National
Vulvodynia
Association

NVA News

Volume XIX, Issue III

Winter 2015

Chronic Sexual Pain: A Guide to Systematic Evaluation

By Deborah Coady, M.D., FACOG

Deborah Coady, M.D., FACOG, is a clinical assistant professor of obstetrics and gynecology at NYU Langone Medical Center. She devoted a major portion of her private practice to caring for women with vulvar pain, and currently writes, lectures, and mentors health care providers to improve care of women with chronic pain. She is co-author of Healing Painful Sex: A Woman's Guide to Confronting, Diagnosing, and Treating Sexual Pain.

One-third of women, at some point in their lifetime, experience painful sexual activity for three or more months. Pain may occur during sexual arousal, intimate contact, or after, sometimes persisting for days. Genital or vulvar pain may also exist steadily, on its own, with sex heightening its severity. Sexual pain is a feature of chronic pelvic pain (CPP), an extremely prevalent condition affecting 30 million women in North America at any one time (1,2,3). Most women with various types of CPP experience painful sexual activity. For example, 75 percent of women with Interstitial Cystitis/Painful Bladder Syndrome (IC/PBS) report sexual pain (4).

In addition to this pain limiting their sexuality, quality of life is impaired for these women. Sexual intimacy is a fundamental desire of most women, as it contributes to a sense of wholeness and femininity, and forges close partner relationships. Women suffering from pain disorders consistently report that lack of sexual activity or enjoyment is their main reason for

(*See SEXUAL PAIN, page 2*)

Diagnosis and Treatment of Lichen Sclerosus

By Gayle Fischer, M.D., MBBS, FACD

Dr. Fischer is an associate professor of dermatology at the University of Sydney in Australia. She is a staff specialist at the Royal North Shore Hospital in Sydney and conducts a vulvar diseases clinic.

Lichen sclerosus (LS) is an uncommon skin disease that primarily affects the genital skin and is 10 times more common in women than men. Its prevalence is unknown, but has been estimated as up to three percent in women. Although LS occurs in all age groups, it is most common in peri-menopausal and post-menopausal women. It can also occur in children and babies. Until recently, it was believed that pre-pubertal LS resolved at puberty, but new evidence contradicts this notion.

(*See LICHEN SCLEROSUS, page 6*)

low quality of life (5,6). Secondary depression, anxiety, low libido, and relationship difficulties are understandably common (7).

Compounding this decline in quality of life are often feelings of shame, guilt, self-blame, and isolation. Despite increasing cultural openness about sexuality, over one-third of women with sexual pain never seek the help of health care providers (HCPs) (1). When they do, many feel misunderstood or dismissed. Fifty percent are dissatisfied with their encounters and feel they are insufficiently treated (8,9). Women frequently report being told after cursory pelvic examinations that their pain must be "in their head." Fortunately, women with sexual pain are benefiting from social media, enabling self-education, self-care and sharing of experiences and resources.

Obstetrician-gynecologists (ob/gyns) are the front line of care for women with sexual pain, because they will usually turn to us first for help. Since most of us have received little formal training or practical experience in this common condition, we often feel ill-equipped to evaluate patients who may present in tears or appear skeptical or hopeless due to previous negative HCP encounters. We also may hold preconceptions that the evaluation of sexual pain is more complex and time-consuming than it really is, and that there are few effective treatments anyway. Patients may detect these attitudes, making it difficult to feel comfortable and optimistic about their care.

The good news is that many advances have been made in understanding the multi-layered causes of sexual pain, and most women can improve and resume or begin a satisfying sexual life after a complete diagnosis and up-to-date treatment. Postgraduate ob/gyn training is being updated to respond to our unmet need of caring for all forms of CPP, through the Committee on Resident Education in Obstetrics and Gynecology's expanded core competencies, which will improve the future for women with these conditions (10).

First, we need to accept and fully acknowledge that sexual pain is a physical pain condition, not a female sexual dysfunction or a psychological disorder. Some patients have wasted months or longer in sex therapy after being referred by their ob/gyns, when pain was the primary issue, and function could not improve until pain was recognized and treated. Once this fact is established in the minds of both the patient and physician, and the patient is invited to become the crucial partner in her care, healing can occur. A mental health therapist who is knowledgeable about physical causes of painful sex may then join the team. Couples counseling is valuable, as the intimate partner often suffers along with the patient, inducing sexual dysfunction and mood disorders. Stress reactions often accompany sexual pain, affecting the immune and autonomic nervous systems, which can impact

(*See SEXUAL PAIN, page 3*)

NVA News

National Vulvodynia Association
P.O. Box 4491, Silver Spring, MD 20914-4491
Tel: (301) 299-0775 Fax: (301) 299-3999
www.nva.org

NVA News is published three times per year.

Editor: Phyllis Mate
Layout: Lisa Goldstein

The National Vulvodynia Association is a nonprofit organization that strives to improve women's quality of life through education, research funding, support and advocacy.

(from page 2)

physical healing (11,12). Providing coping strategies and mind-body therapies, such as yoga and meditation, which mitigate the negative physical effects of stress, is essential (13,14,15).

A Systematic Strategy for Evaluation: The Layer Approach

When I first began to care for women with sexual pain, organized evaluation methods were not available. Not wanting to miss any causes or pain triggers, I needed an efficient strategy to evaluate the pelvis, and developed, for my own use, my Layer approach, which soon became a teaching tool for patients and students. At that time, only two Layers were recognized as causing sexual pain, the surface (vulva and vagina) and the internal female organs (e.g., endometriosis). I knew there were structures between those two Layers that needed to be evaluated: the muscles, nerves, connective tissues, bones, and joints of the lumbopelvic region. Working closely with pioneering pelvic physical therapists who were steadily gaining an understanding of these "in between" Layers, I realized that most sexual pain involved these structures.

Before detailing the Layer approach, I must emphasize that the most revealing step in evaluation is personally obtaining a complete history, which establishes rapport and validation of the patient's pain. Supplement it by using intake forms that the patient fills out ahead of time; an excellent example is the International Pelvic Pain Society's form, available on its website, www.pelvicpain.org. Include baseline self-reported pain measures, such as the Visual Analog Scale (VAS), and the Vulvar Pain Functional Questionnaire (VQ), which is helpful for initiating discussion on sexual concerns and tracking improvements. This questionnaire can be downloaded at www.hermanwallace.com/templates/V-Qquestionnaire.pdf (16). The patient needs to be fully clothed, seated with you in a private consult room, if possible, and given enough time to detail her history from its beginning, including childhood symptoms.

Which sexual activities, positions, menstrual cycle phase, and other triggers cause or worsen her pain? Is the quality of the pain burning, raw, itching, cramping, sharp, or knife-like? Allow her to use her own words. Did it begin after starting combined hormonal contraception or other medications? Is her pain provoked by simply touching the vulvar surface, is it located within the vaginal canal, at its worst with full penetration, or a combination of these? Give her a paper diagram of the vulva to mark painful areas and include it in her chart for future comparisons.

What are the initial and long-term goals the patient would like to attain? She may need to reflect on her priorities, and specific goals may vary greatly between women. She may wish to sit through a movie with her partner without severe pain, or perform specific sexual activities or positions, use a vibrator or tampon, conceive naturally with intercourse, or avoid days of pain after sex. Clarifying goals early, in writing, can be enlightening to the patient, and periodically reviewing progress during treatment serves as an objective measure of improvement.

Complete well-documented history-taking is time-consuming, but it expedites follow-up visits. Because of the time constraints of most busy ob/gyns, this part of the evaluation often takes up the whole first visit. Prepare the patient for this and reassure her that your full understanding of her pain and previously tried treatments promotes efficient effective care. As the physical examination is detailed, and hampered by rushing, bring her back to perform it at a second visit scheduled in the very near future. If a patient brings up her chronic sexual pain in the middle of a scheduled routine checkup, it may be best to postpone the examination; devote the rest of the allotted time to obtaining the all-important history. Start the patient with some self-care therapies between visits by providing written materials, such as *Vulvodynia: A Self-Help Guide* (www.nva.org/shg) or links to online resources, e.g., www.nva.org/tips.

(See SEXUAL PAIN, page 4)

SEXUAL PAIN

(from page 3)

At the second visit (or first if time allows), perform a Layer by Layer examination as described below, and formulate one or more working diagnoses. Schedule testing as needed, and discuss and write out a preliminary treatment plan, using a preprinted fill-in form outlining each Layer. Be open at all visits for the intimate partner or other support person to be present, to take notes, add overlooked items to the history, and allow the patient to feel safe, which is especially important for those who have had demoralizing experiences with HCPs. Keep in mind, you may be the first person to whom the patient has revealed her pain, and her nervousness is normal. As she begins to feel like a partner with you in her care, committing to self-care therapies will be easier.

At each follow-up visit, carry out an interval history and follow-up VAS, VQ, and Layer examination. Discuss test results and reassess goals. Diagnoses and treatments may need revision. Keep the written treatment plan updated. All visits are opportunities to further educate; patients who gain understanding, and with it hope and control, are more likely to experience improvement in their pain levels.

Surface Layer

The vulvar surface requires a comprehensive magnified inspection from above the mons pubis to the anus. Lithotomy stirrups that support the patient's knees are comfortable and less tiring for her. Use a handheld magnifier or colposcope, whichever is convenient for you. Use an excellent light source without a bulb that heats up during a long examination, as burns can occur. The patient can be your best assistant; prepare her to hold a magnifying mirror in one hand, and prop herself up by leaning on her opposite elbow so she can view her vulva in the mirror. She can point out her painful areas and feel in control as she participates and observes your examination. Have her open her labia and retract her clitoral hood herself, as she can more easily tolerate her own touch. All skin and mucosa needs to be inspected for red, white, or dark-colored lesions, erosions, ulcers, nodules, edema, architectural changes, and fissures. Ask the patient to rate the pain intensity she may feel with touch, on a scale of 0 to 5. Use pre-printed vulvar diagrams to record findings; documenting with digital photography helps assess the benefits of therapy later. By no means even think about performing a typical two digit bimanual examination until the very end of the evaluation of all Layers, and first consciously decide if it will add information. In chronic sexual pain it usually will not, and often triggers surface pain or muscle spasms that hinder the rest of the examination.

By far the most common cause of sexual pain in premenopausal women is Localized Provoked Vestibulodynia (LPV). Fortunately, research is leading to better understanding of this mucosal disorder and improving treatments (17,18). It is crucial that LPV not be missed. After your general inspection, give specific attention to the vestibule, at first without touching it, using your patient-assistant for exposure. Note and document all areas of erythema, even if tiny and subtle. To identify LPV's diagnostic feature, allodynia, the Q-tip swab test is key. Begin checking for provoked pain systematically at the outer labial skin, an area unlikely to startle the patient. Gently press the cotton tip enough to dent the surface just 1 mm, and note her pain level, as well as superficial muscle responses. Repeat, gradually moving inward to the smooth vestibule mucosa between Hart's line and the hymenal ring, to delineate tender areas. Repeat this testing *around the clock* with the midpoint of the introitus the clock's center. Be sure to assess the vestibule around the urethra, and the urethra itself, as its mucosa is contiguous and often involved in LPV.

Chronic or recurrent fissures in the posterior fourchette are another cause of introital dyspareunia. Inspect closely for midline scars here, as this area may tear, heal, remain weak, then re-tear with the next penetration. Complete your surface evaluation by assessing for vulvovaginal infections or inflammation, such as Desquamative Inflammatory Vaginitis,

(*See SEXUAL PAIN, page 5*)

SEXUAL PAIN

(from page 4)

with the use of a warmed, lubricated, very narrow speculum, or obtain wet smears and cultures with just a swab. Patients with LPV and pelvic floor disorders often cannot tolerate a speculum, and in these conditions it is usually not necessary, at least at initial examination. Use of dilute acetic acid may also cause significant pain, and is rarely needed.

Vulvar biopsies are best avoided unless a lesion is suspicious for neoplasia (an abnormal growth), as results rarely impact management. There is never a need to biopsy the vestibule. Biopsies of specific lesions to diagnose dermatoses (skin diseases) may be delayed until a follow-up visit, after potential causes of pain in other Layers have been evaluated. Many patients attribute worsening pain to previous biopsies, so decide whether knowing results will help, take as small a piece of tissue as possible, and use a pathologist experienced in vulvar dermatology.

Nerve Layer

Disorders of the pudendal and other pelvic nerves may cause chronic sexual pain in women and men (19,20). These long nerves are subject to the same injuries and diseases as peripheral nerves running through other parts of the body. Nerve compression, injuries resulting in formation of neuromas (a tumor formed of nerve tissue), and peripheral sensitization all may occur in the pelvis.

During the vulvar examination, work with the patient to localize the area that is painful (e.g., clitoris, anus, posterior left vestibule), and if surface conditions do not explain her pain, determine which nerve likely innervates that sensory area. Patients with Generalized Vulvodynia may have trouble delineating specific areas, as burning and itching nerve pain may be felt broadly, i.e., *everything hurts*. Unilateral conditions may be sensed as involving the whole vulva, due to global pelvic floor responses causing nerve and muscle pain. Your careful history and neuroanatomy-based examination will clarify which pelvic nerves may be pain generators.

As the pudendal nerve (PN) is the main sensory nerve of the external genitalia, mentally visualize the course of its three main branches through the pelvic floor during the palpation described below. Inspect for scarring from surgery or childbirth that may have lacerated a nerve branch, creating a neuroma. Neuromas are only occasionally large enough to be palpable and may present as small areas of exquisite tenderness. Consider whether pain is localized to a single PN branch or if the whole nerve itself is involved, deeper in the pelvic floor proximal (close) to its division into branches. The landmark of the ischial spine, under which the pudendal neurovascular bundle passes, is quite easy to locate by single digit vaginal examination; specific pain elicited at this point by light touch is suggestive of PN involvement in the pain process. If the PN is compressed here or proximally in its path from the sacral nerve roots, all of its branches will be affected, including the rectal branch, generating pain that includes the anal area.

Digitally guided transvaginal or transperineal pudendal nerve perineural injections (PNPIs) at the ischial spine are simple for ob/gyns to perform in the office, and many of us gained experience using them for childbirth analgesia. For a well-prepared patient, we can avoid expense, sedation, and x-ray exposure. If a PNPI reduces the patient's pain temporarily, the PN needs to be addressed. An image-guided PNPI from the posterior approach can be planned with an interventional radiologist if clinical suspicion for PN pain remains high despite a negative (no effect) injection, or for a patient who needs sedation for the procedure.

Pain located in the area of one branch of the PN, or of the perineal branch of the posterior femoral cutaneous nerve, can be evaluated by performing specific small volume anesthetic injections directed to a

(*See SEXUAL PAIN, page 10*)

LICHEN SCLEROSUS

(from page 1)

The precise etiology of lichen sclerosus remains unknown, but there is a well-documented association with autoimmune disease, particularly thyroiditis and vitiligo. Many studies have examined the presence of autoantibodies, including those indicating systemic autoimmune disease, such as antinuclear factor. The significance of these autoantibodies is unknown, but it would appear that they are not the cause of LS. It still cannot be said, for certain, that LS itself is an autoimmune disorder.

Lichen sclerosus is an important condition to diagnose correctly for two reasons. First, if not treated aggressively, it may significantly scar and deform the vulva and cause stenosis (narrowing) of the introitus. Second, it is linked to squamous cell carcinoma of the vulva, with a five percent lifetime risk, if left untreated. Therefore, these patients require lifelong observation.

The most common presenting symptom is itch, often of a severe, life-disrupting nature. It is sometimes painful, as a result of excoriation or fissuring (scraping or splitting of skin). Distressing clitoral hyperaesthesia (excessive sensitivity) may occur, and dyspareunia is very common. It can be completely asymptomatic, discovered by chance by the patient or by the general practitioner during a Pap test. The appearance of a well-defined white sclerotic (hardened) plaque, with an atrophic wrinkled surface and areas of purpura (purple rash) and erosion is typical. However, there are many variations. Edema, telangiectasia (small red or purple clusters on the skin), and fissures may also be seen.

The distribution of LS is also very variable. The classic textbook description is of a figure eight encircling the vulva, perineum and perianal skin. However, it can affect only the perianal region, clitoris and internal surface of the labia majora, labia minora or vaginal introitus. It does not involve the hymen, but may involve the introital skin.

If left untreated, the overall appearance is an atrophic, shiny white vulva lacking normal features. It is very typical for the labia minora to fuse to each other below the clitoris and laterally to the labia majora. The fusion line is brittle and tears easily during intercourse. Perineal fissuring and tearing is also common. Eventually the introitus may become significantly stenosed (narrowed), with pooling of urine within the vagina, simulating urinary incontinence. In long-standing cases, atrophy of the vulva occurs with fusion of the labia, burying of the clitoris and disappearance of the labia minora. With end stage disease, epithelial change may be difficult to find and all that is left is gross distortion of the vulva.

The appearance of LS in children is the same as in adults, with atrophy, fusion of the labia and loss of vulvar architecture. Symptoms are different, however, with dysuria (painful or difficult urination) and constipation, common occurrences. Cancer has not been described in children, but scarring occurs just as in adults.

Although vulvar lichen sclerosus has a characteristic clinical appearance, a skin biopsy from the affected site provides diagnostic confirmation and exclusion of alternate diagnoses. A positive biopsy is also helpful in counseling the patient about the critical long-term consequences and need for follow-up. The exception is in children for whom there is a much smaller range of differential diagnosis and biopsy is usually traumatic. The histology is distinctive and uniform across ages and genders. The epidermis is atrophic with hydropic degeneration (swelling) of basal cells and a homogenous pale zone in the upper dermis. There is a lichenoid infiltrate of mainly mononuclear cells in the dermis.

Our research group has recently completed a prospective study of lichen sclerosus in over 500 adult women, comparing patients who adhered to treatment versus those who did not. This study demonstrates that treatment keeps the skin objectively normal and results in minimal scarring. Furthermore, none of the patients who adhered to treatment, and whose skin remained normal, developed squamous cell carcinoma during the seven year observation period. This is the first

(*See LICHEN SCLEROSUS, page 7*)

LICHEN SCLEROSUS

(from page 6)

adequately powered study on long-term management. Lichen sclerosus in adults is typically a lifelong disease. Most patients are unable to stop treatment without eventual relapse, although this may take many months. It is important to counsel patients, making sure they understand that treatment may be for life.

There are two phases of treatment for lichen sclerosus: inducing remission and maintenance treatment. It is now accepted that a potent topical corticosteroid is the gold standard for obtaining remission in vulvar lichen sclerosus. The first report of treatment with clobetasol propionate, a 'super-potent' topical corticosteroid, was published in 1991. Prior to that, weak topical corticosteroids, testosterone and progesterone were used. As a result, the condition was considered very difficult to treat. Lichen sclerosus is, in fact, so responsive to a potent topical corticosteroid that failure to improve should be reason to suspect either that the diagnosis is wrong, the patient is not using the treatment, or there are other confounding factors, such as allergy or superinfection.

For over two decades, most health care providers have used clobetasol propionate to induce and maintain remission, which has unintentionally created a long-term management problem. Clobetasol is too potent to be used consistently enough to maintain normal skin without producing atrophy and irritation. As a result, current guidelines are that it be used to gain control, and then on an *as needed* basis to control itch. Our research shows that, used in this way, there is a risk that the disease may progress silently. By contrast, consistent use of mild to moderate potency corticosteroid achieves normal skin without side effects.

There is no one treatment regimen that fits all LS patients, so treatment should be outcome-based. The broad principle should be to initiate treatment with a potent corticosteroid, used daily until the skin texture and color have returned to normal. The potency of the corticosteroid should then be titrated downward to a level that maintains remission, and then be used preventatively, even when the patient is asymptomatic. Symptom resolution occurs quickly, but resolution of abnormal signs takes longer. Patients must, therefore, continue their daily treatment even after symptom resolution. Patients should be seen every six months, until

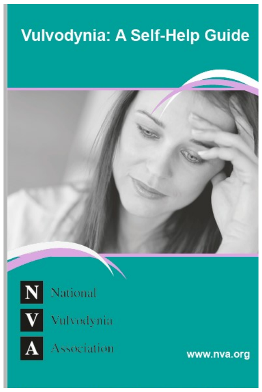
(*See LICHEN SCLEROSUS, page 8*)

NVA Welcomes New Executive Board Member

Susan Kellogg-Spadt, Ph.D., C.R.N.P., is the director of female sexual medicine at the Academic Urology Center for Pelvic Medicine in Bryn Mawr, Pennsylvania. In this capacity, she provides patient care and consultative services as a vulvovaginal/pelvic pain specialist and sexual dysfunction clinician/therapist. Dr Kellogg-Spadt is a professor of obstetrics and gynecology at Drexel University College of Medicine and of human sexuality at Widener University, as well as an associate professor at Rutgers University Robert Wood Johnson School of Medicine. In addition, she is a member of the Board of Directors of the International Society for the Study of Women's Sexual Health.

Dr. Kellogg-Spadt received her Ph.D. in Human Sexuality, her post-masters certificate as an ob/gyn nurse practitioner from the University of Pennsylvania, and an MSN in Maternal Child Health from Loyola University in Chicago. She is an active researcher and has been an investigator in an NIH trial and several industry trials investigating female sexual dysfunction and pelvic pain syndromes. We are very pleased to welcome her to the NVA Executive Board.

NVA Updates Self-Help Guide



The NVA is pleased to announce the publication of a revised version of our popular self-help guide for women with vulvodynia. The guide covers vulvodynia from both the gynecological and chronic pain perspectives, providing suggestions for self-care and advice from other affected women. We thank Purdue Pharma, L.P., for funding this project, including the printing of the first 5,000 copies.

We hope that health care providers, as well as patients, will view this guide at www.nva.org/shg. Health care providers can then order hard copies for their office at www.nva.org/for-health-professionals/order-patient-materials. Alternatively, both patients and health care professionals can order paper copies by contacting our administrator, Tamara Matos, at admin@nva.org or 301-299-0775.

LICHEN SCLEROSUS

(from page 7)

they have been in stable remission for two years, then yearly with the proviso that they come back earlier if they have concerns. In practice, this management regimen is safe and side effects are remarkably few.

Newer treatments for very recalcitrant hyperkeratotic (skin-thickening) lichen sclerosus include intralesional platelet-rich plasma. This has been termed *stem-cell treatment*, but its efficacy has not been confirmed by randomized controlled trials. In some patients with hyperkeratotic disease, ablative laser treatment and narrow band UVB phototherapy can be useful adjuncts to treatment, as can intralesional corticosteroid. None of these modalities, however, is a substitute for ongoing topical therapy.

Topical immunosuppressive agents, such as tacrolimus and pimecrolimus, have been described as potentially playing a role in the treatment of LS in children and adults. The authors who recommend topical immunosuppressives state that they are less likely to cause atrophy. However, we have rarely noted atrophy in our corticosteroid-treated patients, and when it does occur, it always improves with a lower dose. Immunosuppressive agents are more expensive, more likely to sting and have the theoretical disadvantage of increasing the risk of malignant transformation.

Historically, vulvectomy was performed in adults with LS, but the disease recurred. Surgery is no longer considered an acceptable method of treatment and is contraindicated, unless significant fusion of the labia has occurred. Various surgical procedures have been used to treat labial and peri-clitoral adhesions. Simple division of adhesions gives a very satisfactory result, provided that potent topical steroids are used daily post-operatively until healing is well underway. Sometimes it is necessary to apply the post-operative steroid on a dilator.

If lichen sclerosus is diagnosed early and treated aggressively, followed by long-term maintenance therapy, the prognosis is excellent.

(Editor’s note: For a reading list, please contact Tamara Matos at admin@nva.org or 301-299-0775.)■

In Her Own Words

By Jenny Leigh

At 14 years of age, I first noticed vulvar pain when trying to insert a tampon. I assumed it was typical discomfort, but two years later my boyfriend and I decided to have sex and the pain was so excruciating we had to stop. I sat in a tub of lukewarm water, trying to figure it out. We tried at another time, but it was impossible. I decided to stop trying to have sex. For a while I felt like my life was normal, but then I started to have pain sitting. I finally told my mom who took me to a gynecologist. I described my symptoms. The gynecologist took some cultures and determined I had a yeast infection. I felt better after seven days of Monistat, but three weeks later the pain returned in full force. This time the gynecologist prescribed a strong antibiotic instead. It didn't work and my doctor said she couldn't help me. I was terrified.

For the next year, I continued to have yeast infections and used Monistat for temporary relief. Then it was my senior year and it seemed like almost everyone was having sex. My boyfriend and I tried again, without success. I went to college and started googling "vaginal pain." Dozens of articles popped up, but I focused on one that described sexual dysfunction caused by vulvodynia.

That's what I had... vulvodynia! I brought the information to my mom and we discovered the National Vulvodynia Association. I asked for their doctor referral list and found a specialist, but it took months to get an appointment. Instead, I found another vulvodynia specialist, Dr. Gloria Bachmann of Robert Wood Johnson Hospital, in New Jersey. During my Q-tip test, we determined that my pain was in the vestibule. Treatment began with topical creams because I was hesitant to take oral medication. I tried lidocaine 5%, then compounded gabapentin and clobetasol propionate. One or two provided short-term relief. At that point, I agreed to try oral medications, first an antibiotic, then an antidepressant, oral gabapentin, and amitriptyline. The first three weren't helpful, but I felt pain relief with amitriptyline. I could not remain on amitriptyline, however, because it made me feel like a zombie.

Having tried so many treatments that were not helpful, or caused unacceptable side effects, surgery seemed to be my final option. After reading Dr. Andrew Goldstein's book, *When Sex Hurts*, I decided to consult him about the prospect of surgery. After a long telephone conversation, and then a physical examination, Dr. Goldstein told me that a vestibulectomy was my best option. I was scared and wide awake the night before my appointment. The next morning I went to a small surgical center and was hooked up to an I.V. Minutes later I was asleep, and when I woke up, the surgery was over. To be specific, I had a vestibulectomy plus a hymenectomy. After two months of mostly bed rest, the tissue healed. At the post-op examination, Dr. Goldstein did another Q-tip test, starting at the outside of the vestibule. No pain! Then the Q-tip was inserted where the pain had been intense. Nothing...it was incredible! Afterwards, he gave me glass dilators ranging in size from small to large. I was instructed to insert a dilator every day to stretch the vaginal muscles and scar tissue. It was painful at first, but I used them consistently, and after a few weeks, my vagina felt normal again. I was finally able to consummate my relationship with my boyfriend!

Fast forward to today, I have a pain-free normal life and I am able to have sex whenever I choose. The disadvantage of the surgery, losing 25 percent of my vaginal lubrication, was well worth the sacrifice. I simply apply a considerable amount of lubricant before sex. Now I speak about my experience freely to give encouragement to other adolescent girls who are suffering from this condition and don't know where to turn. I want them to know they are not alone and that they should be hopeful.■

convenient point along a branch's usual course, or where you think a neuroma is located. Nerve branch injections that result in pain relief indicate involvement of that branch primarily, or secondarily from myofascial abnormalities, as discussed below.

Clitorodynia (clitoral pain) and the related pain disorder, persistent genital arousal, may result from multiple etiologies, but irritation or compression of the dorsal branch of the PN usually plays a role. Some cases of clitoral pain result from surgical injury to the nerves above the clitoris, so check for suprapubic and groin scarring. Diagnostic blocks of these nerves, and of the dorsal branch, performed along their course well away from the clitoris, will clarify their involvement and direct therapy.

Myofascial Layer—The Pelvic Floor

Just under the surface of the vulva lies the invisible Layer we call the pelvic floor, made up of muscles and the fascia covering and attaching them to each other, and forming their origins and insertions into bone and cartilage. Whether sexual pain begins in this Layer or not, the pelvic floor muscles (PFMs) almost always contribute to its intensity and chronicity. Muscle spasms, myofascial trigger points, and secondary dystrophic changes (from atrophied muscle tissue) add to nerve irritation and compression. Patients often sense both PFM and PN pain as a foreign object in the vaginal canal, which corresponds to the bulkiness of muscles remaining in an abnormal contracted state. Dysfunction of the PFMs is a common component of all types of CPP and is "The Missing Link" in making a complete diagnosis, as recently described by Weiss (21). In women with sexual pain, it is crucial that the pelvic floor be systematically evaluated.

The vast majority of women who have been told they have "vaginismus" actually suffer from LPV and severe PFM dysfunction. Painful experiences from touching, sexual activity, and medical examinations understandably result in avoidance of vulvar contact, which is often misinterpreted as a psychological problem. These patients require preparation with a full explanation of your evaluation, and benefit from dividing the examination into small steps at more than one visit. Use examinations under anesthesia only as a last resort, because, with muscle relaxation, important PFM and nerve findings may disappear. Oral or intravaginal diazepam is an option an hour before examination, but keep in mind that you may underappreciate the severity of myofascial abnormalities with this premedication.

PFM evaluation must focus on both deep and superficial myofascial structures, both vaginally and rectally. Palpate PFMs for tenderness, high tension, tight bands, trigger points, bilateral symmetry, and hypertrophy or atrophy. These muscles include the bulbocavernosus, ischiocavernosus, transverse perineal, levator ani, obturator internus, piriformis, and anal sphincter. Keep in mind that muscle and fascial constrictions around the courses of nerves hinder normal stretching and gliding in the tissues during sexual activity, causing burning pain. Dry needling tight bands and trigger points in the relevant muscles, or injecting them with 0.5cc lidocaine, then palpating to confirm their release, and effect on pain, is a useful diagnostic tool.

Note findings of vaginal relaxation, pelvic organ prolapse, and Bartholin's cysts, but keep in mind that these are usually not sexual pain generators. Many patients with unappreciated LPV have had small Bartholin's cysts surgically excised, without benefit. If they are present, be sure to continue to evaluate all Layers for more likely causes of sexual pain.

Physical therapists (PTs) specializing in pelvic floor muscle dysfunction have taken up the challenge of caring for women with sexual pain, and can help us improve our pelvic floor examination skills. Forge a close relationship with an expert PT in your area for improved evaluation and treatment of painful sex (22).

Musculoskeletal Layer

The musculoskeletal structures of the lumbopelvic area intimately affect the PFMs, and may cause painful sexual intercourse. Intra-articular hip disorders, such as

(See SEXUAL PAIN, page 11)

(from page 10)

femoroacetabular impingement, are common in women and hip evaluation via history and examination are needed in all (23). Observe gait and routinely perform a provocative test for hip impingement, such as the FABER (flexion, abduction, external rotation) test. The obturator internus, part of the pelvic floor along which the PN runs, is a main hip rotator; pain on palpation of this muscle, and at the greater trochanter of the hip, are suggestive of hip dysfunction contributing to painful sex. Also assess for pubic symphysis, coccyx, and sacroiliac joint tenderness. Lumbar disc disease and osteoarthritis are common with aging, and older women may report painful sexual activity in positions that stress these conditions. Further evaluation by an orthopedist and PT may be needed.

Organ Layer: Uterus, Bladder, and Bowel

For years, deep dyspareunia suggested endometriosis, but remember to evaluate for the painful PFM responses that usually co-exist, adding to sexual pain. Postoperatively, painful sex is an often overlooked concern, and evaluating the side effects of hormonal therapies on genital tissues is crucial.

We now appreciate that sexual pain is a common component of the three main CPP disorders that are often co-morbid: endometriosis, interstitial cystitis/painful bladder syndrome (IC/PBS), and irritable bowel syndrome (IBS). Painful bladder syndrome causes urethrodynia and significant introital pain, as LPV often co-exists. Penetration may also induce severe long-lasting pain flares, as the base of the bladder and the often hypertonic (extreme tension) pelvic floor is compressed. Include gentle specific assessment for tenderness of the urethra and bladder base in your single digit examination. Similarly, IBS sufferers frequently have PFM hypertonicity, as well as defecatory dysfunction and anal fissures, causing sexual pain. A complete evaluation must consider the possibility of one or more of these overlapping disorders. Further evaluation of complicated pain in several Layers includes imaging of the pelvic organs, PFMs, and lumbopelvic region.

CASE REPORT
LILY: AGE 26 YEARS
HISTORY & PHYSICAL EXAMINATION

- As a child, had repeated ear infections and antibiotic courses
- Age 12: began urinary frequency, worse at age 15 after painful attempts at tampon use, saw mom's urologist, diagnosed possible IC
- Age 16: developed depression, began sertraline and multiple treatments for recurrent yeast infections; failed elmiron and amitriptyline
- Age 18: symptoms up and down, started oral contraception for cycle control and acne
- Age 23: first boyfriend, severe burning pain with touch, progressed to sitting pain, worsening depression
- Upon examination: exquisitely tender vestibule and hypertonic pelvic floor muscles

Systemic Causes of Sexual Pain

Body-wide disorders may underlie the development of sexual pain in all Layers. There are three interconnected systems that control tissue healing: the endocrine, immune, and nervous systems. Patients may need evaluation for potential disorders in all of these systems. Diabetes, even borderline, can affect sensory nerves in the vulva, just like it causes burning pain in peripheral nerves elsewhere in the body. Consider the possibility of auto-immune disorders, common in women, when inflammatory surface changes do not respond quickly to treatment. Conditions such as Sjogren's, Lupus, and connective tissue disorders may negatively impact mucosa, fascia, and small nerve fibers, leading to painful sexual intercourse.

Menopause is a systemic endocrine condition that affects all Layers in most women to some degree, whether it is medically or surgically induced or occurs naturally. We now know more about how declining

(*See SEXUAL PAIN, page 12*)

SEXUAL PAIN

(*from page 11*)

estrogen and androgen may disrupt vulvar and pelvic tissues, as mucosa, myofascial and sensory neurons contain sex hormone receptors. In some menopausal women, LPV is triggered, with severe sexual pain and vestibular examination findings similar to younger patients (24,25). Topical hormone therapy usually benefits menopausal dyspareunia, and testing baseline and follow-up blood hormone levels is not necessary. But for women who do not respond quickly, re-evaluation for LPV and disorders in other Layers is key to a complete diagnosis in menopause too.

Centralized pain may occasionally be present as a component of chronic sexual pain (26). Findings suggest that this condition includes hyperesthesia, systemic allodynia, lowered pain thresholds, and sometimes co-morbidities, such as fibromyalgia and chronic headaches. Assembling a team of knowledgeable specialists in neurology and rheumatology for further evaluation of systemic conditions is crucial. Research and experience continue to show the benefits of integrating complementary mind-body therapies into the care of complex and systemic pain disorders (27).

CASE REPORT
LILY: AGE 26 YEARS
DIAGNOSIS & TREATMENT

- Diagnosis: Localized Vestibulodynia and Pelvic Floor Muscle Dysfunction
- Comorbidities: migraine headaches, Grave's disease, Irritable Bowel Syndrome
- Treatments with moderate benefit: stopped oral contraception, added topical estradiol and testosterone, pelvic floor physical therapy, Candida prophylaxis
- Able to be sexually active with a supportive partner
- Recurrent pain lasting one day after sex, treated with Botulinum toxin with moderate benefit
- Age 25: underwent vestibulectomy which eased penetration, continues topicals and physical therapy for occasional pain flare

Overall Treatment Principles for Chronic Sexual Pain

Providing a complete diagnosis to your patients with sexual pain is a most important contribution. Almost always multiple Layers are involved, and once recognized, therapies for each pain generator can be individually and systematically employed. Share with patients a written individualized treatment plan addressing each Layer. The vulvar surface must be protected and strengthened, abnormal peripheral and central nerve activity suppressed, and the pelvic floor muscles normalized by an expert physical therapist. Musculoskeletal abnormalities and pelvic organ pain require focused therapies, and underlying systemic conditions must be appreciated and treated. Depression, anxiety, hopelessness, and loss of sense-of-self resulting from sexual pain are improved by both supportive and cognitive behavioral therapy. Develop a relationship with a therapist who is knowledgeable about chronic pain and mind-body practices, which calm the autonomic nervous system and physical effects of pain and stress.

Anticipate pain flares, and have a formal plan in place with the patient before they ever occur. Importantly, re-evaluate persistent or recurrent pain often, Layer by Layer. Address the side effects of medications preemptively and quickly. Avoid opioid pain relievers, which do not relieve chronic pain, but instead may cause bowel and bladder symptoms, endocrinopathies, sexual dysfunction, and mood and cognitive disturbances that may lead to overdose (28).

Patients trust that as ob/gyns with knowledge, experience, and regular involvement with other aspects of women's intimate lives, we hold distinct responsibility for care of chronic sexual pain. Our committed partnership with these patients will improve their quality of care, and provide an essential component of healing: hope for the possibility of cure.

(Editor's note: For references, please contact Tamara Matos at admin@nva.org or 301-299-0775.)■