National Vulvodynia Association

NVA News

Volume XIII, Issue III Fall 2008

Treating Vulvodynia with Manual Physical Therapy

By Stephanie Prendergast, MPT, Elizabeth Rummer, MSPT and Rhonda Kotarinos, PT

Ms. Prendergast and Ms. Rummer are co-directors of the Pelvic Health and Rehabilitation Center in San Francisco, California. Ms. Prendergast also serves on the board of directors of the International Pelvic Pain Society and the Society for Pudendal Neuralgia. Ms. Kotarinos has specialized in the treatment of pelvic floor dysfunction for over 30 years and is a member of the International Pelvic Pain Society and the International Association for the Study of Pain.

Introduction

Vulvodynia is a prevalent syndrome that significantly impacts a woman's physical health and quality of life. The International Society for the Study of Vulvovaginal Disease has established specific terminology to classify the subsets of chronic vulvar pain: generalized, localized, provoked, and unprovoked. For the purposes of this article, the term "vulvodynia" will refer to all the above subsets, as well as vulvar vestibulitis syndrome. As patients and clinicians struggle to understand the complex pathophysiology of vulvodynia, the National Vulvodynia Association (NVA) continues to increase awareness, support research, and facilitate communication between patients and providers. Over the past decade, we have learned that vulvodynia and other chronic pelvic pain syndromes have multiple causes and span several medical disciplines, including gynecology, dermatology, physical therapy and pain management.

In 2003, the American Physical Therapy Association's (APTA) women's health section formed a Vulvar Pain Task Force to develop evidence-based physical therapy guidelines for vulvodynia. Four years later, the APTA Vulvar Pain Task Force concluded, "Chronic vulvar pain may be related to, or caused by, musculoskeletal, neurological, viscerogenic or myofascial dysfunction." The research on physical therapy treatment

See PHYSICAL THERAPY, page 2

The Need for Research on Coexisting Conditions

By Hannele Rubin, MSJ, and Christin Veasley, BS

Hannele Rubin is a New Jersey-based writer specializing in health topics. She is a graduate of Northwestern University's Medill School of Journalism and has written articles for numerous publications. Christin Veasley is NVA's research director and associate executive director.

Kimberly Menacho, 47, a former collegiate gymnast and mother of two teens, has a long list of health problems: vulvodynia, interstitial cystitis, endometriosis, fibromyalgia, irritable bowel syndrome and chronic fatigue. She volunteers as an NVA support leader and teaches fifth grade in Sacramento, California. "It's a demanding job, but I'm pretty high-functioning. My vulvodynia is the most difficult to manage, but for the most part, all of my conditions are pretty much under control," she says. Occasionally, when Menacho gets a bladder or vaginal infection, her symptoms will flare. Then she takes Effexor and does physical therapy, which significantly help to control her pain. In recent years, Menacho's only major limitations are not being able to ride a bicycle or go horseback riding.

See COEXISTING, page 7

Physical Therapy

(from page 1)

shows that addressing dysfunctional muscles, joints, ligaments, connective tissue (fascia), and abdominal organs can reduce or eliminate chronic vulvar pain. Concurrently, researchers in other disciplines have been studying pelvic floor involvement in vulvodynia. In 2006, Denniz Zolnoun, MD, described Vulvar Vestibulitis Syndrome, a major subset of vulvodynia, as "characterized by varying degrees of pain and dysfunction in the mucosa and underlying musculature, and associated dysfunction in the pain regulatory system." Studies continue to emerge indicating that musculoskeletal dysfunction may be a common cause of chronic pelvic pain (CPP). In 2008, Frank Tu, MD, conducted a blinded, prospective, cross-sectional study of 19 women with CPP and 20 healthy control subjects. He found that many women with CPP have pelvic musculoskeletal abnormalities and concluded that the investigation of somatic pain generators is warranted in these patients.

A physical therapist specializing in pelvic floor dysfunction can help identify and treat pelvic abnormalities in vulvodynia patients. Previous literature has described physical therapy treatment of the pelvic floor using biofeedback, real-time ultrasound, electrical stimulation, stretching and strengthening, neural mobilization, and structural and biomechanical correction. Many of these techniques are widely used in effective treatment programs. (See Summer 1996 and Winter 2002 issues of *NVA News*.)

As the field of pelvic medicine has advanced, findings from animal and clinical research have shown that syndromes such as vulvodynia involve musculoskeletal structures that extend beyond the pelvic floor muscles and surrounding joints. Consequently, the medical profession has incorporated manual examination of the pelvic floor muscles, vulvar and external connective tissue, and myofascial trigger points into the evaluation of a patient with vulvar pain. It is our position that incorporating manual physical therapy techniques will improve patient outcome. This article presents the rationale behind the use of manual techniques and how to use them in evaluating and treating vulvodynia patients.

Understanding the Viscerosomatic Reflex

When someone walks into an emergency room complaining of severe left shoulder, elbow or jaw pain, the immediate concern of the medical staff is to rule out an acute heart condition because the heart muscle, when injured, refers pain to these other areas. 'Referred pain' is pain felt at a different site in the body than where the original injury or disease occurred. It can also be conceptualized as a *viscerosomatic reflex* or effect – dysfunction in the viscera (internal body organ) causing dysfunction in the soma (skin or muscle). The acute signs of a viscerosomatic reflex are increased skin temperature, increased moisture of the skin, texture changes within the skin, increased subcutaneous fluid and contraction of muscle. In most cases, once the organ pathology has resolved, these other changes disappear. In a chronic situation, the skin and subcutaneous tissue thickens and muscles become hard, tense and hypersensitive.

Two researchers studying viscerosomatic reflexes are Ursula Wesselmann, MD, and Maria Giamberardino,

See PHYSICAL THERAPY, page 3

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

NVA News is published three times per year.

Editor:
Phyllis Mate

Contributor: Chris Veasley
Layout: Andrea Hall

Physical Therapy

(from page 2)

MD. According to Wesselmann, there has been research conducted on viscerosomatic reflexes associated with the gastrointestinal and urinary organs, but little is known about pain pathways from the female reproductive organs. One of Wesselmann's basic science studies demonstrated that inflammation of the uterus led to a visible skin reaction in rats. Giamberardino's research has focused on muscle hyperalgesia (exaggerated sense of pain) associated with visceral dysfunction. In one study, she assessed the muscle pain thresholds of patients with a history of passing kidney stones. Patients with one to two episodes had muscle hyperalgesia in their lower backs, the area of referred pain from the kidney. Patients with four to six episodes had severe muscle hyperalgesia in their lower backs compared to patients with no history of passing kidney stones. This muscle hyperalgesia persisted in patients many years after passing the stone. During testing, the patients complained that the pain reproduced experimentally in their backs was identical to the pain they had experienced with the original passing of the stone.

Somatovisceral Reflex

Animal studies have demonstrated the role of another reflex, known as the *somatovisceral reflex*. This type of reflex originates in the body wall and terminates in the viscera, e.g., a painful, ongoing stimulus to rats' tail muscles led to detrimental changes in their bladders, even though there was no bladder pathology present. In humans, dysfunctional pelvic floor muscles also can cause irritation to the bladder, resulting in urinary urgency, frequency and pain.

Case Report

The following case report should help to clarify the specific role of the viscerosomatic reflex in vulvar pain. Carrie, a 24-year-old woman with vulvar vestibulitis, had been married for seven months and wasn't able to enjoy pain-free intercourse. As a child, she had suffered from recurrent culture-proven urinary tract infections. She was never able to use tampons and found gynecologic examinations excruciating. Voiding did not produce pain, but she experienced both urinary hesitancy and nocturia, urinating frequently during the night.

During the pelvic examination, Carrie experienced severe pain with vaginal insertion and an exaggerated protective guarding response. Extreme stiffness of the pelvic floor muscles and vulvar connective tissue was noted. The range of motion and force of both shortening and lengthening contractions of her pelvic floor were markedly decreased. Because insertion was so painful for her, we weren't able to complete the entire evaluation. She had extreme myofascial and connective tissue restrictions in the somatic areas that have been designated referral zones for bladder pain and vulvodynia. (See Figure 1, below)

Soon after being evaluated she moved to another city and was not able to undergo a full course of treatment. She returned to the area one year later and reported that she had tried physical therapy treatment with no improvement. Urinating was now painful and she was experiencing a constant sense of urinary urge. She also felt an aching pain most of the time with random sharp, shooting pain throughout the day, as well as vaginal pain triggered by coughing and sneezing. As a result of her worsened condition, a pelvic exam was not performed. Re-evaluation of myofascial and connective tissue in her abdomen, buttocks, and lower extremities confirmed that restrictions in the referral zones had persisted and become more severe.

After Carrie returned to our clinic, we started a treatment plan that included connective tissue manipulation to the

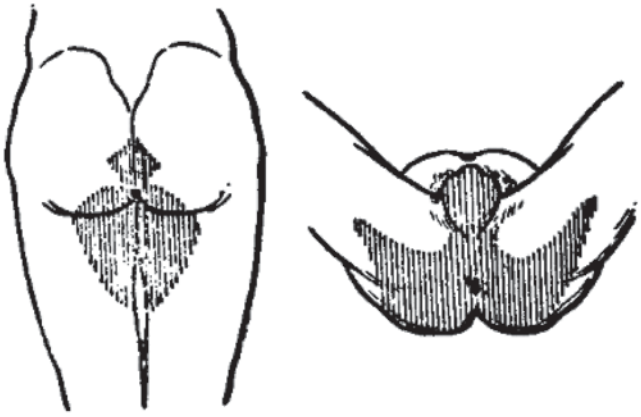

Figure 1: Bladder referral zone

See PHYSICAL THERAPY, page 4

Physical Therapy

(from page 3)

abdomen, buttocks and lower extremities to reflexively desensitize the vulvar tissues. Myofascial trigger points were treated with manual release and stretch techniques, followed by ice application and stretch. After 11 one-hour visits, Carrie was able to undergo a pelvic exam with considerably less pain. She was able to tolerate initiation of internal myofascial and connective tissue manipulation. By the fourteenth visit, she was able to have intercourse and only experienced discomfort following intercourse. For a self-management technique, we taught her how to lengthen the pelvic floor during penetration, which facilitated pain-free intercourse.

After 39 visits she was discharged and started on a self-management home-exercise program. Most of the time, intercourse was comfortable and enjoyable for her. When she did experience pain flares, she was able to resolve them using the self-management techniques. About one year after she completed therapy, she returned for a check-up because she was pregnant and wanted to discuss delivery options. Carrie was experiencing enjoyable intercourse at that time and was virtually pain-free. She went on to vaginally deliver a healthy baby. During delivery, she experienced a small tear that healed normally. Six months after the birth of her child, she phoned to report that she was pain-free with no related problems.

PT Evaluation and Treatment

For patients with vulvodynia, a typical physical therapy treatment regimen consists of one to two hour sessions per week until pain relief occurs. In addition to the manual techniques described below, a comprehensive physical therapy treatment plan includes several other components. The physical therapist works with the patient to correct joint and biomechanical abnormalities, helps the patient make temporary lifestyle modifications and prescribes a home exercise program. As a patient's symptoms dissipate, less frequent physical therapy sessions are required. Typically, women with vulvodynia are treated one to two hours per week for 8 to 12 weeks, with a gradual decrease in frequency for up to one year, depending on the severity and longevity of the condition.

Connective Tissue

Healthy connective tissue is not thickened or painful and moves freely. As mentioned above, the viscerosomatic reflex can lead to vulvar and other connective tissue restrictions, internal and external myofascial trigger points, and pain. To both evaluate and treat vulvar connective tissue dysfunction, a physical therapist must utilize a technique known as skin rolling. This manual technique manipulates connective tissue to normalize its mobility, improve circulation, reduce hypersensitivity and minimize the negative reflexive effect on surrounding muscle, nerve, and viscera.

To assess the vulvar connective tissue, the physical therapist manipulates the vulvar tissue between the thumb and index finger, noting tenderness, mobility, and thickness of the tissue. Any pre-existing scars are also examined for tenderness by palpating and mobilizing them perpendicular to the scar. To perform vulvar connective tissue manipulation, the therapist will gently grasp the vulvar tissue between his/her thumb and forefinger. The therapist will palpate to feel where the tissue is thick and restricted, and mobilize the tissue using the thumb and forefinger to improve blood flow, decrease thickness, and restore mobility. Commonly, this technique reproduces the discomfort or pain a patient feels during intercourse and may cause temporary burning. Although the patient may feel discomfort, therapy-induced symptoms should decrease or remain the same during treatment. If symptoms increase, or the patient cannot tolerate the technique, the therapist will discontinue it until better tolerated.

Since patients with pelvic pain typically have connective tissue restrictions in the thighs, along the bony pelvis, in the gluteals and in the abdomen, all these areas must be evaluated and treated. External connective tissue manipulation involves the therapist 'pinch-rolling' the affected tissue (below the skin and above the muscle) between her thumb and other four fingers, with both hands. When tissue is restricted, manipulating it typically causes a sharp sensation and may cause tissue soreness in the days following treatment. As the patient's tissue normalizes over a series of treatments, skin rolling is no longer painful during or after treatment.

Pelvic Floor Muscles

The internal muscular exam begins with the therapist inserting one finger into the vagina, noting if there is pain or excessive tension upon entry. Motor control should be manually assessed prior to specific muscle

See PHYSICAL THERAPY, page 5

Physical Therapy

(from page 4)

examinations. This is done by asking the patient to concentrically contract (squeeze) and eccentrically contract (push out) the levator ani muscles, the muscles surrounding the vagina, and voluntarily relax or drop the pelvic floor muscles. By palpating the vaginal pelvic floor muscles, the concentric strength of these muscles is scored using Laycock's modified Oxford Grading System . This grading system is a 6-point scale as follows: 0=no contraction, 1=flicker, 2=weak, 3=moderate, 4=good (with lift), and 5=strong. The physical therapist should also note the rate at which the levator ani muscles relax after a concentric contraction. Muscles that are hypertonic, or tight, have difficulty relaxing or returning to a normal length after a single concentric contraction. After noting the motor control of the levator ani muscles, each muscle of the pelvic floor, including the obturator internus, ischiocavernosus, bulbospongiosus, transverse perinea, coccygeus and anal sphincter, must be assessed for tone, presence of myofascial trigger points and areas of muscle spasm and/or tenderness.

Traditionally, strength and motor control of the pelvic floor muscles have been assessed using biofeedback. Unlike biofeedback, a manual exam enables the therapist to assess the strength and quality of the contraction, as well as the tone of the musculature. Sometimes a therapist finds it beneficial to use both biofeedback and a manual assessment. The last component of the internal examination is palpation of the pudendal nerve for tenderness and/or a positive Tinel's sign, otherwise known as the Valleix phenomenon. Upon palpation, if a patient experiences sharp, shooting pain in the sensory distribution of the pudendal nerve, the test is positive. The pudendal nerve, which innervates the majority of the pelvic floor muscles and vulvar tissue, can play a role in pelvic pain syndromes. The nerve can be palpated for tenderness in four locations: at the ischial spine, at Alcock's canal, at the terminus of inferior rectal branch, and along the clitoral branch.

To treat the pelvic floor musculature, the physical therapist inserts one finger in the vagina or the rectum to access the pelvic floor muscles. Manual techniques are employed to normalize muscle tone and motor control, and to eliminate myofascial trigger points. The techniques are performed by directly stretching the muscle, compressing the muscle, and/or using movement to achieve a muscle release. The most desirable technique should decrease muscle tone while causing only minimal discomfort for the patient. After a successful series of pelvic floor treatments, the muscles should have improved tone and motor control, and the patient should report less tenderness upon palpation of the muscles. It is also possible that she will have less vulvovaginal pain.

Myofascial Trigger Points

Another common finding with women who suffer from vulvodynia is the presence of myofascial trigger points in the pelvic floor and the muscles attaching to the pelvis. Myofascial trigger points (MTrPs) are hyperirritable spots, usually within a taut band of skeletal muscle or the muscle's fascia, that are painful upon compression. They cause referred pain, local tenderness and autonomic phenomena such as abnormal sweating, persistent and profuse nasal discharge and tear secretion, and excessive lubrication. Trigger points also cause proprioceptive disturbances, such as dizziness, tinnitus and distorted weight perception of lifted objects. Untreated trigger points can lead to motor dysfunction and muscle weakness of involved and surrounding muscles, and can interfere with adequate muscle lengthening.

Janet Travell, MD, and David Simon, MD, pioneered the research on MTrPs. In their two volume book, Myofascial Pain and Dysfunction: The Trigger Point Manual, they describe how to identify and treat a MTrP. The authors present the recommended criteria for identifying a trigger point, but also state, "There is no one diagnostic examination that alone is a satisfactory criterion for routine clinical identification of a trigger point. Based on experimental information now available, the combination of spot tenderness in a palpable band, and subject recognition of the pain, are the minimum acceptable criteria." Travell's approach to identifying trigger points is utilized by most physical therapists.

A 2005 NIH-funded pilot study compared the efficacy of external and internal myofascial physical therapy versus Global Therapeutic Massage in patients with pelvic pain. Fifty-seven (57) percent of subjects receiving myofascial release therapy reported their symptoms were markedly or moderately improved, compared to 21 percent of subjects in the control group.

In the evaluation of a vulvodynia patient, the physical

See PHYSICAL THERAPY, page 6

Physical Therapy

(from page 5)

therapist should examine multiple muscles for MTrPs that could be contributing to her symptoms. Frequently, trigger points in the obturator internus, ischiocavernosus, bulbospongiosus, transverse perinea, and levator ani muscles have been identified as referring pain to the vagina and/or vulvar tissues. The extrapelvic muscles that must be evaluated include the abdominal muscles, the iliopsoas, the adductors, and the gluteals. The iliopsoas connects the lower part of the spine to the hip, the adductors are in the inside of the upper leg, and the gluteals are muscles in the buttocks that extend, abduct and rotate the thigh.

After identifying the MTrPs, there are two manual techniques the physical therapist can use to eliminate them. In the first technique, the therapist manually compresses the trigger point for 60 to 90 seconds or until she/he can feel the trigger point 'release.' The second technique requires the therapist to compress the trigger point and instruct the patient to very gently contract the involved muscle 10 to 15 times, or until the therapist feels the trigger point release. The choice of technique depends on the preference of the individual therapist and the tolerance of the patient.

Managing Therapy-Related Discomfort

Patients commonly report pain or discomfort during trigger point therapy and connective tissue manipulation. As expected, the extent of the discomfort may be linked to the severity of the patient's condition. Hypertonic muscles, myofascial trigger points, and restricted connective tissue are often tender to touch. As a PT session progresses, the intensity of the discomfort should decrease and the more sessions a patient has completed, the less discomfort she will experience.

If a patient has difficulty tolerating physical therapy or is uncomfortable afterwards, the therapist and patient can modify the program. For example, in the case study above, the physical therapist desensitized the vulvar tissues reflexively through external connective tissue manipulation until the patient could tolerate internal treatment. Patients may request a prescription for 2% lidocaine or other medication from their physician that would make them more comfortable during the sessions. For post-therapy tissue soreness, ice massage can be helpful.

Conclusion

The musculoskeletal component of vulvodynia is significant, and left untreated, can prevent a patient's condition from improving. Using a multi-disciplinary approach, including manual techniques, can help a woman eliminate or manage her condition and restore her quality of life. Physical therapists specializing in pelvic pain disorders can be found through the NVA (www.nva.org), International Pelvic Pain Society (www.pelvicpain.org) and the American Physical Therapy Association (www.womenshealthapta.org).

(*Editor's Note: To receive a footnoted version of this article, with a complete list of references, contact Gigi Brecheen at gigi@nva.org or 301-949-5114*.)

Selected References:

1. Zolnoun D, et al. A conceptual model for the pathophysiology of vulvar vestibulitis syndrome. *Obstet Gynecol Survey* 2006;61:395-401.
2. Strauhal MJ, et al. Vulvar Pain: A Comprehensive Review. *J Sect Women's Health APTA* 2007;31:7-25.
3. Tu F, et al. Physical therapy evaluation of patients with chronic pelvic pain: a controlled study. *Am J Obstet Gynecol* 2008;198:272 (e1 to e7).
4. Chaitow, L (1988) Soft-tissue manipulation: a practioner's guide to the diagnosis and treatment of soft tissue dysfunction and reflex activity. Healing Arts Press, NY, NY.
5. Wesselmann U, Lai J. Mechanisms of referred pain: uterine inflammation in the adult virgin rat results in neurogenic plasma extravasation in the skin. *Pain* 1997:309-317.
6. Giamberardino MA et al. Referred muscle pain and hyperalgesia from viscera. *Journal of Muscle Pain* 1999. 7: 61-69.
7. Laycock J. Clinical evaluation of the pelvic floor. In: Schussler B, Laycock J, Norton P, Stanton SL, eds. Pelvic Floor Re-education. London, United Kingdom: Springer-Verlag;1994:42-48.
8. Prendergast SA, et al. Screening for musculoskeletal causes of pelvic pain. *Clin Obstet Gynecol* 2003;46:773-782.
9. Travell, J. and Simons, D. Myofascial Pain and Dysfunction: The Trigger Point Manual, volume 1. Baltimore, MD: Williams and Wilkins, 1999. ■

Coexisting

(from page 1)

Not all women with vulvodynia suffer from related disorders and it's unusual to have as many coexisting conditions as Menacho does. Over the past decade, however, some clinicians have observed that certain conditions coexist far more frequently in a population of women with vulvodynia than they do in the general population.

Does Menacho think her disorders are related? She reflects on the strain of being a competitive gymnast, a previous back injury and her genetic makeup. "I don't know," she says. "How would you know? But I think it's highly suspect that a certain group of women suffer from many pain syndromes simultaneously."

Research Findings

Some women with vulvodynia have long reported sufferring from multiple conditions, including endometriosis, interstitial cystitis, temporomandibular joint and muscle disorders, burning mouth syndrome, migraine headache, fibromyalgia, irritable bowel syndrome, low back pain, multiple chemical sensitivities, chronic fatigue syndrome and allergies. In general, the potential overlap of these conditions and vulvodynia has not been studied by the medical community. However, there has been some research on a few of the coexisting conditions and the studies' findings are summarized below.

Interstitial Cystitis / Painful Bladder Syndrome

The majority of research in this area has focused on an association between vulvodynia and interstitial cystitis (IC). Also known as painful bladder syndrome, IC is a chronic, painful, inflammatory condition of the bladder wall. Symptoms of IC include urinary urgency and frequency, pelvic pain and painful intercourse. A conservative estimate of IC prevalence is that it affects at least one million Americans, of which 90 percent are women.

In 1990, the first study on both conditions found that 11 out of 36, or roughly 30 percent of women with Vulvar Vestibulitis Syndrome (VVS) also had IC, "a much greater concordance than would be expected to occur by chance," stated the study's author, William McCormack, MD, professor of obstetrics and gynecology, State University of New York Health Science Center-Brooklyn. He proposed that both IC and vulvodynia are syndromes of the urogenital sinus, which is fetal tissue that develops into the urinary and reproductive organs. Between the fifth and twelfth week of embryologic development, the urogenital sinus, a long tube-like structure of the embryo, divides; one portion forms the urethra and bladder and the other forms the vestibule and vagina. "Because all the tissues – bladder, urethra and vestibule – involved in both syndromes derive from the urogenital sinus, the disorders might have a common etiology," proposed McCormack.

A recent study of women with VVS investigated sensitivity of the umbilicus (navel), which also derives from the urogenital sinus. The findings add further evidence that these conditions may represent a generalized disorder of the urogenital sinus-derived epithelium. Lead researcher, Andrew Goldstein, MD, director of the Center for Vulvovaginal Disorders in Washington, DC, tested for umbilical hypersensitivity in 20 women with primary VVS, 16 with secondary VVS and 8 controls. (Women with primary VVS have pain from their first attempt at sexual intercourse or tampon use, whereas women with secondary VVS initially experience painless intercourse or tampon insertion and subsequently develop pain). Goldstein found that women with primary VVS had significantly lower umbilical pain thresholds than women with secondary VVS or controls. Goldstein noted, "An association between IC and vulvodynia has been reported in patients as young as 4 years old, suggesting that these conditions may represent a congenital defect, specifically in the urogenital-sinus derived epithelium. Our data adds merit to the theory that there is a congenital defect in tissue derived from the primitive urogenital sinus in women with primary VVS."

The reported percentage of women who have both IC and vulvodynia varies widely, from 12 to 68 percent, depending on which study you read. The most recently published study, conducted by Donna Carrico, WHNP, at Beaumont Hospital in Royal Oak, Michigan, found that 51 percent of the 70 women with IC also had vulvodynia, as assessed by patient history, pelvic exam and q-tip testing. In addition, women with both conditions had significantly more pelvic floor tightness and pain compared to those with vulvodynia alone. When asked about the connection between pelvic floor muscle dysfunction and these overlapping conditions, Carrico said, "We suspect that pelvic floor muscle tightness puts

See COEXISTING, page 8

Coexisting

(from page 7)

pressure on pelvic nerves, causing neural upregulation and a heightened pain response. It is possible that pelvic floor dysfunction also affects blood flow and cellular function in both the bladder and vulva." Furthermore, Carrico speculates that "women with high levels of inflammation and mast cells (cells that promote an inflammatory response and sensitize peripheral nerves), may be more likely to suffer from both conditions."

The findings of a recent University of Maryland study may shed light on whether IC and vulvodynia are related conditions in some women. As part of a five-year NIH-funded project, John Warren, MD, professor of medicine in the department of infectious diseases, University of Maryland, and colleague Ursula Wesselmann, MD, professor of anesthesiology at the University of Alabama and NVA medical advisory board member, conducted a case-control study of 313 women with IC symptoms of less than one year. Their aim was to determine if 24 non-bladder pain syndromes were more prevalent in women with IC before their bladder pain started. They found that IC patients suffered more often from vulvodynia and 10 other pain syndromes prior to the onset of their IC symptoms; however, only 2 to 8 percent of IC patients reported having vulvodynia prior to their IC, which is much lower than previous reports of 12 to 61 percent in established IC cases.

In a separate publication, Warren and Wesselmann reported that after IC onset, 27 percent of cases had burning genital pain worsened by touch, tampons and sex, all consistent with a diagnosis of vulvodynia. Warren concluded, "Taken together, our data suggest that vulvodynia can occur prior to onset of IC symptoms, but that sequence is uncommon. More often, vulvodynia appears to be a referred pain of IC."

Bruce Kahn, MD, assistant clinical professor of obstetrics and gynecology at Scripps Clinic in La Jolla, California, concurs with these findings. In a recent study, Kahn and his colleagues administered the Pelvic Pain and Urgency/Frequency questionnaire (assessing pelvic pain, urinary symptoms and pain associated with sexual activity), as well as a potassium sensitivity test, to 122 women with generalized vulvodynia. In a potassium sensitivity test, two solutions are separately instilled into the bladder: (i) potassium, which causes pain in women with IC and (ii) water, which does not cause pain. During the test, patients are asked to rate their urinary symptoms and pain levels. Overall, the researchers observed potassium sensitivity in 84 percent of vulvodynia patients, with 80 percent reporting symptoms highly indicative of IC, such as urinary urgency, frequency and pain. Kahn pointed out, "Part of the challenge of recognizing IC comes from the fact that bladder pain localizes poorly. When bladder pain fibers are activated, the signals travel to the spinal cord and then refer to one or more locations anywhere in the pelvis, including the lower abdomen, labia, perineum, vagina, thighs or lower back. Hence, bladder-origin pain may appear to be of gynecologic origin and the bladder is often overlooked as the source of pain. This study, combined with previous findings, lends support to the theory that, in many cases, vulvodynia pain may be referred from the bladder. More research is needed, but in the meantime, our data clearly demonstrate that IC deserves more attention in the differential diagnosis of vulvodynia."

Orofacial pain

Recently, researchers began exploring the relationship between vulvodynia and orofacial pain, specifically temporomandibular joint and muscle disorders (TMJ) and stomatodynia, or burning mouth syndrome (BMS). TMJ refers to a complex, poorly understood set of conditions that cause pain and dysfunction in the jaw joint and the muscles that control jaw movement. The National Institutes of Health estimate that over 10 million Americans have TMJ, and although both men and women suffer, most who seek treatment are women in their childbearing years. According to the International Association for the Study of Pain, BMS is characterized by "unremitting oral burning or similar pain in the absence of detectable oral mucosa changes," and affects almost 4 percent of the population. BMS is more common in women and often occurs during peri- or post-menopause.

After noticing that a significant percentage of her VVS patients complained of pain symptoms suggestive of TMJ, Denniz Zolnoun, MD, assistant professor of obstetrics and gynecology at the University of North Carolina-Chapel Hill, embarked on a study to explore the overlap between orofacial pain and VVS. Zolnoun and her colleagues asked 137 women with VVS to complete a battery of questionnaires to assess symptoms

See COEXISTING, page 9

Coexisting

(from page 8)

suggestive of clinical and sub-clinical orofacial pain (OFP). VVS patients who had been previously diagnosed with TMJ or reported more than three episodes of headache or 'sinus pain' per week, and experienced both provoked and spontaneous pain, were diagnosed with clinical OFP. Those who did not experience spontaneous pain, but reported OFP to touch or pressure, and had more than three episodes of head or sinus pain per week, were classified with sub-clinical OFP.

Zolnoun found that 47 percent of VVS patients had clinical OFP and an additional 31 percent had sub-clinical OFP. Upon formal evaluation by an orofacial pain specialist, the majority of VVS patients exhibited signs and symptoms highly suggestive of TMJ, only one type of orofacial pain. "It is intuitively perplexing as to why an idiopathic orofacial pain disorder is highly prevalent among women with idiopathic genital pain," said Zolnoun. Even more interesting, and consistent with findings from the Michigan IC study, she found that women with VVS and orofacial pain, as compared to those with only VVS, were more likely to report pelvic floor muscle tenderness and an inability to relax pelvic muscles during gynecological exams. The researchers proposed that a subset of women with VVS may share the same genetic vulnerability as women with TMJ. Zolnoun noted, "This subset may suffer from a widespread musculoskeletal pain disorder that is influenced more by their genetic makeup and central nervous system dysfunction than by a local inflammatory process in the vulva. Clearly, the success of biofeedback and physical therapy in certain VVS patients provides evidence that myofascial dysfunction plays a causal role in these women. Our current research focus is to thoroughly investigate the overlap of musculoskeletal pain disorders, such as TMJ and fibromyalgia, and VVS."

The association of BMS and vulvodynia was first reported in 2002 when physicians from the Orofacial Pain Clinic at the University Dental Hospital in Liverpool, England, published a case report of a 59 year-old woman. In 2007, another five patients with BMS and vulvodynia, termed 'vulvostomatodynia,' were the focus of a clinical study at the Dental Clinic at the University of Bari in Italy. The researchers suggested that the coexistence of burning pain in oral and genital mucosa might stem from a common cause and stated that, "although some studies found analogies between oral and vaginal mucosae, further research is necessary to ascertain which factors may predispose women to both conditions." They added that vulvostomatodynia may be rare and difficult to diagnose. However, it's also possible that patients aren't reporting both sets of symptoms to the same doctor, i.e., they're seeing different specialists for each complaint and not reporting all their symptoms to either doctor. Most patients wouldn't consider it relevant to report genital symptoms to their dentist or orofacial specialist, and many clinicians focus solely on a patient's primary complaint and often don't inquire about pain elsewhere in the body.

Andrea, a 54 year-old woman who suffers from vulvodynia and BMS, is one of many patients who deduced that her conditions might be related. After suffering with undiagnosed vulvodynia for six years, she read about the condition online and found a knowledgeable doctor through the NVA. Within five years of her vulvodynia onset, she started experiencing what she describes as a "scalding pain on the tip of the tongue, roof of the mouth, gums and lips." When she brought up BMS with her gynecologists, they had never heard of it. When asked why she initially thought that the conditions might be related, she explained, "Both are burning sensations and involve mucous membranes. The onset of both occurred during peri-menopause. In the beginning, I experienced both conditions intermittently, and after a period of time, both became chronic. I thought they might be related and wondered if they were connected to hormonal changes I was experiencing at that time."

Irritable Bowel Syndrome and Fibromyalgia

There have been only a few studies on the association of vulvodynia and irritable bowel syndrome or fibromyalgia. Irritable bowel syndrome (IBS) is a disorder characterized by abdominal cramping or pain associated with a change in bowel habits, such as recurrent constipation and/or diarrhea. Bloating is another common symptom. As many as 20 percent of the adult population, or one in five Americans, has symptoms of IBS, making it one of the most commonly diagnosed disorders in the US. It is reported more often in women than in men and appears to begin in young adulthood, although it can occur in all age groups. Fibromyalgia (FM) is a chronic pain disorder characterized by widespread musculoskeletal aches, pain and stiffness, soft tissue tenderness, general fatigue and sleep disturbance. It is

See COEXISTING, page 10

Coexisting

(from page 9)

estimated to affect 10 million Americans, mainly women, and is usually diagnosed between the ages of 20 and 50. A 2006 study of 77 women with vulvodynia and 208 controls, conducted at Robert Wood Johnson Medical School, found that women with vulvodynia were 3.1 and 3.8 times more likely to have either a comorbid diagnosis of IBS or FM, respectively.

A 2007 study by investigator Colleen Kennedy, MD, assistant professor of obstetrics and gynecology at the University of Iowa, also found that women with VVS were 3.4 times more likely to suffer from IBS. She commented on the study's findings, saying, "We don't know whether this reflects a common etiologic pathway, whether conditions like IBS predispose women to certain vulvar conditions (perhaps by the irritant nature of diarrhea, for example) or whether treatment for vulvar conditions can lead to bowel symptoms. Clearly, additional substantive research is warranted."

Further research on the possible overlap of FM and vulvodynia was conducted at Queen's University in Canada. In a 2006 study, 16 women with VVS and an equal number of matched controls underwent a tender point examination by an experienced rheumatologist. VVS patients were found to have significantly more painful tender points and higher pain intensity and unpleasantness ratings compared to controls, highly indicative of FM. In addition, the researchers had previously found that women with VVS who underwent functional magnetic resonance imaging during application of pressure to the posterior vestibule had significantly higher activation levels of certain parts of their brains, including the insular and frontal cortical regions, similar to what had been reported in patients with FM and IBS. "These results suggest that the mechanisms involved in VVS may be genital specific in some women or possibly centrally mediated in others," disclosed lead author Caroline Pukall, PhD, assistant professor of psychology at Queen's University. "What we don't know at this point is which condition exists first – the generalized sensitivity or the vulvar pain. For example, an untreated vulvar irritation could lead to central changes in sensory processing in genetically predisposed women, resulting in altered central pain processing and a widespread increase in sensitivity. On the other hand, women with VVS may be more sensitive to pain in general, and develop vulvar pain through a locally occurring event, such as a vulvar injury," explained Pukall. "Clearly, further controlled, and ideally prospective studies, are needed to be able to answer these questions," she added.

Future Research Direction

Although some research findings and patient reports suggest a connection between vulvodynia and one or more of the disorders described above, many questions remain unanswered. Fortunately, there is a growing effort by the patient advocacy and health care communities to put medical specialists in these fields in communication with each other. Efforts are also underway to educate the medical community and the public regarding the possible overlap of these disorders. Recently, the NVA joined with other non-profit organizations serving these patient populations to discuss how to promote research on the apparent overlap of these conditions. In 2008, The National Institutes of Health (NIH) also sponsored two meetings to discuss recent findings and how to generate research in this area. (See *NVA Presents at NIH Meetings on Comorbid Disorders*, p. 12.)

In September 2007, the NIH committed up to $37.5 million for a related research initiative, The Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP). This research network consists of up to six Discovery Sites focused on determining possible relationships between IC and other pain syndromes such as fibromyalgia, irritable bowel syndrome, vulvodynia and migraine headache. The ultimate aim of this collaboration of international experts from multiple medical disciplines (e.g., urology, gastroenterology, gynecology, and epidemiology) is to develop prevention and treatment strategies for IC and related disorders. The NIH announced the recipients of the 5-year MAPP grants in fall 2008.

"For the first time, specialists from various fields of medicine are coming together to discuss and study these conditions. It's long overdue and great to see. And it's ultimately what is needed to improve patient care," commented Robert Moldwin, MD, director of the Pelvic Pain Center at the Long Island Jewish Medical Center in New York.

See COEXISTING, page 11

Coexisting

(from page 10)

Improving Patient Care

Not surprisingly, study after study demonstrates that the more pain conditions a woman suffers from, the greater the physical, psychological, social and sexual consequences she experiences.

Susan Bilheimer, 53, of Boca Raton, Florida, suffers from IC, vulvodynia, fibromyalgia, IBS, pelvic floor dysfunction, migraine headache and VVS. "With each additional symptom and condition I developed, I found myself more worn down and demoralized," Susan disclosed. "Women's lives, self-esteem and relationships are crumbling because of these pain conditions," she added. To help fellow sufferers, Susan is writing a book on sexual pain disorders that will provide information and empower women to speak out and find the help they deserve. She feels optimistic that women will receive better care in the future. "Having interviewed over a dozen medical experts, both health care providers and researchers, I feel relieved and hopeful about the future of treatment for those of us who suffer with these disorders."

In addition to the research initiatives discussed above, what else is happening in the medical community to increase the likelihood that women will receive better care?

Changing the 'Don't Ask, Don't Tell' Mentality

First and most importantly, the 'don't ask, don't tell' mentality has started to change. Women's health care is becoming more comprehensive instead of body-part specific. According to Dr. Kennedy, doctors have to ask more questions. "If we don't ask about it, it may not come up, especially with disorders you wouldn't think are related, such as vulvodynia and orofacial pain," Kennedy stated. Donna Carrico, WHNP, has already seen changes happening, observing that, "Health care providers are starting to screen for multiple conditions during a woman's physical exam. Even if a patient doesn't think certain symptoms are relevant to her primary complaint, she should tell her provider about all of them."

Early Intervention and Individualized Care

We still have a lot to learn about the temporal relationship between vulvodynia and other pain conditions. If we continue to gather evidence that some of these pain conditions are related, perhaps prompt treatment for the first presenting condition would not only slow its progression, but also reduce the likelihood that a subsequent pain condition will surface.

Since each patient is unique, the key to effectively managing chronic pain is to implement an individualized, multidisciplinary treatment plan. "While there may be commonalities, each patient is unique," noted Dr. Kennedy. "For some women there may be a predisposing genetic component, for others it may be hormonal and yet others may have a neurological component," she added.

"You really have to differentiate each patient's underlying factors to help them get better," said Dr. Richard Marvel, director of the Center for Pelvic Pain in Baltimore, Maryland. "I have treated hundreds of women with coexisting disorders, and in most cases, their pain results from multiple factors that are operating simultaneously. For example, if a woman with vulvodynia has a tender pelvic floor, treating the pelvic floor muscle dysfunction is a critical part of her vulvodynia treatment. If you don't identify all factors at play and develop an individualized treatment plan to address each factor, the patient's improvement will be limited."

Combination Therapy

In general, our understanding of pain syndromes is changing. As Dr. Moldwin explains, "Clinicians used to think that if a patient experienced bladder or vulvar pain, that the pain must be originating specifically from those sites. Now we know that isn't necessarily true in all cases. For example, in some women, the pain may not originate in the bladder or vulva alone, but can also be affected by how the patient processes pain in the central nervous system. This new understanding is helping us to manage women's pain better, because we can treat it on several different levels. I have much better success at reducing a given patient's symptoms when I incorporate a local therapy that acts directly on the bladder or vulva, in combination with one that works on the central nervous system."

Most Importantly – Impart Hope

Sheila Moore, 52, of Lansing, Michigan, has experienced a long, painful journey of misdiagnosis and

See COEXISTING, page 12

NVA Presents at NIH Meetings on Comorbid Disorders

In June 2008, NVA participated in two ground-breaking meetings on chronic pain conditions that can coexist with vulvodynia. The first meeting, Can Studies of Comorbidities with Temporomandibular Joint and Muscle Disorder (TMJ) Reveal Common Mechanism of Disease?, was organized by the TMJ Association and co-sponsored by the National Institutes of Health (NIH). This event brought together international research scientists and clinicians to present studies on TMJ, vulvodynia, interstitial cystitis, endometriosis, irritable bowel syndrome, fibromyalgia and chronic fatigue syndrome. The meeting's primary goal was to encourage research that will identify universal underlying mechanisms in these disorders. After opening remarks by several NIH Institute Directors, including Dr. Vivian Pinn, director of the NIH Office of Research on Women's Health, there were presentations by representatives of 10 patient advocacy organizations. NVA's associate executive director, Christin Veasley, made specific recommendations on the type of research needed to improve our understanding of vulvodynia's cause(s) and treatment.

After the meeting, the TMJ Association condensed the expert presentations and patient testimony into a document offering recommendations for future NIH research. This document will be disseminated to NIH Institute Directors and members of Congress in the coming months. Its primary recommendation is to launch a multiphase genome-wide association study that would enlist patients suffering from multiple chronic pain conditions and then identify risk factors and genetic variations that increase the likelihood of developing one or more of these conditions. If genes common to TMJ and coexisting conditions are identified, a series of prospective, longitudinal studies could investigate how acute pain develops into chronic pain.

In late June, the National Institute of Diabetes and Digestive and Kidney Diseases hosted a meeting titled, Defining the Urologic Chronic Pelvic Pain Syndromes. A group of international specialists from different medical disciplines assembled to (i) determine how to incorporate assessment of coexisting disorders into diagnostic protocols for interstitial cystitis (IC) and (ii) develop diagnostic protocols to enable all clinicians to properly diagnose IC and other pelvic pain conditions. A panel of representatives from five patient advocacy organizations addressed the important role of their groups in generating research. "Advocacy organizations serve as the coordinating body between the patient, medical and research communities. To advance research and improve patient care, we must all work together," stated NVA's ChristinVeasley. ■

Coexisting

(from page 11)

mistreatment while seeking help for vulvodynia, IC, fibromyalgia and IBS. She has one critical piece of advice for health care providers treating women in pain. "The most important assurance a provider can offer does not require an education or cost a penny. It is unconditional hope. Even though a provider may not have all the answers, a clear commitment to improving the patient's quality of life is essential. The clinician imparts hope by assuring the patient that he/she will work with her until they find answers. Nothing is more important," asserts Moore.

(Editor's Note: A list of non-profit organizations serving women with the disorders described above can be found at http://www.nva.org/about_nva/links.html. To obtain a complete set of references for this article, contact Gigi at gigi@nva.org or 301-949-5114.)

Selected References

1. Burrows, L.J. et al. Umbilical hypersensitivity in women with primary vestibulodynia. *J Reprod Med* 2008; 53:413-6.
2. Kennedy, C.M. et al. Bladder and bowel symptoms among women with vulvar disease: are they universal? *J Reprod Med* 2007; 52:1073-8.
3. Warren, J.W. et al. Sites of pain in interstitial cystitis. *J Urology*, accepted for publication.
4. Kahn, B.S., et al. Prevalence of interstitial cystitis in vulvodynia patients detected by bladder potassium sensitivity. Presented at the American Urological Association annual meeting, 2006.
4. Zolnoun, D.A. et al. Overlap between orofacial pain 5nd vulvar vestibulitis syndrome. *Clin J Pain* 2008; 24:187-91.
6. Arnold, L.D., Bachmann, G.A. et al. Vulvodynia: Characteristics and associations with comorbidities and quality of life. *Obstet Gynecol* 2006;107:617-24.
7. Pukall, C.F. et al. Tender point examination in women with vulvar vestibulitis syndrome. *Clin J Pain* 2006; 22:601-9. ■