

Support 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?

The appeal of this method of giving is that the donor is entitled to take a charitable deduction for the full current value of appreciated securities held longer than one year, and is able to avoid paying the capital gains tax that would be due if the securities were sold.

For more information, please contact NVA Executive Director Phyllis Mate at 301-299-0775 or via e-mail at mate@nva.org. ■

Subjects Needed

Researchers at Johns Hopkins Hospital are currently looking for volunteers to participate in a study concerning changes in pain perception over a 3-4 month period.

Volunteers who have Vulvodynia are needed as well as those who don't experience any chronic vaginal or vulvar pain. To participate you must be between the ages of 18 and 45, currently menstruating regularly, and not pregnant. **You are especially needed if you are taking oral birth control medication and have Essential Vulvodynia and Vulvar Vestibulitis Syndrome** (diffuse pain throughout the vulvar region and also pain with tampon insertion and/or sexual intercourse).

You **do not** have to be from the area surrounding John Hopkins Hospital (Baltimore, Maryland) to take part in this study. Correspondence can be done via mail and phone.

If you are interested in participating in this study or would like more information, please contact Chris Sanders at the Blaustein Pain Treatment Center, Johns Hopkins Hospital, at **410-614-5775** or via e-mail at **csanders@bme.jhu.edu**. ■

Vulvodynia Study in Mid-Atlantic Area

Researchers at the Johns Hopkins Hospital in Baltimore, Maryland are currently seeking women who have Vulvodynia to participate in a study concerning sensory perception changes. If you are between the ages of 18 and 45, are currently menstruating, are not pregnant, and have been diagnosed with Vulvar Vestibulitis Syndrome for at least 6 months, you are an appropriate candidate for this study. You will be asked to come to Johns Hopkins Hospital for a two hour testing session. Volunteers are also needed for a control group consisting of women who **do not** suffer from Vulvodynia.

If you are interested in participating in this study or would like more information, please contact Chris Sanders at the Blaustein Pain Treatment Center, Johns Hopkins Hospital, at **410-614-5775** or via e-mail at **csanders@bme.jhu.edu**. ■

THE NVA NEEDS YOUR CONTRIBUTION

I WANT TO SUPPORT THE NVA AND RECEIVE MORE INFORMATION ON VULVODYNIA.

Name _____

Address _____

_____

Phone (H) _____ (O) _____

The NVA needs the support of everyone: patients, families, and health care providers.

❑ $35 ❑ $50 ❑ $100 ❑ Other $ _____

❑ Yes, I would like to be contacted by other NVA supporters in my area.

❑ No, I do not want to be contacted. Please keep my name confidential.

Please send your check or money order, payable to NVA, together with your name, address and telephone number to: NVA, P.O. Box 4491, Silver Spring, MD 20914-4491.

N
V
A

NATIONAL VULVODYNIA ASSOCIATION

P. O. Box 4491 ❖ Silver Spring, MD 20914-4491