National Vulvodynia Association

NVA News

Volume XV, Issue II Fall 2010

New Research Differentiates Primary and Secondary PVD

By Catherine Leclair, MD

Dr. Catherine Leclair, an associate professor of obstetrics and gynecology and director of the Vulvar Health Program at Oregon Health & Science University in Portland, was the 2006 recipient of the Dr. Stanley C. Marinoff Vulvodynia Career Development Award. In 2007, Dr. Leclair and colleagues Martha Goetsch, MD, and Terry Morgan, MD, were awarded an NVA research grant to investigate the differences between primary and secondary provoked vestibulodynia. Their findings are summarized in this article.

Vulvodynia, otherwise known as chronic vulvar pain, is a common, yet poorly understood health concern for women. Women's quality of life can be severely altered by vulvodynia, making daily activities, such as sitting, walking and sexual relations, very difficult (Danielsson 2001, Arnold 2006). Additionally, affected women often suffer from isolation, depression and sexual dysfunction, because the personal nature of this condition makes it difficult to discuss with family, friends and even health care professionals (Jensen 2003, Schmidt 2001).

The International Society for the Study of Vulvovaginal Disease has identified two prominent subtypes of vulvodynia: generalized unprovoked vulvodynia and localized provoked vulvodynia, which is often centered in the vestibule; the latter condition is also known as Provoked Vestibulodynia (PVD) or vulvar vestibulitis syndrome. (The vestibule is the moist, pink-colored area of the vulva that surrounds the vaginal and urethral openings.) PVD affects approximately 15 percent of the adult

See PVD, page 2

New Vulvodynia Guidelines Published

In a recent issue of the British Journal of Dermatology, Dr. Debashis Mandal, a vulvar specialist at the University of Manchester in the United Kingdom, and nine other members of the British Society for the Study of Vulvovaginal Disease (BSSVD), published recommendations for the management of vulvodynia. This is the second clinical guideline written about the condition. The first, written in 2005 by Dr. Hope Haefner, in collaboration with 12 other vulvovaginal experts, features a diagnostic and treatment algorithm, as well as detailed information on the most commonly prescribed vulvodynia treatments. The BSSVD guideline is intended to supplement rather than replace the earlier document; it offers 12 diagnostic and treatment recommendations, and then goes on to summarize the strength of research evidence supporting each recommendation. Overall, the authors suggest that clinical care for women with vulvodynia follow the principles of chronic pain management, with focus on treating a woman's physical pain *and* improving her quality of life and sexual functioning. The following is a summary of the new BSSVD guidelines.

See GUIDELINES, page 7

PVD

(from page 1)

female population (Goetsch 1991, Harlow 2003). Friedrich (1988) originally defined the condition as a triad that included: (i) pain with vaginal penetration, (ii) tenderness with vestibular touch, and (iii) vestibular erythema. Most women who present with this condition complain of painful sexual intercourse and have difficulty with sexual intimacy. Although there is ongoing research in this field, the cause(s) of PVD remains unknown. Researchers have studied vestibular tissue specimens in hopes of uncovering information about the unique quality of this condition. Early research noted that there are tissue changes associated with PVD, such as evidence of an abnormal inflammatory process and an increased number of "pain-sensing" nerve fibers in the sensitive vestibular skin (Bohm-Starke 2001, Chadha 1998, Tympanidis 2003, Westrom 1998, Bohm-Starke 1998). These findings are intriguing, as they are unique to the condition and suggest possible etiological pathways for the disorder.

Current research is focused on determining the complex underlying mechanisms responsible for the initiation and maintenance of PVD. An important focus of this work is investigating the relationship between tissue abnormalities and altered pain sensation experienced by affected women. Through the generosity of two research grants from the NVA, our research team at Oregon Health & Science University (OHSU) studied vestibular tissue samples to further our understanding of this condition. In doing so, we chose to differentiate women with *primary* and *secondary* PVD. (*Primary PVD* refers to vestibular pain that begins during the first attempt at vaginal penetration, whereas *secondary PVD* refers to vestibular pain that occurs after a period of pain-free intercourse.) Classifying women in this way enabled us to investigate similarities and differences between the two groups, adding to our knowledge of the underlying pathology of this disorder.

Research and Findings

In our first small prospective study, we obtained vestibular tissue from 20 women with primary or secondary PVD during surgery (vestibulectomy) and from four control women undergoing a tissue biopsy (Goetsch 2010). We then stained the tissue to examine the presence and number of nerve fibers and inflammatory markers, such as lymphocytes and mast cells, as well as estrogen, progesterone and androgen receptors.

We found more nerve fibers in vestibular tissue from women with PVD compared to controls. Furthermore, we observed a greater number of nerve fibers in tissue taken from women with primary PVD compared to those with secondary PVD. Interestingly, secondary PVD tissue contained more

See PVD, 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

PVD

(from page 2)

lymphocytes than primary PVD specimens, while both groups demonstrated an increased number of mast cells compared to controls. We did not find any inflammation in the control group, nor did we observe a significant difference in the number of vestibular estrogen, progesterone and androgen receptors among the three groups.

Although our first study was limited by its small size, these intriguing findings suggested that different pathways may lead to PVD in primary and secondary subgroups. We hoped to clarify our findings by studying a larger number of women and initiated a second study, analyzing 88 vestibulectomy specimens collected from premenopausal women at OHSU between 2002 and 2008. Like our first study, we compared the presence and number of nerve fibers, inflammatory markers and hormone receptors found in tissue from women with primary and secondary PVD.

Similar to our previous findings, we found an increased number of nerve fibers in all PVD samples, with primary PVD specimens showing greater nerve density than secondary PVD samples. Although both subtypes exhibited increased inflammatory changes, the difference in the number of lymphocytes and mast cells was not significant between the two groups. However, we did find hormone receptor differences in the larger study. Primary PVD specimens contained more estrogen receptors than secondary specimens, but only when the samples were limited to women whose symptoms began within the past five years. Additionally, we found an increased number of progesterone receptors in primary PVD tissue, compared to secondary PVD samples.

Implication of our Findings

The difference in vestibular tissue abnormalities in the primary and secondary PVD subgroups suggests that there may be multiple underlying pathways leading to the same clinical condition. Our findings, combined with those from other research studies (Gerber 2002, Foster 2007, Bornstein 2007), lead us to propose that PVD may be initiated or influenced by hormonal abnormalities in some women and by an abnormal inflammatory process in others.

Admittedly, our current understanding of the relationship between hormonal alterations and PVD is limited. Some authors have speculated that oral contraceptive (OC) use may trigger or maintain PVD in some women (Bouchard 2002, Johannesson 2007, Sjoberg 1997), but our findings did not support such an association. In our large retrospective analysis, after adjusting for OC use, we found greater numbers of both estrogen and progesterone receptors in women with primary PVD whose symptoms started within the past five years. Since OC use did not differ in the primary and secondary PVD subgroups, our findings cannot be attributed to OC use alone. In my clinical experience, few patients note changes in their vestibular pain associated with OC use. Additionally, Johannesson (2007) observed only minor differences in receptor status in a controlled study comparing tissue specimens from women using OCs to specimens from non-users. When we compared samples from OC users to those of non-users, we did not find significant receptor differences, which would likely be expected if OC use truly plays a role in the development or maintenance of PVD. Therefore, at this time, the significance of alterations in vestibular estrogen and progesterone receptors is unclear.

Several studies have implicated estrogen deficiency as a trigger for some women with PVD. Primary PVD may represent a continuation of vestibular tenderness from pre-pubertal girlhood, during which estrogen levels are very low. Additionally, some postpartum or postmenopausal women may

See PVD, page 4

PVD

(from page 3)

experience pain consistent with secondary PVD due to the rapid decline in estrogen experienced after childbirth or menopause. These hormonal events may initiate or influence other biological changes, e.g., nerve fiber density, that once established, maintain the chronic pain cycle.

An abnormal inflammatory process in the vestibular tissue may represent another pathway by which some women develop PVD. In both studies, inflammation was measured by lymphocyte and mast cell infiltrates. Although secondary PVD samples exhibited greater inflammation than primary PVD specimens in our smaller study, we did not find significant differences in inflammation between the groups in our larger study. Nonetheless, we observed evidence of inflammation in both subtypes, an abnormality not observed in control specimens. Thus, we consider these cellular features integral to maintaining the pain process in some PVD patients. Since neurotrophins (proteins that affect the development and function of nerve cells) and inflammatory mediators have been implicated in the maintenance of abnormal pain processing, inflammatory changes that lead to altered nerve density in some women with PVD warrant continued investigation.

Conclusion

Our results suggest that there are different underlying pathways in the development of primary and secondary provoked vestibulodynia. Our hope is that future studies will compare the two subtypes, and in doing so, begin to clarify the multiple pathways by which women develop chronic vulvar pain.

(Editor's Note: The results of Dr. Leclair's first NVA-funded study are summarized in: Goetsch MF, et al., Histologic and receptor analysis of primary and secondary vestibulodynia and controls: a prospective study. Am J Obstet Gynecol*, 2010; 202: 614-15. To receive a reference list for this article, e-mail gigi@nva.org or call 301-949-5114.)* ■

New Patient Booklets Available

In July 2010, NVA released three new booklets for women with vulvodynia and updated our self-help guide, *I Have Vulvodynia...What Do I Need to Know?* This project was supported, in part, by an educational grant from Purdue Pharma, L.P.

Vulvodynia, Pregnancy and Childbirth NVA's 40-page Pregnancy booklet is the first resource of its kind for women with vulvodynia. It discusses managing vulvar pain during pregnancy, alternate methods of conception and childbirth options.

My Partner Has Vulvodynia - What Do I Need to Know? After reading this booklet, partners will have a better understanding of the challenges facing women with vulvodynia. It encourages partners to be supportive and offers advice on maintaining sexual intimacy.

How to Apply for Disability Benefits This booklet, intended for those who cannot work because of the severity of their vulvodynia, gives step-by-step guidance for compiling and submitting a successful claim to the Social Security Administration.

Current NVA donors can view or download these booklets at NVA's Online Resource Center: www.nva.org/login.php. For a printed copy, please contact Gigi Brecheen at gigi@nva.org or 301-949-5114. Health care providers can review the guides prior to purchasing copies for their offices by contacting Gigi. ■

What to Expect During Pregnancy

This article is excerpted from NVA's new booklet for patients titled, *Vulvodynia, Pregnancy and Childbirth*.

Your Changing Body

In addition to concern about the body changes all women experience throughout pregnancy, many women with vulvodynia are understandably anxious about how it will impact their vulvar pain. To date, no studies have investigated how vulvodynia is affected by pregnancy and childbirth. Some vulvodynia experts who practice obstetrics have observed that vulvar pain doesn't usually change much during pregnancy. That said, they do acknowledge that symptoms can either improve or worsen in some women. This article will discuss pregnancy-related changes that may affect vulvodynia and offer advice for managing some of them.

Pelvic Pain and Comfort Measures. As pregnancy progresses, the increased weight of the baby will put additional pressure on the pelvis. In addition, hormones, particularly relaxin, soften and relax the muscles and ligaments to accommodate the growing uterus and open the pelvis in preparation for childbirth. Some women experience spasms of the muscles that support the pelvis, and this may affect women whose vulvodynia is associated with pelvic floor muscle or sacroiliac joint dysfunction. You may feel pressure in the pelvis, back pain, or both. Additionally, you may experience sharp, stabbing pains in the middle of the pelvis, or "pins and needles" in the cervix. These sensations may feel different than vulvodynia, or may cause a flare-up of prior symptoms. Women who experience pelvic discomfort should ask their provider about pain relief measures. These measures may include chiropractic manipulation, physical therapy or massage therapy with health care providers who have experience treating pregnant women.

Some women develop varicose veins in the vulvar area, in addition to those commonly seen in the legs. Pregnancy hormones relax the walls of the veins, causing them to expand to accommodate extra blood volume. When veins accumulate extra blood in or near their valves, they may bulge. Varicose veins are harmless, but can be very uncomfortable during pregnancy. They usually subside within a few months after delivery. You should not vigorously massage varicose veins, because it can cause a blood clot. To ease the discomfort of varicose veins in the legs, you can wear specially designed support stockings; ask your health care provider for advice. For vulvar varicosities or pelvic discomfort, many maternity clothing stores sell belly-support belts, which are designed to take the pressure of the baby's weight off your pelvis. For extra support, you also can try wearing snug-fitting (non-maternity) leggings, with the waistband placed below your belly.

Increased blood volume in the vulvar area also can cause engorgement of the genitalia, which can be painful. If you experience painful pelvic varicosities or genital engorgement, try elevating your pelvis by lying down and placing a pillow under your hips. Alternately, you can lie on the floor with your legs up a wall. Scoot your buttocks as close as you can to the wall before lifting your legs, and place a pillow or folded blanket under your hips. This position also can provide relief for varicose veins or swelling in the legs. Come out of the position if you become dizzy or light-headed, and be sure to roll onto your side before attempting to stand up.

If your vulvar pain continues or flares up during pregnancy, remember the non-drug comfort measures that have worked for you in the past. (To view a list of self-help tips, visit http://www.nva.org/Self_Help_Tips.html.) Extra pounds can put more pressure on the pelvis and varicose veins, so try to stay within the weight-gain limits recommended by your health care provider.

See PREGNANCY, page 6

Pregnancy

(from page 5)

Vaginal Health. Vaginal secretions may increase considerably during pregnancy, appear bluish-violet in color and take on a thicker consistency. Tell your health care provider if the discharge contains blood, turns watery, or has a foul odor, because it may represent an incompetent cervix or leakage from the water bag. A pus-like, yellow, green, cheesy, or foul-smelling discharge may be the sign of a yeast or bacterial infection. Pregnancy makes the vagina warmer, moister and sweeter, all of which increase the growth of yeast, the most common type of vaginal infection during pregnancy. If you think you have an infection, resist the temptation to self-diagnose and see your provider, because many women misinterpret the normal increase in vaginal discharge during pregnancy as a yeast infection. *Do not self-medicate during pregnancy.*

In the first trimester, most physicians prefer to treat a yeast infection externally for symptomatic relief only. If drugs are absolutely necessary, using older medications with a long history of safety is preferred. Neither oral Diflucan nor Ancobon (flucytosine) should be used during pregnancy. Because terconazole (vaginal suppository/cream or topical cream) is absorbed systemically, it is generally not used in the first trimester, and is only used later in pregnancy if simpler agents fail. Self-help remedies to battle yeast include cutting down on sugar in your diet, eating yogurt or taking oral acidophilus tablets or powder, and washing off the discharge with a handheld showerhead. Again, consult with your health care provider before using any oral/topical prescription or over-the-counter medication or supplement while pregnant.

Preparing for Childbirth

As you enjoy the pleasures of pregnancy and cope with some discomforts, don't forget the things you need to do to prepare for the birth of your baby. You should decide what type of childbirth class you want to take and sign up early. For information on different types of childbirth classes, see www.pregnancy.about.com/od/childbirthclasse1/p/cbeclasses.htm. Also, consider whether you want to write a birth plan, which communicates your preferences for labor and delivery, and/or use a doula, an experienced companion who will stay with you during labor, delivery and beyond. All of the above can help you prepare both physically and mentally. Some providers believe that using perineal massage and/or Kegel exercises during the last weeks of pregnancy can help minimize trauma to the perineum. Although there are no guarantees, you may want to consider using these techniques.

Perineal massage. Some practitioners recommend perineal massage to prepare the tissue for birth and prevent tearing or the need for an episiotomy, but studies have shown varying results. The perineum is the area between the vulva and the anus. There are natural changes in the vulvar, perineal and vaginal tissues at the end of pregnancy, which allow more stretch during birth than would be possible even a few days before or after. Many women with vulvodynia have pain only with touch, or that is exacerbated by touch, so they would find perineal massage painful. If it is not uncomfortable for you to do, it may be reassuring. The possible advantage, however, is not sufficient to justify any significant discomfort.

To perform perineal massage, wash your hands. Lubricate your thumbs with the same lubricant you use for intercourse and insert it just inside your vagina. Do not use baby oil, mineral oil, petroleum jelly or hand lotion, which are less well absorbed by the body than vegetable- or water-based products. Press downward towards the rectum and slide your thumbs across the bottom and then up the sides of the perineum. Continue for 10 minutes. Repeat daily from the 34th week of pregnancy until delivery. Your provider may perform this technique during labor

See PREGNANCY, page 12

Guidelines

(from page 1)

Recommendation 1: "An adequate pain history should be taken to assess the degree of symptoms and the impact on the woman. The clinician should determine which subtype of vulvodynia the woman has according to ISSVD definitions." (Grade C)

In 2003, the International Society for the Study of Vulvovaginal Disease (ISSVD) modified the definition of vulvodynia to "vulvar discomfort, most often described as burning pain, occurring in the absence of relevant visible findings or a specific, clinically identifiable neurologic disorder" (Haefner 2006). In addition, the ISSVD adopted new terminology that classifies subsets first by location, and second by stimulus, into the following categories: 1) *generalized vulvodynia,* defined as the involvement of the whole vulva, and 2) *localized vulvodynia,* defined as involvement of a portion, or component of the vulva, such as the vestibule, clitoris or other specified site. Both localized and generalized vulvodynia can be further categorized as provoked (sexual contact, non-sexual contact or both), unprovoked (spontaneous) or mixed (provoked and unprovoked). Furthermore, *provoked vestibulodynia* (formerly vulvar vestibulitis syndrome) was then defined as introital dyspareunia associated with discomfort on vestibular contact. Since there are many vulvodynia subgroups, and optimal treatment for each one differs, the authors suggest that health care providers first classify a woman's vulvodynia according to the ISSVD definitions. They note that pudendal neuralgia or nerve entrapment can present with symptoms similar to vulvodynia, but that treatment differs, so providers should also evaluate women for these other conditions (Labat 2008). (See Differentiating Vulvodynia and Pudendal Neuralgia, by Dr. Richard Marvel, in the Winter 2007 issue of *NVA News.)*

Clinicians should obtain a detailed pain history, utilizing a visual analogue scale (patients rate pain severity on a scale of zero to ten) and, when available, a woman's pain diary. They should also consider using validated pain assessment tools such as the McGill Pain Questionnaire.

Recommendation 2: "If appropriate, patients with sexual pain (dyspareunia) should have a sexual history taken to identify sexual dysfunction." (Grade C)

Since several studies have found that women with vulvodynia report reduced sexual arousal, more negative sexual feelings and less spontaneous interest in sex (Schover 1991, Stewart 1994, Coulson 2007), the authors recommend that clinicians obtain a detailed sexual health history that includes questions about pelvic floor muscle functioning, as well as difficulty with lubrication and/or orgasm. If a woman is experiencing sexual dysfunction as

	Classification of Grade Level
A	Requires at least one randomized controlled trial as part of a body of literature of overall good quality and consistency addressing the specific recommendations.
B	Requires the availability of well-controlled clinical studies, but no randomized clinical trials on the topic of recommendations.
C	Requires evidence obtained from expert committee reports/opinions and/or clinical experiences of respected authorities. Indicates an absence of directly applicable clinical studies of good quality.

See GUIDELINES page 8

Guidelines

(from page 7)

a consequence of her vulvodynia and she or her partner are distressed by changes in their sexual relationship, providers should refer them to a knowledgeable sex/couples therapist.

Additionally, the authors note that women with vulvodynia may experience anxiety and depression as a consequence of living with chronic pain (Schover 1991, Stewart 1994, Jadresic 1993). Although the guideline doesn't provide specific recommendations for managing these conditions, most vulvodynia experts encourage clinicians to ask patients if they are experiencing depression and anxiety and, if necessary, offer appropriate treatment or referrals.

Recommendation 3: "The diagnosis of vulvodynia is clinical." (Grade C)
Vulvodynia is a diagnosis of exclusion, which means that all other causes of vulvar pain must be ruled out before a diagnosis of vulvodynia is considered. Since studies examining vulvar biopsies from women with vulvodynia have not demonstrated one specific pathological feature, the authors conclude that a biopsy isn't necessary to diagnose the condition. Some researchers report a chronic inflammatory infiltrate in biopsies, while others have found a similar inflammatory pattern in controls (Chadha 1998, Prayson 1995, Morelli 1994, Lundqvist 1997). The authors do, however, recommend that clinicians carefully examine the vulva during office visits subsequent to initiating treatment for vulvodynia, because other vulvar conditions that require a biopsy, e.g., vulvar dermatoses, may develop. They also advise against routine patch testing, a method used to determine if a specific substance causes skin inflammation, to exclude a contact allergy. Furthermore, they note that the routine use of magnetic resonance imaging (MRI) is unnecessary to diagnose the condition because the incidence of pathology causing referred pain to the vulva, e.g., sacral cysts, is very low (Lewis 1997).

Recommendation 4: "A team approach may be necessary to address the different components of vulvodynia. A lead clinician should triage patients and consider referral to other health professionals that play a role in vulvodynia management, e.g., pain specialist, physical therapist and clinical psychologist." (Grade B)
Since vulvodynia is (i) a chronic pain disorder, (ii) affects the genital area, and (iii) may involve pelvic floor muscle dysfunction, experts favor a multi-disciplinary approach. Treatment may include visiting a gynecologist or vulvovaginal specialist, urogynecologist, dermatologist, neurologist, pain management specialist and/or physical therapist. Also, because vulvodynia often interferes with sexual relationships and can cause depression and anxiety, experts may recommend that some women consult a psychologist or sex therapist. The authors suggest that the severity of a woman's condition, combined with her specific needs, should dictate the amount of care she requires. Women with mild symptoms may be well served by visiting their specialist as needed, whereas women with severe constant pain may require a more extensive pain management approach that includes supportive counseling (Munday 2007, Masheb 2009). The authors also propose that women with severe and difficult to manage symptoms be referred to a pain clinic, and that advanced pain management strategies, e.g., spinal cord stimulation, be considered for women whose pain is not alleviated with more conservative therapies (Nair 2008).

Recommendation 5: "Combining treatments should be encouraged." (Grade C)
Since recent research suggests that there are likely multiple pathways by which women develop

See GUIDELINES page 9

Zolnoun Awarded Second NIH Grant

Last year, NVA awarded a pilot research grant to Denniz Zolnoun, MD, assistant professor of obstetrics and gynecology and director of the Vulvar Pain Clinic, and Andrea Neely, assistant professor of pharmacology, both of the University of North Carolina – Chapel Hill (UNC), to investigate underlying mechanisms in vulvodynia and temporomandibular disorders (TMD). Testing the theory that vulvodynia and TMD share common central pathophysiology, they are comparing pain sensitivity and circulating cytokines (substances released by immune system cells) in four groups: women with vulvodynia, women with TMD, women with concurrent vulvodynia/TMD and healthy controls. This study aims to provide: (i) a better understanding of the key mechanisms that drive vulvodynia and TMD, (ii) more accurate differentiation of distinct subgroups of vulvodynia and TMD patients, and (iii) the development of new therapeutic strategies tailored to these subgroups.

In fall 2009, Dr. Zolnoun included preliminary data from the NVA-funded study in an application to the National Institutes of Health (NIH). In April 2010, the NIH awarded her a grant to study *Central and Peripheral Mechanisms of Persistent Pain in Vulvar Vestibulitis Syndrome (aka Provoked Vestibulodynia or PVD)*. Zolnoun's current study is one part of a five-year project titled, *Complex Persistent Pain Conditions: Common and Unique Pathways of Vulnerability,* conducted by Dr. William Maixner, director of the UNC Center for Neurosensory Disorders. She will expand upon her NVA-funded project to identify both shared and unique biological, genetic, and psychosocial factors associated with the development and maintenance of five chronic pain conditions: PVD, TMD, fibromyalgia, headache and irritable bowel syndrome. In an effort to identify subgroups of patients with persistent pain conditions, they will recruit 1,500 patients that meet examination-based case definitions for one or more of these disorders and compare vulvar skin and pelvic floor muscle pain sensitivity, central nervous system pain processing mechanisms and genetic variations in cases and controls.

This comprehensive study will use measurement tools developed by Dr. Zolnoun during her prior NIH-funded research, *Refining Diagnostic Criteria of a Pain Disorder: Vulvar Vestibulitis Syndrome*. The primary aim of that study was to establish the reliability and reproducibility of a device she developed to measure vulvar skin and pelvic floor muscle pain sensitivity in women with PVD. The overriding goal of Dr. Zolnoun's research is to determine the underlying mechanisms and/or perpetuating factors for each subgroup of PVD patients and then utilize specific treatments that target those factors.

To read summaries of other NIH-funded studies on vulvodynia, please visit: www.nva.org/nih_funding.html. ■

Guidelines

(from page 8)

vulvodynia, the authors discuss the usefulness of combining treatments. For example, Munday's 2007 publication reported improvement in 27 of 29 patients treated with a combination of medical treatment, physical therapy, dietary advice and psychotherapy.

Recommendation 6: "Patients should be given an adequate explanation of their diagnosis, relevant written information and appropriate contact information. When prescribing treatments, clear instructions should be given on how to take medication." (Grade C)

The authors highlight the importance of explaining vulvodynia to newly diagnosed women, addressing

See GUIDELINES page 10

Guidelines

(from page 9)

any concerns they may have about living with the condition. They also recommend that providers distribute educational materials to women and counsel them about self-help measures. Additionally, clinicians should emphasize the importance of eliminating, or at least minimizing, exposure to common vulvovaginal irritants such as soaps, feminine hygiene products, over-the-counter creams and detergents.

Recommendation 7: "Topical agents should be used with caution to avoid the problem of irritancy. A trial of a local anesthetic agent may be considered in all vulvodynia subsets." (Grade C)

Although topical agents are commonly prescribed for vulvodynia patients, the authors note that few controlled studies have been conducted to determine their effectiveness and that a recent randomized trial found a high placebo response to a topical (Bornstein 2009). However, they do suggest using topical lidocaine ointment 15 to 20 minutes prior to sexual intercourse to make penetration more comfortable, but women should be advised that it may irritate already sensitive vulvar tissue or cause penile numbness in their partners. Also, oral contact must be avoided when using a topical anesthetic. A study of women with provoked vestibulodynia (aka vulvar vestibulitis) by Zolnoun and colleagues (2003) did demonstrate the long-term effectiveness of applying a cotton ball soaked in 5 percent lidocaine to the vaginal opening daily at bedtime. A few publications have described the use of other topical agents, such as capsaicin, ketoconazole, estrogen, steroids, interferon and nifedipine, but more research is needed to determine their efficacy (Bornstein 2009, Friedrich 1988, Morrison 1996).

Recommendation 8: "Tricyclic antidepressants (TCAs), e.g. amitriptyline or nortriptyline, are an appropriate initial treatment for unprovoked vulvodynia. Other drugs may be considered, including gabapentin and pregabalin, which can be given in addition to a TCA." (Grade B)

The authors endorse tricyclic antidepressants as an appropriate pharmacological option for treating vulvodynia, particularly in women whose pain is unprovoked or spontaneous (Munday 2001). In general, the TCA dosage should be gradually increased, as tolerated, until a woman's pain is well-controlled (McKay 1993, Reed 2006). They recommend that providers discuss the most common TCA side effects such as dry mouth, constipation and weight gain, before initiating treatment, because they can affect treatment compliance. If a woman's pain is not well-controlled with a TCA and/or she experiences unacceptable side effects, the use of other types of "pain blocking" medications, such as anticonvulsants (e.g., gabapentin, pregabalin) or selective serotonine norepinephrine reuptake inhibitors (duloxetine, venlafaxine, milnacipran), is warranted (Ben-David 1999). Due to our limited understanding of the underlying mechanisms of vulvodynia, and the scarcity of controlled clinical trials, the optimal drug treatment regimen for vulvodynia remains unclear.

Recommendation 9: "Surgical excision of the vestibule may be considered in patients with localized provoked vulvodynia (vestibulodynia) after other measures have been tried. Only a minority of patients may be suitable for surgery. If surgery is offered, adequate counseling and support should be given to the patient both pre- and postoperatively." (Grade B)

While surgical management is the most widely studied treatment for provoked vestibulodynia (PVD, or vulvar vestibulitis), results are difficult to compare because there are several methodological flaws in the research. The authors note that modified vestibulectomy (removal of a portion, or all,

See GUIDELINES page 11

(from page 10)

of the vestibule) followed by vaginal advancement appears to be the most successful surgical procedure (Kehoe 1996, Goetsch 1996, Weijmar Schultz 1996, Woodruff 1985). They conclude that vestibuloplasty, a procedure in which the vestibular nerve supply is severed, but the painful tissue is not removed, is ineffective (Bornstein 1995). Unfortunately, most surgical studies do not include long-term outcome data, however, one researcher reported that 83 percent of women who completed a questionnaire one year after vestibulectomy said they would recommend the procedure as an effective treatment for PVD (Eva 2008). A few studies, including one by Abramov (1994), suggest that surgical success rates could be improved with postoperative sex therapy, which includes the use of vaginal dilators.

Recommendation 10: "Pelvic floor muscle dysfunction should be addressed in patients with vulvodynia who have sex-related pain. Techniques to desensitize the pelvic floor muscles are likely to be beneficial." (Grade B)

According to White and colleagues (1997), women with PVD who experience pain with intercourse frequently suffer from concurrent pelvic floor muscle dysfunction. Pelvic floor muscle therapy includes the use of exercises, external and internal soft tissue massage, trigger point release, biofeedback training, dilator therapy and the use of vaginal trainers (Glazer 1995, McKay 2001, Murina 2008, Goldfinger 2009, Bergeron 2002). The authors note that no studies have identified the optimal technique(s) and that success depends on a number of factors, including the therapist's expertise, the degree of patient support, and the number and length of therapy sessions. The effectiveness of pelvic floor muscle therapy in women with fairly constant unprovoked pain (i.e., generalized vulvodynia) remains unclear. Glazer and colleagues (1998) found abnormalities in the pelvic floor muscles of women with generalized vulvodynia, but no controlled studies have been conducted to determine the efficacy of pelvic floor therapy in this patient population.

Recommendation 11: "Acupuncture may be considered in the treatment of unprovoked vulvodynia." (Grade C)

Only a couple of case reports on the effectiveness of acupuncture have been published and there is too little data to draw any conclusions at this time (Powell 1999).

Recommendation 12: "Intralesional injections may be considered in patients with provoked vulvodynia." (Grade B)

The use of subcutaneous injections of steroid/anesthetic combinations has been reported in the literature with varying degrees of success (Murina 2001, Dede 2006, Segal 2003). A few small studies have used Botox injections for vulvodynia, but larger controlled studies are needed in order to draw a conclusion on its effectiveness (Yoon 2007, Brown 2006, Dykstra 2006, Petersen 2009).

Conclusion

The BBSVD guideline group developed the above clinical recommendations to aid health care providers in the diagnosis and medical management of vulvodynia, and increase awareness of the condition. They emphasize the importance of utilizing a team approach in the management of vulvodynia, especially for women with severe pain that is difficult to control. Their article, *Guidelines for the Management of Vulvodynia*, may be viewed online at http://www.medscape.com/viewarticle/722852. The first *Vulvodynia Guideline* (2005) by Dr. Hope Haefner and colleagues can also be viewed online at: http://journals.lww.com/jlgtd/Fulltext/2005/01000/The_Vulvodynia_Guideline.9.aspx.

(Editor's Note: If you would like to receive a reference list for this article, e-mail gigi@nva.org or call 301-949-5114.) ■

Pregnancy

(from page 6)

as you begin to push the baby out. During labor the tissue will stretch much more easily, and if there is sufficient time, possibly enough to prevent tearing or the need for an episiotomy.

Kegel exercises. During pregnancy, pelvic floor muscles may sag due to the increased weight of the uterus and the relaxing effect of the pregnancy hormones. In general, many physicians recommend practicing these pelvic floor contractions before the birth to condition the muscles, improve circulation to the perineum and provide better support for the uterus and other pelvic organs. Some women with vulvodynia have pelvic floor muscle dysfunction, however, and Kegel exercises may be contraindicated for them, since they can exacerbate pain or lead to increased muscle spasm. Speak to your health care provider before beginning a regimen of Kegel exercises during pregnancy.

Doula. From the Greek word for "woman's servant," a doula has no medical training. Instead, she provides companionship and moral support, and can act as an advocate for the parents. She can run interference with the hospital staff, allowing the woman's husband or partner to remain by her side. She can help a woman keep her birth wishes in perspective when the unexpected occurs, instruct her in labor comfort measures, answer questions and help her relax. Although she does not give medical advice, she can explain the doctor's suggestions. Studies have shown that women who are supported by a doula had shorter labors and were less likely to need a Cesarean (8% in the supported group vs.18% of non-supported mothers), forceps or vacuum extraction, or epidural anesthesia; these women were also less likely to need an episiotomy and had fewer perineal tears. Before choosing a doula, ask about her training and certification. If possible, interview two or three people, either in person or on the phone. Ideally, look for one who lives near the hospital where you will deliver and has worked with your obstetricians before. If you don't interview prospective doulas in person, be sure you and your partner meet with her before the birth to review your birth plan and discuss the role she will play in supporting you through childbirth. If you cannot afford the services of a doula, consider asking a close friend or family member, preferably one who has given birth and agrees with your childbirth preferences, to attend the birth. (For more information, or to locate a doula in your area, visit www.dona.org.)

Birth Plan. Writing a birth plan can help you focus on what is most important to you about your baby's birth. Of course, every pregnant woman's first priority is to have a healthy baby. As a pregnant woman with vulvodynia, your next priority may be to avoid anything that might exacerbate your pain. Due to a lack of research, health care providers do not have a specific protocol for the best way to approach labor and delivery when the mother has vulvodynia. After educating yourself about childbirth and talking to your provider, you will be able to form your own opinion about what approach is best for you. A birth plan is the best way to articulate this approach. Once agreed upon with your provider, it can also help you communicate your wishes to the hospital or birthing center staff. Although your provider should be familiar with your medical history by the time you go into labor, the nurses or other birth attendants will not know you have vulvodynia unless you tell them. Once you are in active labor, you may not be able to communicate as effectively as you want. After you have written your birth plan, show it to, and discuss it with, every doctor and nurse in the practice you use for your prenatal care and be sure to bring it with you to your hospital or birthing center. For help in creating a birth plan, visit www.birthplan.com.

(Editor's Note: To read the entire pregnancy booklet online or purchase hard copies, see page 4.) ■