National Vulvodynia Association

NVA News

Volume XIV, Issue I Winter 2008

Primary and Secondary PVD: Are They Different?

Questions and Answers with Caroline Pukall, PhD

Dr Pukall is an assistant professor in the department of psychology at Queen's University in Kingston, Ontario, Canada, and a sex therapist who treats vulvodynia patients in her private practice. She trains graduate students in pain management and sex therapy techniques at Queen University's psychology clinic.

In 2005, the NVA awarded a four-year research grant to Dr. Caroline Pukall to examine the differences between women with *primary* and *secondary* Provoked Vestibulodynia (PVD), also known as vulvar vestibulitis syndrome. Patients diagnosed with *primary* PVD have experienced vulvar pain since the first time they had sexual intercourse, whereas patients with *secondary* PVD have experienced a period of pain-free intercourse prior to pain onset. Now that Dr. Pukall's study is coming to a close, we asked her to discuss her findings.

NVA: Before we discuss your study, can you tell us why you chose to do research on vulvodynia?
Dr. Pukall: I treat women with vulvodynia in my private practice and have seen its impact on women's lives and relationships. As a scientist-practitioner who conducts research and sees patients clinically, I think it is essential to perform sound studies to both help patients in the clinic and to bring their complaints and experiences into the realm of scientific investigation; only with these two components can we truly help large groups of women suffering from vulvodynia.

NVA: There were some preliminary studies conducted on primary and secondary PVD before your study began in 2005. Please summarize the findings of those studies.

See PRIMARY and SECONDARY, page 2

The Impact of Provoked Vestibulodynia on Couples

By Jennifer Connor, PhD, LMFT

Dr. Connor is an assistant professor of educational leadership and community psychology at St. Cloud State University in St. Cloud, Minnesota. She is a licensed marriage and family therapist.

At the age of 23, after a very frustrating year of medical appointments, I was diagnosed with vulvar vestibulitis syndrome (aka Provoked Vestibulodynia or PVD). The year was 1993 and I'm not sure I would have been properly diagnosed had I not moved out of state to pursue my master's degree and found an excellent doctor. For many years, it seemed that medical professionals hadn't even heard of vulvodynia. Then eight years ago, while earning my doctorate in marriage and family therapy, I came across an announcement from the National Institutes of Health inviting vulvodynia research applications. As a researcher I was intrigued. As a woman with vulvodynia, I was ecstatic, moved and surprised. About the same time, I noticed a shift in the general medical

See COUPLES, page 9

Primary and Secondary

(from page 1)

Dr. Pukall: In general, preliminary studies comparing primary and secondary PVD demonstrated some differences between the two subtypes. As expected, the groups differed in a number of demographic variables; for example, women with primary PVD were more likely to be younger and unmarried at symptom onset, and therefore less likely to have had children. There were also differences with respect to medical history, pain characteristics, psychological characteristics and treatment response. For example, women with primary PVD were more likely to report histories of childhood bedwetting and dysmenorrhea (painful menstruation) than women with secondary PVD. Some studies also demonstrated that women with primary PVD report a history of more severe vulvar pain and higher pain ratings when heat is applied to their forearms.

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

NVA: Why did you choose this particular topic for your study?
Dr. Pukall: From the preliminary studies, it seemed to me that women with primary PVD might be suffering from a more severe and generalized condition than those with secondary PVD. I think that research differentiating PVD subtypes is very important and that it is likely that more than two subtypes will be identified in future studies. If we understand the different characteristics of each subtype, we can begin to develop individualized and more effective treatment strategies.

NVA: Some PVD patients choose surgical treatment. Is there a difference in surgical outcome for women with primary, as opposed to secondary, PVD?
Dr. Pukall: Two studies found that women with primary PVD were less likely to benefit from surgical intervention than women with secondary PVD, however, another study found no difference in surgical success if both groups had experienced pain for the same length of time. This possible difference has led some clinicians and researchers to speculate that primary and secondary PVD result from different etiological (causal) pathways.

NVA: What were the goals of your four-year research project?
Dr. Pukall: The overall goal of our research is to determine how women with primary and secondary PVD differ. For our investigation, we've used four comparison measures: gynecological examinations, interviews and questionnaires, sensory testing and brain imaging. Our study is the first to compare women with primary and secondary PVD on multiple dimensions and its results will help future researchers decide whether the two groups should be studied separately. As mentioned before, if we find

See PRIMARY and SECONDARY, page 3

Primary and Secondary

(from page 2)

significant differences between the two subgroups, it should help clinicians formulate individualized treatment plans and preventive strategies.

NVA: Can you describe the groups in your study?
Dr. Pukall: The study is ongoing, so we are still collecting data from participants. We aim to have an age-matched sample of three groups of women between the ages of 18 and 60: 27 with primary PVD, 27 with secondary PVD and 27 controls. The primary PVD group is composed of women who reported dyspareunia, or painful intercourse, from their first sexual intercourse experience. The secondary PVD group is composed of women who developed dyspareunia after a period of pain-free intercourse. Women who served as controls did not report any type of chronic vulvar pain or dyspareunia. This interview will focus solely on the two PVD groups.

NVA: Can you describe the four comparison measures you used in greater detail?
Dr. Pukall: First, the women received a thorough gynecological examination that included a visual and manual examination of external and internal reproductive sites. Next, the gynecologist administered a 'cotton-swab' test, in which she palpated several vulvar areas, including the vulvar vestibule (area surrounding the vaginal opening) with a cotton swab. The gynecologist also assessed muscle tension by first inserting a finger, followed by a speculum, into the vagina. During the cotton-swab test and speculum insertion, a research assistant recorded the women's pain intensity ratings.

Next, the graduate student working on the project conducted structured interviews that included questions on demographics, medical and gynecological history, sexual and relationship functioning, and pain levels during intercourse or other activities. Using a scale of 0 to10 with 0 representing no pain and 10 as the worst pain imaginable, participants reported a pain intensity score for the first time they engaged in sexual intercourse and then rated pain with intercourse over the previous six months. They also reported the overall duration of their pain symptoms and percentage of occasions when intercourse was painful.

Following the interview, women were asked to complete the following four questionnaires on psychosocial and psychosexual adjustment. The *SF-36 Health Survey* is a 36-item measure of health-related quality of life that assesses physical functioning, role limitations because of physical health problems, role limitations because of mental health problems, vitality, mental health, social functioning, bodily pain and general health. The *Body Exposure during Sexual Activity Questionnaire* is a 28-item measure of body image in the specific context of sexual activities. This questionnaire is designed to assess the extent to which an individual experiences anxiety or self-consciousness regarding her body's exposure during sex and the extent to which she wishes to avoid such exposure. The *Female Sexual Function Index*, with 19 items, measures overall sexual functioning during the previous four weeks by rating six areas: desire, arousal, lubrication, pain, orgasm and satisfaction. Finally, women are given the 10-question *sexual-esteem section of the Sexuality Scale* to assess their sexual self-esteem, i.e., whether they have a positive attitude about how they relate sexually to others.

NVA: You mentioned that the fourth measure was quantitative sensory testing. How did you measure that?
Dr. Pukall: Quantitative sensory testing is a technical term for a type of measurement involving the

See PRIMARY and SECONDARY, page 4

Primary and Secondary

(from page 3)

application of different forms of stimulation, such as pressure or heat, to a given body area. During the application the participant indicates what sensation he or she perceives, e.g., non-painful pressure, painful pressure or heat pain. In our study, participants underwent quantitative sensory testing during the late follicular phase (days 7 to 12) of their menstrual cycle. We conducted thermal testing on the underside of the arm between the wrist and the elbow and in the posterior vulvar vestibule. As increasing temperature was applied to each area, participants reported when they (i) felt a non-painful warm sensation (warmth detection), (ii) perceived a painful sensation (heat pain threshold), and (iii) could no longer tolerate the heat (heat pain tolerance).

We randomly tested three areas of the forearm (upper, middle, lower) and the 3, 6 and 9 o'clock positions of the vulvar vestibule. When participants experienced warmth detection, pain threshold and pain tolerance, they pressed a hand-held control to make the applied stimulus return to normal skin temperature. For each stimulus, participants verbally rated the intensity and unpleasantness on a 0 to 10 numerical rating scale.

NVA: What is the final phase of the study?
Dr. Pukall: We have just begun the fourth and final phase of our study in which we will perform a series of brain scans on 10 women with primary PVD, 10 with secondary PVD and 10 control women. First, we will obtain a three-dimensional anatomical image of the brain using Magnetic Resonance Imaging and perform functional scans measuring brain activation in response to different forms of stimulation. We will then apply different pressures to the vulvar vestibule, as well as a non-vulvar area, using a pressure device called a vulvalgesiometer. During stimulation, we will present words intended to either distract or focus women on the pain. We expect similar brain regions to be activated in all three groups; however, we think that women with primary PVD will have higher activation levels than women with secondary PVD, who will, in turn, have higher activation levels than controls. We also expect that women with PVD, as a group, will show activation in pain-related brain areas in response to hearing pain words, regardless of whether the accompanying stimulation is painful or non-painful pressure.

NVA: With the first three phases of this study completed, what are your findings?
Dr. Pukall: Recently, we published our preliminary findings, comparing 13 women with primary PVD to 13 women with secondary PVD (online *Journal of Sexual Medicine,* November 19, 2008).

The visual and manual examination of the genitals revealed no significant group differences in mucosal atrophy, i.e., thinning of the vulvovaginal skin. Three women with primary PVD (23 percent) and four with secondary PVD (31 percent) displayed muscle tension upon insertion of a single digit by the gynecologist. We did not find significant differences in pain ratings with the cotton-swab test or speculum insertion. When the women with secondary PVD were asked to compare the pain they first experienced with sexual intercourse to their current symptoms, all reported that their initial pain was different.

When provided with a list of events that could be related to pain onset, women with secondary PVD reported the following possible connections. Two women attributed the onset of pain to childbirth and two reported it began with a partner change. Other reported triggering events were a recurrent urinary tract infection, hormonal changes due to the onset of perimenopause or birth control use and life stress. Five women didn't recall a specific event triggering their pain.

See PRIMARY and SECONDARY, page 7

The NVA's Year in Review: 2008

NVA continues to make progress on behalf of women with vulvodynia and what follows is a summary of our most important accomplishments in 2008.

Online Tutorial for Patients

NVA submitted a proposal and was awarded a grant from The Patty Brisben Foundation to develop an online educational tutorial for women with vulvodynia. The overall goal of this program is to empower women to advocate for their own health care and build a strong partnership with their health care provider. In addition to providing the most up to date clinical and research information, the tutorial will cover chronic pain and sexual intimacy issues, and give practical advice on coping with vulvodynia.

Online Tutorial for Healthcare Providers

A 2007 grant, also from The Patty Brisben Foundation, enabled NVA to update its online healthcare professional tutorial (http://learn.nva.org) and add continuing medical education accreditation to the program, making participation more valuable for medical professionals. The response to the online tutorial has been very positive, with over 10,000 healthcare providers viewing it since January 2008.

Medical Research Grants

Reflecting our strong commitment to accelerating vulvodynia research, we allocated over 40 percent of last year's revenue to funding research and currently fund eight vulvodynia studies. Our 2008 year-end appeal raised over $25,000 for research, which is now $50,000 because a committed supporter matched every donation. With this positive response, we can award at least two new research grants in early 2009. Several prior grant recipients have used pilot data from NVA-funded studies to secure multi-million dollar NIH funding. Detailed summaries of all research studies funded by NVA can be viewed on our website (www.nva.org) by clicking on 'NVA-Funded Research' in the left-hand column of the home page.

Vulvodynia Registry

In December, the NVA received an exceptionally generous donation from a longtime supporter to facilitate the creation of a vulvodynia registry. This registry will contain a collection of data on the effectiveness of different treatments in women with vulvodynia. Women who participate in the project will provide researchers with biological specimens for analysis. The purpose of the registry is to help researchers determine (i) which treatments are effective for specific subtypes of vulvodynia and (ii) how women who respond to a specific treatment differ from those who do not. The ultimate goal of the project is to generate individualized treatment guidelines for vulvodynia patients. In early 2009, NVA plans to award a grant to a multidisciplinary team of clinicians and researchers to start developing the registry.

Dr. Stanley C. Marinoff Vulvodynia Career Development Award

In 2006, as a tribute to founding medical board member, Stanley C. Marinoff, MD, NVA created the *Dr. Stanley C. Marinoff Vulvodynia Career Development Award* to encourage medical professionals, early in their careers, to pursue a clinical or academic interest in vulvodynia. The award provides seed money to conduct medical research, write a publication, or develop/enhance a vulvar pain clinic. The goal of this program is to increase the number of knowledgeable and qualified clinicians and scientists in the field of vulvodynia. The 2008 recipient of this award, Beri Ridgeway, MD, is currently completing a fellowship in female pelvic medicine and reconstructive surgery at The Cleveland Clinic in Ohio. In her 12-month research project, Dr. Ridgeway is investigating the effectiveness of the anticonvulsant pregabalin (Lyrica) in the treatment of vulvodynia.

See YEAR IN REVIEW, page 6

Year in Review

(from page 5)

In November 2008, NVA received 7 applications for the 2009 Career Development Award. Because there are several outstanding proposals this year, NVA will select *two* recipients in January 2009.

Donor Funds Conference Exhibits

In January 2008, the NVA received a generous grant for health care provider education from Ms. Doris Bernstein's family foundation. This grant has enabled us to reach thousands of medical professionals by exhibiting at six national health care conferences this past year. Last March, NVA exhibited at a women's health conference, Women's Health 2008: The 16th Annual Congress, where NVA medical advisory board member, Elizabeth Stewart, MD, gave a lecture on vulvovaginal health. In May, the NVA exhibited at the American College of Obstetricians and Gynecologists' annual meeting in New Orleans, Louisiana, attended by 3,500 health care providers. For the first time, the meeting included *seven* symposia on vulvodynia and female sexual medicine, in addition to a day-long course on vulvodynia. Later in May, the NVA hosted a booth at the annual meeting of the American College of Nurse Midwives in Boston, Massachusetts. The conference, attended by 1,500 women's health clinicians, included a full-day workshop on vulvovaginal disorders and a women's health exposition for the public. In June, the NVA exhibited at the American Academy of Nurse Practitioners' annual meeting in Washington, DC, attended by 3,200 nurse practitioners. Lastly, this past September, NVA hosted a booth at *Pain Week 2008,* which included vulvodynia in several lectures on urogenital pain syndromes. Most of the pain meeting's attendees were primary care physicians, a group that we think it's important to educate about vulvodynia.

Success on Capitol Hill

In 2008, NVA made exceptional progress on Capitol Hill, convincing Senators and Representatives to increase pressure on the National Institutes of Health (NIH) to fund vulvodynia research. First, with the help of Senator Tom Harkin (D-IA), language on vulvodynia was again included in Congress' FY2009 NIH Appropriations Bill, strongly urging the NIH to substantially increase the amount of funding for vulvodynia research and create a specialized panel of experts to review future research applications on vulvodynia. In October, Reps. Lois Capps (D-CA), Nita Lowey (D-NY), and Tammy Baldwin (D-WI), and NVA's Christin Veasley, invited Duane Alexander, MD, the Director of the National Institute of Child Health and Human Development (NICHD), to Capitol Hill. Dr. Alexander was specifically asked to outline the steps NICHD will take in 2009 to increase funding of vulvodynia research. He committed to issuing a *Program Announcement with Special Review,* inviting members of the medical and scientific communities to submit vulvodynia research proposals that will be scored by a panel of experts in the field. This type of announcement, which NICHD plans to release in spring 2009, publicizes that NICHD has a serious interest in fostering vulvodynia research. We are optimistic about this new funding opportunity. Coincidentally, the timing is excellent, because data from the nine studies NVA funded in 2007 will be analyzed in time for those researchers to submit NIH applications under the new Program Announcement. We immediately alerted our prior research grant recipients of this upcoming funding opportunity.

NVA continues to collaborate with the NIH Office of Research on Women's Health (ORWH) on the *National Vulvodynia Awareness Campaign*. In early 2009, educational materials on vulvodynia will be mailed to thousands of health centers, including 3,700 government-supported rural and inner-city clinics, and 1,600 university student health centers. Additionally, ORWH, with the assistance of NVA, is planning a vulvodynia conference for medical professionals, to be held in fall 2009. ■

NIH Funds Vulvodynia and Pelvic Pain Research

In fall 2008, two researchers received multi-year grants from the National Institutes of Health (NIH) to continue their work on vulvodynia and pelvic pain. Melissa Farmer, a PhD candidate at McGill University and previous NVA research grant recipient, was awarded a 3-year predoctoral fellowship grant from the National Institute of Neurological Disorders and Stroke. With her award, Ms. Farmer will continue developing an animal model of vulvodynia. The overall goal of her research is to study the role of peripheral mechanisms and a genetic risk factor in the development of vulvodynia. Specifically, she will study whether (i) frequent vulvovaginal candidiasis (yeast) infections in mice are associated with changes in vulvar sensitivity; and (ii) whether chronic vulvovaginal infection increases sensory nerve fiber density and modifies local pain receptors. She will also investigate whether the melanocortin-1-receptor (MC1R) gene is involved in the development of vulvodynia, by testing mice that do not carry the MC1R gene.

In September 2008, the National Institute of Child Health and Human Development awarded a grant to Frank Tu, MD, MPH, assistant professor of obstetrics and gynecology at the North Shore University Health System in Illinois. Dr Tu, a pelvic pain specialist, received a 5-year *Patient-Oriented Research Career Development Award.* His long-term research goal is to identify modifiable disease mechanisms in urogenital pain syndromes. Dr. Tu's current project will test the hypothesis that patients suffering from painful bladder syndrome also show increased pelvic floor muscle sensitivity, by assessing these patients' pain thresholds when pressure is applied to pelvic floor muscles during a gynecological exam**.** The purpose of this research is to improve diagnosis and treatment of pelvic pain syndromes and related conditions such as vulvodynia, both of which are associated with increased pelvic floor muscle sensitivity. According to Dr. Tu, "Objective, valid measures of pelvic floor muscle dysfunction will allow for the rational application of mechanism-specific treatments, which would improve patient care and quality of life for millions of women." ■

Primary and Secondary

(from page 4)

We averaged the pain intensity ratings for both subtypes and found that women with primary PVD reported significantly higher pain ratings than women with secondary PVD; on a 10-point scale, the primary subgroup's average pain score was 7, whereas the secondary subgroup's was 5. The women in both groups did not differ significantly with respect to the amount of time since their pain first started or the overall percentage of occasions that intercourse was painful. Women with primary PVD also exhibited a trend toward higher pain ratings during intercourse over the prior six months than those with secondary PVD, with an average rating of 7.3 versus 6, respectively.

NVA: Were there any group differences on the questionnaire responses?

Dr. Pukall: On the *SF-36 Health Survey,* women with primary PVD reported significantly more role limitations because of emotional distress than women with secondary PVD. Women with primary PVD also displayed a trend toward lower social functioning due to fatigue, anxiety and depression; however, neither subgroup differed significantly from healthy individuals on this measure. On the *Body Exposure during Sexual Activity Questionnaire*, women with primary PVD reported greater anxiety and self-consciousness regarding body exposure during sex than women with secondary PVD. However, there were no significant differences with

See PRIMARY and SECONDARY, page 8

Primary and Secondary

(from page 7)

respect to the total *Female Sexual Function Index* or subscale scores, or the *sexual-esteem subscale of the Sexuality Scale.* It is important to note that both subgroups of women with PVD scored within the sexual dysfunction range on the Female Sexual Function Index.

NVA: Were there any differences between the two subtypes in sensory testing?
With sensory testing at the forearm, we did not find significant between-group differences in warmth detection or heat pain threshold, but there was a trend towards a significant difference in heat pain tolerance. Women with primary PVD exhibited lower heat pain tolerance than the women with secondary PVD, i.e., they were less able to tolerate high temperatures. We did not find any significant difference in pain intensity or unpleasantness ratings for warmth detection, pain threshold or pain tolerance at the forearm.

With testing in the vulvar vestibule, we found that women with primary PVD detected a non-painful warm sensation at lower temperatures than women with secondary PVD. Women with primary PVD also reached heat pain threshold at lower temperatures than women with secondary PVD. These results indicate that women with primary PVD are more sensitive to non-painful and painful heat stimuli than women with the secondary subtype, although there was no significant difference in pain tolerance. This result may be due to a ceiling effect, because many of the women (five in each group) did not feel pain tolerance at the maximum temperature of 51°C (124° F) and only one woman with primary PVD reached pain tolerance at a temperature below 48°C (119° F).

NVA: Dr. Pukall, currently what conclusions can be drawn from your research?
Dr. Pukall: Our study's results suggest that women with primary and secondary PVD do differ in some aspects of pain reporting, psychosocial functioning, and genital and non-genital sensitivity. Future studies with larger sample sizes and additional variables of interest are needed to more fully compare the two subtypes. Given the possibility that causal factors and treatment outcome differ in primary and secondary PVD patients, future investigators designing treatment studies should consider investigating the subtypes separately.

NVA: What are your future research plans?
Dr. Pukall: Recruitment for our study will be complete soon and we plan to publish the final results comparing the three groups (primary and secondary PVD, and controls), once the analyses are conducted. In the meantime, we are doing brain imaging of participants for the final phase of the study and are very eager to see the pattern of results. Outside of these studies, we are examining many factors in vulvodynia, including patterns of interaction in vulvodynia-affected couples, treatment outcome, effects of increased blood flow on vulvar pain sensitivity and the role of pelvic floor muscle function. In addition to our vulvodynia research, my students and I are involved in studies examining healthy and problematic female sexual arousal and the role of social support in same- and mixed-sex couples.

Selected References:
Bohm-Starke NY, Rylander E. Surgery for localized, provoked vestibulodynia: A long-term follow-up study. *J Reprod Med* 2008;53:83–9.
Sutton K, Pukall C, Chamberlain S. Pain, psychosocial, psychosexual, and psychophysical characteristics in women with primary versus secondary vestibulodynia. *Journal of Sexual Medicine*, 6, in press.
(*Editor's Note: To receive a footnoted version of this article, with a complete list of references, email gigi@nva.org.*) ■

Couples

(from page 1)

community's awareness of vulvodynia, but not among marriage and family therapy (MFT) practitioners. I decided to help increase awareness of vulvodynia in the MFT community by choosing to study vulvodynia's impact on couples' relationships, a topic which had never been studied in the MFT and family studies disciplines.

The project began with the recruitment of women with vulvodynia both through the NVA's web site and from medical clinics in the Minneapolis area. In total, 29 people participated, 13 couples and three single women. I conducted one to three hour semi-structured, face-to-face interviews in participants' homes, with the exception of two couples interviewed by phone. The interview consisted of many questions, including the following: What were your experiences prior to receiving a diagnosis of vulvodynia? How did you feel about the medical professionals you visited during that period? What do you think caused the disorder? How has it impacted your identity as an individual and as a couple? What has been the most difficult part of your experience with PVD? I interviewed couples together for the majority of the session, but also met with each person separately. Additionally, women provided information on their diagnosis history and pain levels.

Participants were primarily Caucasian, college educated, and ranged from 27 to 55 years of age. The women had been diagnosed with PVD for an average of 5.5 years and the average current pain level was 3 on a 10-point scale. (0= no pain, 10= severe pain). They scored the worst vulvar pain they had ever experienced as an 8 out of 10. Many women had experienced some pain relief with treatment, but several continued to seek more effective medical treatment.

I analyzed participants' responses using 'phenomenological reduction guidelines,' the purpose of which is to focus on the dominant and recurring themes of a person's experience. After setting aside any bias, I examined each transcript repeatedly and identified significant statements made by each participant. Next, I grouped these significant statements into "essences," or experiences that seemed significant to the majority of participants. Lastly, I read the participants' significant statements multiple times, organized them into broad categories and searched for common underlying meanings. The following four essences were identified as critical: (i) 'in search of'; (ii) the process of developing a personal understanding of PVD; (iii) developing strategies for coping with painful intercourse; and (iv) feelings of isolation. Each essence is described below.

In Search of…

Women reported searching for information on PVD, pain relief, a knowledgeable provider and respect. They felt that they had to be strong advocates for themselves in seeking proper diagnosis and treatment, which they attributed to a lack of medical research and health care provider training in vulvodynia. Many traveled great distances, even going out of state, to find medical care. Almost all of the women tried numerous medications and treatments; both men and women reported feeling exasperated by the lack of treatment guidelines. Some women experienced frustration in their search for a health care provider who would treat them respectfully. All but two women eventually found competent and compassionate health care providers who were able to "think outside of the box."

Developing a Personal Understanding of PVD

As individuals and as part of a couple, participants needed to develop both a personal and mutual

See COUPLES, page 10

Couples

(from page 9)

understanding of PVD. Only one woman knew of the condition prior to being diagnosed. Most women were confused by the symptoms when they first appeared, which was compounded by needing to visit multiple doctors for a diagnosis. Many women expressed concern that they were somehow to blame or 'less of a woman' after diagnosis, whereas others focused blame on the lack of competent medical assistance. For the majority of women, the ambiguity of the condition led to feelings of guilt and failure. Several men expressed disbelief and anger towards their partner at some point, but most couples reported that the interpersonal conflict lessened after a diagnosis was made. All couples acknowledged having to find new means of co-creating non-sexual intimacy. Many felt their relationship was stronger because they had to develop non-sexual means of connecting and work to understand PVD together.

Strategies for Coping with Painful Intercourse

All couples adapted their sexual lives to cope with the chronic pain. At some point, most women became non-sexual, used alternatives to vaginal sex or endured painful intercourse. Factors influencing their choice included personal levels of pain or sexual desire, use of antidepressant medications, having small children and/or other health problems. Of the participants who tried alternatives to vaginal intercourse (e.g., oral sex, manual stimulation), about 50 percent found the new technique marginally satisfactory, most often due to a feeling that using alternatives was abnormal. The other 50 percent found the alternatives just as rewarding as vaginal intercourse. Of the 11 couples that continued to have vaginal intercourse, all made adjustments, such as gentler penetration, using supplemental lubrication and planning sexual intimacy around the pain. The women had to communicate when their pain was severe, because it fluctuated day to day, leading to a couple dynamic in which the woman was in charge of deciding when to have sex.

Feelings of Isolation

Both men and women expressed feeling isolated from society and their own support system. They felt different from other couples that they perceived as sexually healthy. Many respondents chose not to discuss their PVD with friends, family members and coworkers because they feared others would be uncomfortable discussing a disorder involving female genitalia. In addition, many felt embarrassed discussing the condition because they thought very few people, if any, would have heard of it. Couples often turned to each other to lessen feelings of isolation.

Summary of Key Findings

Our findings revealed many of the emotional and sexual challenges faced by couples dealing with PVD. Both women and men displayed varied responses, e.g., some women blamed themselves, others did not. Some couples experienced minimal distress and tension in their relationships, while other couples' relationships were significantly impacted. For women, distress often took the form of guilt, self-blame and/or feeling 'incomplete.' Men reported feelings of confusion, guilt, resentment and rejection. Both men and women expressed feelings of isolation because their friends and family didn't understand PVD or its effect on their lives.

Most couples supported each other in many ways, while some couples struggled to work through their feelings of conflict and anger. While some were frustrated by the situation itself, they did not experience relationship conflict. These couples searched for behavioral techniques that would improve their sexual intimacy and were interested in working

See COUPLES, page 11

Couples

(from page 10)

with therapists to deal with their emotional distress. Couples communicated with each other more than before to develop a shared understanding of PVD, enabling some women to express feelings of guilt. Men found that learning more about PVD kept them from feeling personally rejected by their partner's disinterest in sex. Some couples searched for ways to achieve intimacy thru nonsexual means, whereas others felt a sexual relationship was essential in meeting the need for intimacy. Several respondents expressed disinterest or discomfort with using alternatives to vaginal intercourse, even after health care providers recommended and informed them about alternatives. They felt the natural end goal of sexual intimacy was vaginal intercourse. Even couples that continued to have vaginal intercourse reported that their sex life had become unnatural and continued to search for more satisfying adaptations. Respondents who reported satisfaction with the changes in their sex life either accepted there would be some pain with vaginal intercourse or valued alternatives to vaginal intercourse.

For the Medical and Mental Health Communities

The fact that both women and men felt that PVD took its greatest toll on their sexual relationship suggests that health care professionals should encourage these couples to see a sex therapist. Hallam-Jones (2001) found that 95 percent of vulvodynia patients preferred couple therapy to individual therapy, underscoring the need for mental health professionals to develop effective couple therapy techniques.

Our study found that women often have to become their own health advocates to find effective and respectful medical treatment. By becoming familiar with local medical resources, therapists can help patients find competent and compassionate providers. It is important for mental health therapists to understand the difficulties many women have experienced prior to receiving an accurate diagnosis and proper treatment. Women may need to process insensitive or dismissive remarks made by a health care provider. Based on our findings, both physicians and mental health therapists should encourage women with PVD to invite their partner to their gynecological appointments.

Several women reported that medical professionals suggested they broaden their sexual repertoire to employ techniques such as oral sex and outercourse, instead of vaginal intercourse. However, many men and women expressed hesitation and lacked knowledge of alternate techniques. Before couples can feel comfortable broadening their sexual practices, they may need to explore what they consider 'normal' and how to expand that concept. Several participants found that by challenging themselves to critique their sexual preferences, they were able to have satisfying sex lives that did not always include vaginal intercourse. Many couples said that once they worked through not knowing what caused the woman's symptoms, they were able to develop a unique non-sexual intimacy that they viewed as a positive attribute in their relationship. Couples should be encouraged to feel hopeful that intimacy can be maintained by communicating and supporting one another.

Not all participants reacted the same way to the woman's diagnosis and symptoms. Some men blamed their partners and others didn't. Some women had to work through feelings of self-blame, guilt and failure, whereas others didn't. A thorough psychological assessment should determine whether self-blame, depression or anxiety accompany the pain symptoms. Couples universally expressed feeling misunderstood by professionals, friends and family. Some may need assistance in

See COUPLES, page 12

Couples

(from page 11)

dealing with insensitive remarks made by people in their social network. The lack of empathy often caused them to stop communicating with others about their health problems, leading to further isolation. If there is a vulvodynia support group in the area, these couples could benefit from the interaction with other affected couples.

A Note to the MFT Community

Our study uncovered several MFT areas that warrant further investigation. Many participants reported attending individual, couples and sex therapy sessions with varying degrees of success. No couples or sex therapy interventions have been developed specifically for PVD, so there are no evidence-based therapies available. This is a much needed area of research; in our study, many couples expressed the need for assistance in building a stronger relationship with his/her partner. Research might also help us understand why some couples dealing with PVD are capable of turning a potentially damaging situation into a meaningful one, whereas others are not**.**

A Personal Note

Finally, as a vulvodynia patient myself, I offer the following recommendations to fellow sufferers. It is important to educate yourself about this condition and to become your own advocate. Reading the NVA's newsletters is an excellent start. In addition, there is an increasing amount of information about treatments in medical journals. Remain hopeful that you can have a satisfying relationship. It is very important that you share information and communicate openly with your partner. Be open to exploring a sexual life of your own, not necessarily what society deems ideal. Having vulvodynia will challenge you to explore new sexual techniques, and over time, you may find them even more satisfying than sexual intercourse.

Get involved. People in this study talked about discovering a new purpose and some became advocates for other sufferers. All participants reported great satisfaction from taking part in our study, and in the process, learned something new about themselves. Seek out support for yourself and your partner. You may have to educate the people you know or find new people to support you in this facet of your life. Consider connecting with others through the NVA's support network or the internet. Finally, stay hopeful. There are times when I don't want to deal with this condition anymore and other times when it consumes me. I met many other women who expressed the same sentiment. Despite these moments of frustration and impatience, I remain hopeful. We know so much more about vulvodynia now than we did 15 years ago, and I'm sure that, as we move forward, research will contribute to our knowledge of the physical, emotional and sexual aspects of this condition.

References:

Connor, J. et al. (2008). Vulvar pain: A phenomenological study of couples in search of effective diagnosis and treatment. *Family Process*, 47, 139-155.

Hallam-Jones, R. et al. (2001). Sexual difficulties with a group of patients with vulvodynia. *Sexual and Relationship Therapy*, 16, 113-126. ■