



National



Vulvodynia



Association

# NVA News

Volume VIII, Issue III

Summer 2003

## A Discussion of Sexual Intimacy and Vestibulitis

**With Susan Kellogg-Spadt, Ph.D., CRNP and Loretta Sernekos, Ph.D.**

*Dr. Kellogg-Spadt is the Director of Sexual Medicine at the Pelvic Floor Institute in Philadelphia, Pennsylvania, where she is a nurse practitioner specializing in vulvodynia and female sexual dysfunction. Loretta Sernekos, Ph.D., is one of Dr. Kellogg-Spadt's patients.*

LS: Would you describe your study on sexual intimacy and vulvar vestibulitis as well as its key findings?

SKS: All women in the study had been diagnosed with vestibulitis for at least one year and the study consisted of two parts. Part one was a quantitative, descriptive study of 110 vestibulitis patients who completed a 100-question survey focusing on their experiences with vestibulitis (with responses on a scale ranging from "Agree Strongly" to "Disagree Strongly"). These patients also completed a four-question short-answer section. Part two of the study was a qualitative, exploratory interview study of 12 vestibulitis patients who were asked 40 in-depth questions about their experiences with vestibulitis. These interviews were taped and transcribed. Study participants were also asked questions about their percep-

tions of their partners' experiences in dealing with vestibulitis.

The most important finding was that the script of the sexual relationship between couples dealing with vestibulitis appears to change in a very predictable way with identifiable stages. In stage one, within three to eight months, there was usually a departure from any kind of sex play because intercourse hurt. In some patients arousal alone hurt and in other patients foreplay "might lead to" intercourse which hurt, so foreplay became "off-limits." Avoidance ensued. This first stage, therefore, is characterized by abstinence. Approximately 8 to 12 months after diagnosis, when the couple realized that a cure would not be readily achieved, "one-way" sex

*See INTIMACY, page 2*

## Common Traps in Diagnosis of Vulvovaginal Disorders

**By Elizabeth Stewart, M.D.**

*Dr Stewart is the director of The Stewart-Forbes Vulvovaginal Service at Harvard Vanguard Medical Associates in Boston, and assistant professor of ob/gyn at Harvard Medical School. She is the author of The V Book, a book for women on vulvovaginal health and disease.*

**I**f you've experienced a vulvovaginal problem at any point in your life, you may have had trouble finding a knowledgeable clinician to help. That's because there is very little information taught about the subject in medical and nursing school curricula. Today in America there is a growing emphasis on "Women's Health." We receive a full rundown on pregnancy, labor and delivery, as well as menopause, which was a taboo subject as recently as 20 years ago. Breast-cancer receives well-deserved attention in the media. There's also been great emphasis on the benefits of exercise and physical fitness for general health. But the vulva and vagina have been left out!

*See DIAGNOSIS, page 8*

## Intimacy

(from page 1)

play began. The woman typically initiated some kind of "release" for her partner, but saw it very much as a functional behavior. Our study suggested that this is when a woman's libido, or desire for her own sexual satisfaction, began to fall off. Women in this stage often described themselves as "servants," "caregivers" or even "prostitutes." The second stage, then, is characterized by service-type sex play.

In the third stage, women resolved that they were going to "do it no matter what." Women in this stage voiced fears of losing their marriages or jeopardizing their relationships. So they used Lidocaine, drank alcohol, took pain-killers, i.e., they used whatever they had to use to get through the act of intercourse, no matter how painful. Sometimes women engaged in intercourse to become pregnant, while at other times it was simply to "prove" they could do it. The third stage, then, is characterized by painful intercourse on an infrequent basis, usually once every three to six months. In this

stage, most women continued to have low libido and tended to become the sole initiator of penetrative play. Women tended to be the initiator for two reasons: (1) partners shied away from initiation because of fear of causing pain; and (2) the women wanted to "get things back to normal" even though they knew penetration would probably be painful.

In some ways, the woman being the initiator is a wonderful idea because she can control when sex play occurs and in what fashion. However, among heterosexual couples, what's devastating at this point is that the male partner feels emasculated because he no longer feels in control and has lost his script as the initiator of play. It was also devastating for the women who now felt unattractive, not only because they had a painful vulva, but because they were not being sought after by their partners. Being pursued and "swept off my feet" was recalled as a "lovely feeling," because women felt wanted, desired and feminine. In essence, as the initiation roles changed, male partners felt less masculine and female partners felt less feminine. Unfortunately, unless a couple either seeks therapy or is in an excellent health-care milieu that realizes that this is a common scenario, they can become sexually estranged. Intimacy as seldom as one to three times per year may remain the pattern of coping with sexual pain even if the woman starts to feel better.

LS: Could you explain the term "script"?

SKS: Scripts are a type of pattern or sequence that people follow in everyday life. Scripts are influenced by our families, our cultures and our past experiences, and are often subconscious. Everyone has sexual scripts. Couples (and not just couples dealing with vestibulitis) follow certain patterns that pre-empt and define their sex play. Maybe the woman takes a certain nightie out or lubricants are placed on the night stand, or the couple goes to a certain place for dinner, etc.

LS: So each person understands what's happening, even if the cues are non-verbal. We don't have to think about them; the meaning is obvious and comforting in its familiarity.

SKS: Exactly. It's all scripted. But if you alter the script too dramatically so that initiation patterns are disrupted,

*See INTIMACY, 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](http://www.nva.org)

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

**Editor:**  
Phyllis Mate

**Layout:** Andrea Hall **Contributor:** Christin Veasley

---

The National Vulvodynia Association is an educational, nonprofit organization founded to disseminate information on treatment options for vulvodynia. The NVA recommends that you consult your own health care practitioner to determine which course of treatment or medication is appropriate for you.

---

NVA News, copyright 2003 by the National Vulvodynia Association, Inc. All Rights Reserved. Permission for republication of any article herein may be obtained by contacting the NVA Executive Director at 301-299-0775.

---

## Intimacy

(from page 2)

it can be very devastating to couples. Not necessarily the act, but the pattern that is going on, in which the acts are embedded, i.e., the script.

LS: Getting back to your findings, so far we have three stages. What was the final stage?

SKS: The final outcome for couples in the study usually went one of two ways. For some couples, the woman remained the sole initiator of sex play, but even if she did, sex remained infrequent. Other couples in the study who achieved and maintained intimacy in a healthy way were those who regained the "rhythm" of their initiation. Their new scripts involved the partner initiating intimacy at least 50 percent of the time. Typically, the woman with vestibulitis, once in a treatment program, began to experience periods when she felt that she could try to be intimate. She would learn to tell her partner, "I'm feeling a little better. I'm really happy about that. In fact, I'd like to try being together sometime in the next 4-7 days." She would then say or do nothing more and the partner now had a window in which he or she could initiate intimacy with the woman. In this way, each partner felt that their original sexual scripts were supported and maintained.

LS: In other words, the woman gave the partner "permission" to initiate.

SKS: Precisely. The partner would initiate, knowing pretty much that the woman was going to be receptive. The woman felt desired and feminine because her partner took the opportunity within her "wellness window" to say, "Honey, I love you and I want to be with you." Therefore, the balance in their intimacy was regained. The woman with vestibulitis still had to set the boundaries so she felt safe, but her partner was able to act within those boundaries. This was the healthiest sexual play pattern and the most dramatic sexual play alteration that we saw in vestibulitis patients.

Another interesting pattern in long-term vestibulitis patients is that, even after the woman has had several instances of pain-free intercourse, she may still be haunted by the specter of pain. She might question, "If we go too long or too rough, will it come back?" Those are normal feelings. This fear is often expressed as "I'm better now and I don't understand why I still don't get excited about having sex." It is very important through-

out the process for the couple to be supported by a professional sexual health care team so the couple can work through these issues.

LS: So some women become the sole initiator for the entire time they experience vestibulitis. Do some couples just abstain from *all* sex play while the woman has vestibulitis symptoms?

SKS: Yes, but we found that vestibulitis patients are usually not happy with either option. Many have remained the initiator for the long-term, but in a one-on-one interview, they'd say, "What I would give to be swept off my feet and be sought after." And most women who continued to avoid all sexual behavior expressed intense feelings of regret and sadness.

LS: In some ways, my experience was similar and, at the same time, it was atypical. At the onset of vestibulitis, when I didn't have a diagnosis and was running from doctor to doctor, vaginal intercourse became this "monster thing" in my mind! It loomed huge, taking on a weight that was out of proportion to the actual sexual practices of my husband and me. Vaginal penetration became the be-all and end-all of sex in my mind. So for the first four months, I shut myself off from most sexual contact with my husband, waiting until I could get back to "normal." Looking back now, I think, "That was ridiculous. Throughout our marriage, we hadn't engaged in intercourse all the time, by any means!" But there I was, waiting to feel better and be "normal" again. To this day, I am amazed at how quickly I fell into the mindset of equating vaginal intercourse with sexual intimacy. My husband and I had always playfully touched, squeezed, nuzzled, etc., without an expectation of anything more to follow. But suddenly this type of contact made me anxious because I was worried that it *might* lead to something more. It also reminded me of what I had lost, and that made me sad and fearful for the future. So I'd say I followed the first stage rather closely.

SKS: Another important finding from the study was that alternative expressions of intimacy which might result in orgasm were *not* the norm for long-term vestibulitis couples. It might have seemed intuitive that if one level of sex play was "off limits," other avenues would be pursued, but that was not the case. In every single

See *INTIMACY*, page 4

---

## Intimacy

(from page 3)

interview, the focus was on coitus, always. This held true across ages, from women in their 20s to women in their 60s, and it crossed cultural boundaries and marital status. Having really *listened* to what the women were saying, it's now clear to me that the focus on coitus reflected the pervasive American/western cultural script that says "penis-in-the-vagina" equals "real sex."

LS: When you have a patient who tells you about problems in her sexual relationship and you can see clearly what stage she's in, what do you tell her?

SKS: I tell her the results of the research. That's *why* the research was done, in order to better understand both the sexual adjustment of women with vestibulitis and the dynamics of scripting. I found that the cultural script of intercourse was stronger than I had anticipated. Finally, so much of what I had been seeing as a health care provider specializing in vulvodynia made sense to me! Interestingly, in clinical practice, this script is equally strong for men with various sexual dysfunctions. The drive to resume intercourse is generally very strong.

LS: I lived that script, at least for the first 4 months. I look back and think, "That was another person inside my head. What was going on there?"

SKS: That was the Loretta who watched TV shows, read every story and listened to songs on the radio. You grew up in this culture, too, and absorbed cultural norms. Working with couples, we will commonly "assign" intimate behaviors ranging from manual pleasuring to oral play or outercourse-type thrusting. We find that the couples are often most compliant with "outercourse" because it is non-threatening and because it mimics what they consider to be "real sex."

LS: Could you define "outercourse" for me?

SKS: Penile thrusting against the lower abdomen, in between the thighs, or between the buttocks. The penis does not enter the vagina, so there is little chance of irritation or pain. Although many couples find this a viable alternative initially, after a finite number of months, women often say, "Now I need to have intercourse, and I would like you to give me something to help me have intercourse." Since conducting the research, I understand that it's my job to not only facilitate intercourse (often with the help of agents such as Lidocaine,

ice, etc.), but also to help couples with the initiation of intercourse in terms of their comfort levels with their gender roles. We tell patients, "One of the healthiest things for you to do when you're feeling a little bit better is to use progressively-sized dilators, because then you'll know when you're feeling well enough for penetration."

LS: My experience differed from those of the women in your study in that, four months after the onset, it became clear I wasn't going to feel better soon and had to get on with the business of living and being a sexual being. I figured that I'd better throw out the definition of "normal" sex and redefine "normal"! Around that time, I realized that if the main goal of sex is emotional and physical intimacy, there are lots of ways to accomplish intimacy that do not involve vaginal penetration. I also realized — and I want to emphasize that this thinking evolved over time — that it is possible to have both vestibulitis and a wonderful, satisfying sex life, even if it might not be possible to return to the same sex life I enjoyed before vestibulitis. So for my husband and me, becoming sexually intimate again took a somewhat different path than the couples in your study. Initiation issues did not loom quite so large, although my husband went out of his way to not make me feel pressured to engage in sexual activity, and I do think he was somewhat reticent to initiate for a while as a result. I found that once we threw out the idea of vaginal intercourse, it felt liberating to just go back to doing what felt good and being playful about sex. Without the "goal" of vaginal intercourse, sex could be slowed down and savored. I felt, in a way, that my husband and I had to reinvent what sex meant to us. We started off very slowly, just enjoying a naked cuddle, a massage, a long, sensuous kiss, i.e., sex play with no specific penetrative or orgasmic goal in mind. We did whatever pleased us. I also realized how healing simple physical touch could be and mentally kicked myself for depriving myself of that for months. Skin-to-skin contact felt good again! I began to read a lot about sex, looking for ideas I could use. At the bookstore, I had to wade through a lot of "how-to" books that assumed sex equals intercourse, but I found some gems that treat sex as a fun, wide range of activities. If a vestibulitis patient says she wants to rethink the whole idea of what sex is, or if her vestibulitis is not yet responding to treatment and intercourse remains nearly impossible, what do you suggest?

See *INTIMACY*, page 5

---

## Intimacy

(from page 4)

SKS: I may suggest relationship counseling, preferably with someone who has specifically dealt with vestibulitis and is not just experienced in “sexual dysfunction” per se. The counselor will actually guide couples through the steps of regaining physical intimacy. Often, couples know they are in a bad place, but they don’t know how to get out of that bad place.

LS: How do you prepare a vestibulitis patient to resume intercourse or penetrative activity once you think she is ready?

SKS: Vestibulitis patients need to test the water a little bit, so we use dilator placement, speculum placement and/or finger placement to build confidence and give us an idea of where we are. If there is a pelvic floor dysfunction history, patients have usually had physical therapy and/or biofeedback. We encourage the use of a warm bath, a prescription muscle relaxant, ice and/or Lidocaine before sexual activity, as well as generous amounts of lubricants. Obviously, thrusting time should be limited and gentle, and positions should be chosen carefully. Often the side-lying position is best for these women. Some prefer traditional missionary or female superior positions, depending on the vulvar area that is painful to them. Many women find that circular thrusting, rather than in-and-out technique, is best tolerated.

LS: I also found it helpful to keep the first attempt at intercourse as short as possible. That way, my confidence soared and I wasn’t apprehensive the next time. What do you recommend after intercourse?

SKS: We recommend using cold water, removing some of the lubricant, perhaps applying an icepack and then going back to bed for snuggling, even if it’s with an icepack. As long as the couple knows what to expect, loving in this way can be very satisfactory.

LS: Did your study teach you anything about the feelings of the partner, even though the partners were not interviewed directly?

SKS: Women in the study reported that their partners felt helpless. Even female partners reported feeling helpless and they stopped initiating intimacy, too. And in my practice, the biggest theme that emerges from speaking with men is powerlessness. They say things like, “I can’t make her feel better, I can’t initiate sex. I sit next

to her on the couch and she moves away. I don’t even want to have sex with her, but she keeps thinking I do.”

LS: One day I made a comment about the male libido to my husband, and he said, “You know, sometimes all I really want is a back rub!” That was a real “moment” for me, although we were both laughing at the time. It was liberating to hear him say that. I thought, “all he really wants is the cuddling and the loving intimacy.” That shook me out of my mindset! Here I was, happily married for years and vestibulitis had made me revert to thinking like a teenager, i.e., “He may leave me if I don’t give him sex.” I think his comment about the back rub and the way he gently reminded me one day that our marriage was about love and not sex, helped me move on and begin to think about intimacy in new ways.

SKS: I think we sell men short sometimes, thinking that they are such libidinal creatures, that they *have* to get to the endpoint of intercourse. They need cuddling too. At some point in the vestibulitis experience, it’s important that they come into the office and hear, from the provider’s mouth, “I think it best that you don’t have penetrative play right now.” Hearing that takes the pressure off both partners and the couple is encouraged to just cuddle and enjoy each other. Additionally, since clitoral function is usually unaffected in women with vestibulitis, it’s important to encourage patients to explore that aspect of their sexuality and to reassure the couple that “no penetration” does not preclude other forms of sexual intimacy. The more the couple communicates and continues to touch while dealing with the diagnosis, the less likely the woman will feel guilt or her partner will feel doubt about her desire to be with him.

LS: From my own experience, knowing in advance that no attempt at penetration will be made creates a feeling of safety and relaxation. It’s hard to feel sexy and aroused when you’re worried that sexual activity might go somewhere painful! That brings me back to the libido issue again. I’ve talked with women, even some who are in a long phase when their vestibulitis is quiet, who say, “I just don’t have a libido anymore. I don’t want sex and I force myself to go through the motions.” They don’t want to feel that way but can’t help it, which makes them sad. I know this is a complicated issue, with both physical and psychological components, but what do

See *INTIMACY*, page 6

## Intimacy

(from page 5)

you do when a woman tells you her libido seems to have disappeared?

SKS: First, it's important to ascertain the extent to which the woman feels that her pain will recur. Then we assure the woman that she can use pain-relieving medications or creams and encourage her to see how her body will respond. As I've already mentioned, we discuss the couple's initiation patterns to see if that is affecting her libido. Also, many vestibulitis patients take anti-depressants with sexual side effects. We may add other medications that can counteract those sexual side effects, or we may change the anti-depressant to another type without sexual side effects. Depending on where she is in her life cycle, we may check hormones to see if they are a contributing factor and prescribe supplemental hormones if necessary. We also assign erotic reading, self-stimulation exercises and discuss things she might do to feel sexy. In other words, anything that would help a non-vestibulitis patient with the same problem might help a vestibulitis patient with low libido. Sex therapy is another possible intervention. Unfortunately, there is no "magic bullet" and it takes time to help women with this issue.

LS: One last question about women who are not currently in a long-term relationship. Vestibulitis can have a devastating effect on a woman's dating habits and her confidence in finding a long-term partner. How can these women handle sexual intimacy with a new partner in such a way that the partner doesn't get scared off and the woman still feels sexually attractive?

SKS: We counsel women to refrain from sexual intercourse until they have a comfortable level of sexual communication in the relationship. And then, in a *non-intimate* scenario, perhaps having coffee at the local coffee shop, the woman should bring up the subject. She should explain what vestibulitis is, perhaps give the partner a brochure and explain that it's not contagious — this is very important. One example is to say, "I am so turned on by you that I'd like to continue what we've been doing these last few weeks, and if you're willing to go slowly, we can move toward intercourse together over time. Are you willing to be patient with me?" In twelve years, dealing with scores of patients in similar situations, I know of only one partner who walked away from a woman when communication was handled in this fashion. Only one! Most partners are just so relieved the woman didn't say she has HIV! Conversely, if a woman

tries to talk about vestibulitis when she's "in the middle of the act," or just tries to suffer quietly and the act is devastatingly painful, it is a prescription for disaster. Honesty is the best policy, but there's a time and place for disclosure.

### Suggested Readings:

Gach, Michael Reed. *Acupressure for Lovers: Secrets of Touch for Increasing Intimacy*. New York: Bantam Books, 1997.

Joannides, Paul and Gross, Daerick (illustrator). *Guide to Getting It On!* Waldport, OR: Goofy Foot Press, 2000.

Kellogg-Spadt, Susan. Suffering in Silence: Managing Vulvar Pain Patients. *Contemporary Nurse Practitioner* 1995; 1(6):32-38.

Kellogg-Spadt, Susan and Giordano, Jennifer. Vulvar Vestibulitis and Sexual Pain: New Insights. *The Female Patient* 2002; 27 (April):51-53.

Maxwell-Hudson, Clare. *The Complete Book of Massage*. New York: Random House, 1988.

Winks, Cathy, and Semans, Anne. *Good Vibrations Guide to Sex*. San Francisco: Cleis Press, 2002.

Yorke, Andrew. *The Art of Erotic Massage*. New York: Sterling Publications, 1988.

(Editor's Note: Part 2 of this article, dealing with sexual intimacy and dysesthetic vulvodynia, will appear in the next NVA News.) ■

### Shop and Donate!

If you plan to shop at amazon.com, first go to [www.nva.org](http://www.nva.org) and click on a book link to Amazon's website.

Five percent of whatever you spend will be donated to NVA. (You don't have to buy the book.) Thanks!

## Grassroots Advocacy Leads to Capitol Hill Briefing

In an effort to raise awareness of vulvodynia and obtain more federal funding of vulvodynia research, the NVA went to Capitol Hill in early August to make a presentation to congressional health staffers. The 90-minute briefing was co-sponsored by Senators Russell Feingold (D-WI) and Tom Harkin (D-IA).

In her introductory remarks, NVA's executive director Phyllis Mate briefly summarized the latest research findings on vulvodynia prevalence and thanked the Senate and House of Representatives health staffers for attending, pointing out that their presence meant a great deal to the millions of women suffering from vulvodynia. Mate introduced Christin Veasley, NVA director of professional programs, who described the subsets of vulvodynia, its diagnosis and treatment, and its impact on quality of life. Veasley also outlined current vulvodynia research projects funded by the National Institute of Child Health and Human Development, as well as the NVA's recommendations to Congress on vulvodynia research that needs to be done.

Vulvodynia specialist Richard Marvel, M.D., of the Greater Baltimore Medical Center, discussed the need for the medical community to focus its attention on vulvodynia as well as other chronic pain conditions. Marvel explained that the majority of gynecologists do not receive training in pain management and therefore are ill-equipped to handle chronic pain conditions. Following Dr. Marvel, patient advocates Anne

Modest and Laurie Hudicek spoke eloquently about their personal experiences with vulvodynia and its devastating effect on their physical, personal and social lives.

The Capitol Hill briefing was the direct result of the efforts of Madison, Wisconsin NVA support group member Caroline More. Earlier in the summer, More had organized a roundtable that included staff members from several local legislative offices, including Senator Herb Kohl (D-WI), Congresswoman Tammy Baldwin (D-WI) and Governor Jim Doyle. Veasley, formerly the Madison, Wisconsin support group leader, gave a presentation at the briefing, and local patients Bridget Fonstad and Jada MacLean spoke candidly about their struggle with vulvodynia. Following the briefing, Veasley and More met with staff from U.S. Senator Russell Feingold's (D-WI) Wisconsin office and teleconferenced with staff in his Washington, DC office. During this teleconference Senator Feingold's staff members expressed interest in helping the NVA organize the early August Capitol Hill briefing.

The NVA is indebted to Caroline More for her initiative and hard work in putting the Wisconsin briefing together. We would also like to express our appreciation to Peter Reinecke, chief of staff to Senator Harkin, and to Senator Feingold and his staff, especially Shannon Lightner and Mary Frances Repko, for organizing the Capitol Hill briefing. ■



*Left to right: Christin Veasley, NVA director of professional programs; Phyllis Mate, NVA executive director; and Anne Modest, patient advocate.*

### New e-mail address?

We'd like to have your current e-mail address so we can send notices of late-breaking news to you.

If you want to update your address, just send an e-mail to [rose@nva.org](mailto:rose@nva.org) with your name, new address and the word "update" on the subject line.

# Diagnosis

(from page 1)

The end result is that vulvovaginal care today means that countless women contend with undiagnosed lower genital symptoms, waste millions of dollars on over-the-counter antifungal creams, endure ongoing vulvar pain and painful intercourse and feel desperate that no one can help!

This summary of the "Top Ten Traps" will focus on the most common misconceptions clinicians hold about the diagnosis and treatment of vulvovaginal problems.

## TRAP # 1

**"Vulvar complaints are easy; this is just vaginal itch!"**

There is a tendency on the part of clinicians (and women too!) to equate all vulvovaginal itching with a yeast infection. It is important to recognize that vulvovaginal itching frequently happens for multiple reasons: 1) the area is kept damp by sweat gland function, 2) it is exposed to the wear and tear of urinary, bowel, menstrual and reproductive functions, and 3) sometimes even conscientious self-care by women determined to keep the area clean and dry can cause it. Itching is the hallmark of vulvovaginal problems. Yes, yeast itches, but so do use of irritating products, allergy, low estrogen, any skin problem, and so on. Table 1 lists multiple causes of vulvovaginal itching.

Clinicians, in addition to failing to recognize the spectrum of possible causes of vulvovaginal itchiness, often maintain the attitude that treatment is easy. "I can't do any harm with an antibiotic," they think. Or, "I can't do

**Table 1: Common Causes Of Vulvovaginal Itching**

Allergy	Low estrogen
Bacterial vaginosis	STDs
Dermatitis (eczema)	Skin diseases
Desq. inflam. vaginitis	Systemic diseases
Drug reactions	Vaginitis
Local irritants	Vulvodinia

any harm with an anti-fungal." Not so! Antibiotics promote yeast for many women, setting off a cascade of events which lead to great misery. If the problem is not yeast or infection, inappropriate use of antibiotics and anti-fungals delays proper diagnosis. In many women, the ingredients in several topical creams sensitize the skin, producing irritation and allergy. Women, especially those with vulvodinia, frequently receive one antibiotic and antifungal after another leading to intractable pruritus, recurrent discharge, relentless pain, and disabling sexual difficulties.

## TRAP # 2

**"I don't see anything wrong under the microscope. No problem!"**

Some clinicians don't even examine specimens under the microscope to make a diagnosis. Others who do use the microscope, but do not see yeast or trichomonas, mistakenly conclude that a woman does not have a problem. But using a microscope can provide other important information besides confirming the presence of yeast and other pathogens. One can see which types of cells from the vaginal wall are present, indicating whether adequate estrogen is present or whether inflammation is a problem. For example, the presence of many white blood cells under the microscope indicates that something abnormal is happening and necessitates a culture for yeast and specialized cultures for sexually transmitted diseases. Above all, by using the microscope, clinicians can see what kind of bacteria predominates in the vaginal smear. If lactobacilli (bacteria that promote vaginal health) dominate the slide, the clinician immediately knows that this patient does not have a bacterial infection. No culture for bacteria is required! No antibiotics are necessary! Failure to utilize the microscope and to recognize all the information available from such examination, leads clinicians to prescribe a lot of antibiotics that women don't need.

## TRAP # 3

**"Yeast is easy to spot; this isn't yeast!"**

As mentioned above, when clinicians use the microscope and do not see yeast, they often conclude that yeast is not present. But yeast is not at all easy to figure out, since it does not show up under the microscope about 40 percent

See *DIAGNOSIS*, page 9

---

## Diagnosis

(from page 8)

of the time! This may be because a woman comes for a visit at a time when she is not having symptoms, or because she has recently used some yeast cream or a Diflucan tablet. In the absence of these situations, however, yeast may be causing vaginitis but may not be seen because yeast does not always grow in some cultures. Clinicians often send a swab to the lab and ask them to put it in the appropriate material for growing yeast. But in the time it takes the dry swab to get to the lab and be put in the proper medium, the sample deteriorates and the yield is poor. Any woman who has a vulvovaginal complaint with negative microscopy should have a special culture for yeast done right in the exam room using Sabouraud's medium, a special material for growing yeast.

In addition to the inaccuracies of diagnosing yeast, most clinicians have the misperception that all yeast should go away after a single treatment. But all yeast infections are not the same! There is the simple occasional episode, but yeast can also be complicated, i.e., severe, repeated, not always responsive to standard treatment, and influenced by other diseases and concurrent treatments. This kind of yeast problem requires not just a simple treatment, but ongoing treatment for weeks or months.

### TRAP # 4 "It's Yeast!"

Many years ago in medical school, doctors were taught that they could make a diagnosis of yeast just by looking at vaginal secretions. Today we know that inspection alone is inadequate. One must look under the microscope for adequate diagnosis. But clinicians can be fooled by findings under the microscope- rolled up vaginal cells, hairs or cotton fibers or vaginal cell borders that overlap and look like the branching hyphae of yeast.

In order to diagnose yeast accurately you need: 1) a visit when fully symptomatic; 2) a visit after you've been off any yeast medications for two weeks; 3) a careful history and physical examination; 4) accurate microscopy; and 5) yeast culture on Sabouraud's medium.

### TRAP # 5 "This must be a vaginal bacterial infection. Send a vaginal culture!"

When a patient has a vulvovaginal complaint, clinicians often immediately assume that there is an infection. Vulvodynia and vulvar skin diseases are still not well recognized and contact irritation is typically not considered, so clinicians perform a routine vaginal culture. But there are billions of bacteria normally found in the vagina and a bacterial culture will always grow them! This is a waste of time, since they are normal inhabitants and not causes of disease or symptoms. Staph, strep, E coli and gardnerella are all present in the healthy uninfected vagina!

How do you figure things out? First, you check the acid-base balance (vaginal pH). The healthy vagina is acidic, i.e., pH is <4.5. Then you examine the specimen under the microscope to see which kind of bacteria predominate. If lactobacilli dominate the slide, it indicates a healthy vagina. It does not matter what a culture grows. A routine vaginal culture misleads by always growing normal inhabitants.

But remember, you always need a special culture for yeast if it is not seen. Yeast grows in any pH so a normal pH only rules out bacteria, not yeast. Sexually transmitted disease such as gonorrhea and Chlamydia are not vaginal invaders, but actually grow in the cervix. Consequently, they require other specialized testing.

### TRAP # 6 "It's BV."

Bacterial vaginosis is the most common vaginal complaint, causing discharge, odor, and perhaps some itching (but never painful intercourse.) **BV is an imbalance of bacteria, not an infection.** BV occurs because, for an unknown reason, the normal lactobacilli get wiped out and other bacteria overgrow, causing discharge and odor.

There are very clear criteria for diagnosis of BV: 1) pH is elevated above 4.5; 2) There is discharge that sticks to the vaginal wall; 3) Clue cells, i.e., cells from the vaginal wall crusted with bacteria, can be seen with a microscope; 4) Absence of lactobacilli and overgrowth of other bacteria can be seen using a microscope. It is important to remember that BV will not lead to the

See *DIAGNOSIS*, page 10

## Diagnosis

(from page 9)

presence of a lot of white blood cells under the microscope, nor does it cause pain or inflammation, so those findings require another explanation.

### TRAP # 7

**“Strong steroids (cortisone) should never be used on the vulva!”**

This attitude, and the belief that you can make a diagnosis just by looking at vaginal discharge, continues to dominate medical opinion despite decades of evidence to the contrary. There are a number of skin problems with unknown causes that may affect the vulva and cause intense itching. Skin conditions with complicated medical names beginning with “lichen,” e.g., lichen sclerosus, lichen planus, and lichen simplex chronicus cause a lot of discomfort. Eczema is also very common. We do not know how to cure these problems, but we do know how to manage them safely and effectively with cortisone cream.

Cortisone cream comes in a spectrum of strengths, from very mild (hydrocortisone) to ultrapotent clobetasol. The clinician chooses the strength of cortisone depending on assessment of the skin condition. Generally, physicians are wary of cortisone because it has the reputation for causing bad side effects, e.g., thinning of the skin and causing red stretch marks called striae. However, negative side effects can be avoided when the cortisone is used for a short window of time to control the itching. Afterwards, cortisone use may be tapered to a maintenance program of once or twice a week. (If you stop the treatment entirely, the itching always comes back.) We have numerous dermatologic studies showing the safety and efficacy of such management.

### TRAP # 8

**“I’ll just do your Pap smear and you’re out of here.”**

Clinicians are often so eager to put the speculum in place to do the pap smear, that they fail to carefully examine the vulva. Two inflammatory vulvar skin problems, lichen sclerosus and lichen planus, can silently scar the vulva (although they often cause intense itching.) These conditions can only be detected by carefully examining the vulva, and, if necessary, by taking a biopsy.

The word vulva means “cover.” The outer lips or labia majora cover the rest of the vulva. Unless the cover is

lifted, meaning that the labia are parted, changes indicative of lichens may be missed. The thin inner lips (labia minora) can flatten and then disappear completely, or the labia minora can stick together at the top or the bottom of the vaginal opening, making it narrowed. The hood of the clitoris (prepuce) can scar and stick to the clitoris, ultimately covering it entirely. Lichen sclerosus can occur at any age, but most frequently appears in childhood and after menopause. It can be stopped in its tracks with cortisone cream that prevents the scarring from happening.

### TRAP # 9

**“Intercourse is a little uncomfortable? Just relax!”**

Until 1980, pain with intercourse and vulvar pain were regarded as psychological in origin. We know now that there are many possible causes for this type of pain. (See Table 2.) The most common cause of painful intercourse in women under the age of 50 is vulvar vestibulitis. In women over 50, it is lack of estrogen.

For accurate diagnosis of vestibulitis a clinician needs to:

- 1) rule out vaginitis with multiple wet preps and Sabouraud cultures;
- 2) remember that routine vaginal cultures will always grow bacteria that normally inhabit the vagina without causing disease;
- 3) perform a meticulous skin exam for normal architecture, skin color, absence of lesions;
- 4) retract the clitoral hood, checking for scarring;
- 5) confirm the presence of labia minora on both sides;

**Table 2: Possible Causes of Vulvar Pain and Painful Intercourse**

Bartholin gland abscess	Dermatitis
Uterine or ovarian disease	Herpes
Interstitial Cystitis	Vaginitis
Vulvar skin diseases	Psychosexual
Vulvodinia/vestibulitis	Low estrogen

See *DIAGNOSIS*, page 11

---

# Research Participants Needed

## Mechanisms of Pain in Vulvodynia

Researchers at Johns Hopkins Hospital are looking for women to participate in research studies concerning the mechanisms of pain in vulvodynia, a chronic pain syndrome of the vulvar and vaginal area. If you are at least 18 years old and if you have been diagnosed with Vulvodynia for at least 6 months you might be an appropriate candidate for these research studies. Women who are pregnant or had a hysterectomy are not eligible. (Support: National Institutes of Health, National Vulvodynia Association; Principal Investigator: Ursula Wesselmann MD, Dept. of Neurology, Johns Hopkins Hospital.) Info: 410-614-4517; women@bme.jhu.edu.

*The NVA is pleased to note that a portion of the above research is supported by an NVA research grant to Dr. Wesselmann at Johns Hopkins University in Baltimore.*

## Survey on Marriage and Chronic Pain

Married women who have been diagnosed with vulvodynia and/or vulvar vestibulitis are needed to participate in a survey-based study of marriage and chronic pelvic pain. This study will assess relationships between perception of disability, quality of marriage and quality of life for women with vulvodynia. Participants must be married for at least one year and have a diagnosis of vulvodynia or vulvar vestibulitis. On a one-time basis only, couples will be asked to fill out surveys on quality of life, marriage and pain experiences. The principal investigator is a physical therapist completing dissertation work in the field of marriage and family studies.

Interested individuals please contact: Susan Theve-Gibbons, MS, PT; Doctoral Candidate, University of Connecticut; 401-466-2540; gibbons@hartford.edu.

---

## Diagnosis

(from page 10)

- 6) culture for herpes or do type specific antibody blood tests;
- 7) biopsy any questionable area;
- 8) culture the urine if urinary symptoms exist and request urologic evaluation for frequency or urgency; and
- 9) perform a Q-tip test of the vestibule.

### TRAP # 10

**"I have never seen a case of vulvodynia."**

There seems to be a great deal of mystery associated with vulvodynia, possibly because clinicians tend to think of it as constant burning. It is important to realize that although the discomfort may be constant for some, vulvodynia can be episodic in nature and some women experience long symptom-free periods. Although burning is a common symptom of vulvodynia, women also complain of soreness, rawness, constant irritation, pins and needles, aching, stinging, "yeast" symptoms or simply constant awareness of the vulva.

Furthermore, vulvodynia is a great masquerader, constantly fooling clinicians. It is often thought to be recurrent yeast, recurrent BV or "infection" with strep; atrophy that is not responsive to treatment with estrogen

cream, tablets, or ring; urinary tract infection or urethral syndrome (although urine cultures are negative); or a skin condition unresponsive to cortisone.

### Conclusion

In summary, the best advice I can give to women is twofold. First, that they learn what is normal for the vulva and do their own exams a couple of times a year. Of equal importance, women should choose a clinician who listens to their concerns and performs a thorough vulvovaginal examination.

### References:

- Harlow BL and Stewart EG. A population-based assessment of chronic unexplained vulvar pain: have we underestimated the prevalence of vulvodynia? *J Amer Med Women's Assoc* 2003;58:82-88.
- Neill SM and Ridley CM. Management of anogenital lichen sclerosis. *Clin Exper Derm* 2001;26:637-643.
- Sinha P, Sorinola O and Luesley DM. Lichen sclerosis of the vulva. *J Reprod Med* 1999;44:621-624.
- Meana M, Binik YM, Khalife S and Cohen DR. Biopsychosocial profiles of women with dyspareunia. *Obstet Gynecol* 1997;90:583-9. ■

---

# THE NVA NEEDS YOUR CONTRIBUTION

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

Name \_\_\_\_\_

Address \_\_\_\_\_

Phone (H) \_\_\_\_\_ (O) \_\_\_\_\_

E-Mail Address \_\_\_\_\_

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

\$40       \$60       \$100       Other \$ \_\_\_\_\_

\$60 Health Care Professional

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

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

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



**NATIONAL VULVODYNIA ASSOCIATION**

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