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HEALTH FEATURES

Unvoiced pain affects women who hurt during sex

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Provoked vestibulodynia affects about 16 percent of women of reproductive age and as many as 20 percent of those under 19.

When sex researcher and registered psychologist Lori Brotto recalls stories she's heard from women who experience extreme pain during sex, she describes them as "heart-wrenching". Women with the condition known as "provoked vestibulodynia" (PVD) are not only embarrassed but also tend to feel anxious, frustrated, hopeless, helpless, diffident, and alone.

"This affects your entire essence of yourself as a woman," the director of the UBC Sexual Health Laboratory tells the *Georgia Straight* in a phone interview. "This is

excruciating genital pain. It's more than dryness or a little bit of pain. It's sharp, stabbing, razor blade-like pain. Some women can't even put in a tampon or wear jeans."

Also known as vulvodynia or vulvar vestibulitis syndrome, the condition is characterized by pain limited to the vestibule, which is the area that surrounds the opening of the vagina. Severe discomfort occurs during or after pressure is applied to the vestibule; besides intercourse, a gynecological examination, prolonged sitting, or even riding a bike can trigger it.

Provoked vestibulodynia affects about 16 percent of women of reproductive age and as many as 20 percent of those under 19.

But even though it's so prevalent, the disorder is often missed by family doctors and even obstetricians and gynecologists, Brotto says. In fact, women with the condition see, on average, 11 different health specialists over a period of five years before they get a proper diagnosis.

That PVD is so commonly overlooked by medical professionals only makes things worse—physically and psychologically—for women who have it.

"Women start thinking: "'Is it just me? Is it something I've done? Is it a sign I don't love my partner? Is it a sexually transmitted illness?' And then it just snowballs from there.

"A lot of doctors assume it's a yeast infection," Brotto says, noting that women are then typically prescribed cream that just makes pain with sex more intense. "There are no visible signs," she adds. "There's no redness; the tissue looks totally normal. So doctors end up saying: "'I don't see anything. It must be in your head.'

"They'll say the woman must be frigid or should just have a glass of wine. Those kinds of comments are damaging and dismissive."

Just as the condition itself is complex, so is treatment. The way Brotto sees things, helping women with PVD get to the point where sex is not just pain-free but also pleasurable requires a multipronged approach.

To that end, she's assembled a team of obstetrician-gynecologists, psychologists, and pelvic-floor physiotherapists who together treat women through the multidisciplinary vulvodynia program (MVP). Based at the Gordon and Leslie Diamond Health Care Centre at Vancouver General Hospital, the program aims to offer evidence-based, quality health care.

(Program staff will be presenting a free educational seminar on painful sex on July 6 at VGH. Visit the MVP [website](#) for detail.)

Among the speakers is Marcy Dayan, a registered physiotherapist who focuses on vaginal and rectal pain. In an interview with the *Straight*, Dayan explains that having PVD creates a vicious cycle: when women experience intense pain with sex, they begin to dread it. Then they'll start to tense up, physically and emotionally, during foreplay, which in turn makes sex more painful.

"Even a kiss on the cheek can make someone start freezing up," Dayan says. "They'll tighten their muscles."

Through physiotherapy focusing on the pelvic floor, women can learn to relax the muscles that support the pelvic organs and surround the vaginal opening.

Dayan also uses biofeedback and vaginal inserts to help women learn to relax the muscles of the pelvic floor and, consequently, reduce or eliminate pain. As a result, their anxiety tends to lessen as well.

"When they learn that they can manage the pain, it's really reassuring for women," she adds. "It increases their confidence". It allows for intercourse to be put back on the menu."

Before women can start treatment, though, they need a proper diagnosis. Brotto urges women to be persistent, noting that they shouldn't use cream for a yeast infection unless their doctor has taken a bacterial culture and tested for it.

At the MVP, women commit to four months of treatment that involves physiotherapy, educational sessions, and group cognitive-behavioural therapy. The wait list to get in is about four months.

Other forms of treatment have been used for PVD but aren't as effective as a multidisciplinary, educational approach, Brotto claims. Medications like antidepressants and anticonvulsants are sometimes prescribed, since certain ones have a side effect of reducing pain. But they can have other side effects, like fatigue, dizziness, and headaches.

Botulinum toxin, better known as Botox, has shown some promise in treating PVD. But Brotto says evidence is weak and that the idea of having repeated injections in the vulva doesn't go over well with many people with genital pain, so compliance rates are low.

In some cases, surgery to remove the skin around the entrance to the vagina (called a vestibulectomy) can reduce pain.

Brotto says raising awareness of PVD is crucial in helping women seek help.

"A number of women don't want to talk about it, even with their doctor, because they're so embarrassed," she says. "We call it the 'unvoiced pain'."