

Provoked vestibulodynia: A qualitative exploration of women's experiences

A unique program allows women with vulvovaginal pain to attend educational seminars, group therapy, and individual physiotherapy and gynecology appointments offered by collaborating health care providers at one clinic.

ABSTRACT: Provoked vestibulodynia is the most common cause of superficial dyspareunia in women of reproductive age. Our objective was to qualitatively explore the experiences of women with provoked vestibulodynia prior to their referral to the Multidisciplinary Vulvodynia Program located in the ambulatory care centre at Vancouver General Hospital.

Methods: We interviewed 19 women ranging in age from 20 to 54 (mean age = 30.84 years, SD 9.06) who had met diagnostic criteria for provoked vestibulodynia and completed the Multidisciplinary Vulvodynia Program. A semi-structured interview format was used and responses were recorded, transcribed, and analyzed.

Results: Women reported having pain with sexual intercourse 70% to 100% of the time (mean 95.3%, SD 8.21) and a history of such pain rang-

ing from 6 months to 20 years (mean history = 65.24 months, SD 69.60). Provoked vestibulodynia was found to be deleterious to the psychological and sexual health of all participants. Women reported substantial psychological and relationship distress. Women also reported negative experiences with the health care system resulting from physicians invalidating their concerns, failing to make a diagnosis, and recommending treatments the women perceived as ineffective.

Conclusions: Both primary care physicians and specialists can play a key role in diminishing a woman's suffering by improving their knowledge of and ability to diagnose provoked vestibulodynia, providing accurate information about this condition, and making timely referral to experienced treatment providers.

Background

Vulvodynia refers to chronic pain involving the vulva for which no obvious cause can be found. Women with this condition complain of 6 months or more of uncomfortable sensations such as burning, stinging, or rawness in the genital area. Estimates of the lifetime prevalence of this condition range from 4% to 28%.¹⁻² The majority of women with vulvodynia (90%) will seek help from their family doctors.³ Women will also seek help from gynecologists, dermatologists, urologists, and alternative medicine practitioners. Many will seek help from multiple specialists. Unfortunately, many health care providers do not feel comfortable or competent dealing with vulvovaginal conditions, and despite numerous consultations and interventions, these patients often

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receive health care they do not perceive as helpful.³

Provoked vestibulodynia or PVD (formerly known as vulvar vestibulitis syndrome) is a form of vulvodynia and is the most common cause of sexual pain in women under the age of 30.⁴ The name refers to the fact that pain is localized to the vestibule or entrance to the vagina and is provoked by touch. Women experience pain with the insertion of a tampon or speculum. Pap tests are painful. The pain interferes with sexual activities such as foreplay and intercourse. Thus, the condition is deleterious to emotional well-being, sexual health, and intimate relationships.

The cause of PVD is unknown and likely multifactorial; neurological,⁵ psychological,⁶ and muscular⁷ factors may be involved, making the management of PVD complex. A variety of medical, behavioral, and surgical treatment options have been recommended in the literature, but high-quality research to support any particular strategy is lacking.⁸ It has been speculated that women with PVD may benefit most from a multidisciplinary and integrated health care approach.⁹

In 2008, the Multidisciplinary Vulvodynia Program (MVP) was established and began operating out of the Women's Clinic (UBC Department of Gynaecology) in the Gordon and Leslie Diamond Health Care Centre. Initially, women who were referred to the Women's Clinic with a complaint of vulvodynia and/or sexual pain were triaged to the MVP. Over time, physicians began referring patients with vulvodynia directly to the program. Once a program staff member determines a referral is appropriate, an assessment appointment is scheduled. Women are initially assessed by a gynecologist, who obtains a detailed medical history and psychosexual history and performs a gynecological

examination. The examination consists of inspection of the external genitalia, cotton swab palpation of the vulva and vestibule to identify areas of allodynia and hyperalgesia. If appropriate, a speculum and bimanual exam are conducted. After the assessment appointment, women who fulfill entry criteria are offered a spot in the program.

Women who satisfy the program's criteria are of reproductive age, have had dyspareunia secondary to PVD for at least 6 months, and are able to participate in group education and therapy sessions. Women are not accepted if they are postmenopausal, have a primary complaint of chronic unprovoked vulvar pain, have pain that is likely due to another cause (e.g., lichen sclerosus), or cannot participate in group sessions (e.g., because of a lack of English fluency). Limited resources (human and financial) mean the program operates 1 day per week and is limited to women with PVD only. The current wait time for an assessment is approximately 4 months.

Cohorts of 8 to 12 women are enrolled at a time. Each woman attends seminars, group therapy sessions, and individual sessions (10 appointments in all) scheduled over 12 weeks.

To begin, the women take part in two 60-minute educational seminars led by gynecologists with expertise in sexual medicine and genital pain. The purpose of these sessions is to pass on accurate information about PVD. The first seminar includes a structured discussion of the clinical symptoms and signs of PVD; current theories about causation and pathophysiology; and

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the medical, behavioral, and surgical treatments for PVD. The second seminar reviews the negative impact of pain on a woman's sexual response cycle, and a discussion about the impact of PVD on a couple's sexual relationship.

After the seminars, the women participate in three 90-minute group cognitive behavioral therapy (CBT) sessions with a clinical psychologist. These sessions are aimed at introducing, practising, and refining skills in cognitive challenging, and clarifying the role of thoughts, emotions, and actions in genital pain. Behavioral exercises in mindfulness, diaphragmatic breathing, and progressive muscle relaxation are practised in the sessions and recommended for homework between sessions.

During the period when CBT sessions are held, each woman has three

individual sessions with a pelvic floor physiotherapist. The physiotherapy sessions include instruction in bio-feedback (with surface electromyography), pelvic floor relaxation, and the use of vaginal inserts to address vaginismus. Each woman is also seen twice by a gynecologist over the course of the program—once after the educational seminars and once at discharge.

At the end of the program, patients return to the care of their referring physicians with a detailed discharge plan. Women are encouraged to continue with any of the different therapies they tried during the program that they perceive to be helpful.

To the best of our knowledge, this program is unique in North America in that it involves three components (educational seminars, group therapy sessions, and individual physiotherapy and gynecology appointments) delivered concurrently in one clinic, allowing for direct and immediate collaboration between health care providers. To evaluate the effectiveness of this resource-intensive program, we decided to explore the quality of our patients' lives and the quality of their interactions with the health care system prior to enrollment in the Multidisciplinary Vestibulodynia Program.

Method

After a study designed to explore women's experiences with provoked vestibulodynia was approved by the UBC Clinical Research Ethics Board, we identified women who had participated in the Multidisciplinary Vulvodynia Program from December 2008 to September 2009. Knowing that qualitative research can provide a better understanding of women's experiences than that obtained using standard questionnaires, we invited each woman who had completed the program to take part in an individual in-person or telephone exit interview. The interviews were conducted by a trained research assistant uninvolved in the MVP. Participants were interviewed using a semi-structured interview format and asked the following open-ended questions: What has been the impact of vulvodynia on your life? What was your experience with the health care system before the MVP? The interviews were recorded, transcribed, and analyzed for thematic content by the three authors of this article, who independently read through the transcripts and identified possible themes. The researchers then met and compared the themes they saw emerging from the data. A coding

framework was developed and the transcripts were read again and coded appropriately. The coded data were then reviewed in a horizontal manner to identify the emerging themes.

Results

From December 2008 to September 2009, 46 women completed the MVP and 30 of these women agreed to be interviewed. Nineteen of the interview recordings were of sufficient audio quality (determined by an independent transcriptionist) to be transcribed and analyzed. The demographic and pain characteristics of responders and nonresponders were compared and no significant differences were found.

Participants ranged in age from 20 to 54 (mean age = 30.84, SD 9.06) and some had experienced pregnancy and childbirth (mean number of pregnancies = 0.60, SD 0.83; mean number of children = 0.13, SD 0.35). Other demographic characteristics of participants are presented in **Table 1**.

Participants reported having pain during intercourse 70% to 100% of the time (mean = 95.30%, SD 8.21); and a history of such pain ranging from 6 months to 20 years (mean = 65.24 months, SD 69.60). Specifics regarding the pain characteristics of

Table 1. Demographic characteristics of 19 study participants.

Highest level of education	
Some postsecondary education	18
High school education	1
Marital status	
Married	10
Common-law	5
Divorced	1
Single	3
Ethnic background	
Euro-Canadian	11
South Asian	6
Middle Eastern	2

Table 2. Pain characteristics of 19 study participants.

Questions	Responses*
Have you ever had pain-free sexual intercourse?	No = 3 Yes = 16
Have you had intercourse in the last 6 months?	No = 4 Yes = 13
Proportion of time you experience pain with intercourse?	100% = 12 >70% = 6 (mean = 95.30%, SD 8.21)
Duration of your pain condition?	6–240 months (mean = 65.24 months, SD 69.6)
Intensity of your pain when "worse"? (0 = no pain, 10 = worst pain)	6/10–10/10 (mean = 8.53, SD 1.05)
Intensity of your pain when "usual"? (0 = no pain, 10 = worst pain)	2/10–10/10 (mean = 5.6, SD 2.31)

*Not all participants answered all questions

participants are presented in **Table 2**.

Major themes emerged when the responses to the interview questions were reviewed. Some sample responses are presented in **Table 3** and **Table 4** and are discussed in more detail below.

Question 1: What has been the impact of vulvodynia on your life?

Vulvodynia was associated with psychological distress, sexual problems, and relationship difficulties. Participants reported negative changes in their mood, including frustration, anxiety, stress, and depression. One participant said the condition “Affects your mood... often you are on the brink of depression a lot. Confidence is affected... I could go on and on, but basically it really, really affects who you are.” Another participant expressed feelings of hopelessness and helplessness: “There seemed to be no hope, this is how it is going to be and I am going to be like this forever.” Many reported feeling “not normal”: “I feel like there is something wrong with me and that I am different than the average person.”

Participants reported changes to their sexual response cycle, including diminished sexual self-esteem, loss of sexual interest/desire, and diminished sexual arousal: “I think the condition has 100% affected my sex drive and my ability to get aroused.” Many grieved over their inability to engage in sexual intercourse: “It had a huge impact... [on my long-term relationship] in that sexual intercourse is not something that we can do.” Not surprisingly, the condition affected participants’ sense of “being a woman” and some reported avoiding both sexual and physical intimacy, including “any kind of touch.”

The condition had a profound negative impact on existing relationships: “It is always a constant struggle

Table 3. Sample responses to question 1 (What has been the impact of vulvodynia on your life?) presented by theme.

Psychological distress	<p>“It was always on my mind, why was [this] happening to me?”</p> <p>“Every time we try [to have intercourse] I feel disappointed for a week or so.”</p> <p>“I have sort of put up walls... there is a lot of mental and emotional baggage that comes along.”</p> <p>“At night it is hard to think about anything else.”</p> <p>“You feel like there is no hope.”</p> <p>“Very confusing. Very emotionally draining.”</p>
Sexual problems	<p>“Sex... isn’t really a part of my life anymore, and that’s part of who I am as a woman... Not to have [sex] is really devastating.”</p> <p>“The fact that I cannot satisfy him [sexually]... is stressful for me and... for him too.”</p> <p>“The loss of interest in sex, that is just really hard, because part of you wants to but then part of you really can’t find it, can’t find the interest, that probably has been one of the toughest things.”</p> <p>“I can’t have sex with my husband.”</p>
Relationship difficulties	<p>“It’s mostly affected... the relationship that I have with my husband... The relationship has gone downhill.”</p> <p>“Impacted our relationship to the point of closeness and intimacy, not just around sex.”</p> <p>“It has really affected my relationship with my husband.”</p> <p>“It was really hard for me to explain it... and he kind of backed away on me.”</p>

Table 4. Sample responses to question 2 (What was your experience with the health care system before the MVP?) presented by theme.

Unhelpful	<p>“It takes so long to diagnose.”</p> <p>“It... took visits to many doctors.”</p> <p>“I felt like the doctors that I saw, because they were so unsure about what was happening, it made me feel even less confident to talk about it with them.”</p> <p>“Some doctors even recommended that I do nothing and see what happens, which obviously doesn’t do anything.”</p> <p>“Not knowing and... being prescribed the same treatment again for yeast, several times.”</p> <p>“I felt like I was trying all these things and having no success for quite a long time.”</p> <p>“I ended up going to multiple doctors just thinking ‘My doctor doesn’t care.’”</p> <p>“One of them [a gynecologist] made me feel uncomfortable... she told me to just try this cream, there is nothing I can really do beyond that.”</p> <p>“She said... ‘I will check with my colleagues’... she never got back to me.”</p>
Destructive	<p>“The response was always ‘Oh it looks normal to me.’... It’s difficult for me to counter that.”</p> <p>“[Doctors] telling me ‘You look fine’ or ‘It’s in your head.’”</p> <p>“He told me I was crazy.”</p> <p>“I had said ‘if he doesn’t do something... I’ll cut it out myself’... he gave me a website and said ‘Look this up, it is for people who enjoy mutilating themselves.’”</p>
Facilitative	<p>“The new gynecologist has been fantastic, very thorough and very understanding and compassionate and listens and doesn’t rush you out.”</p> <p>“My GP refers to specialists... which I think is great.”</p> <p>“She referred me to this program, because I think she knew what was going on.”</p> <p>“My GP referred me to a private physiotherapist and a psychologist... so it was fairly easy to get help.”</p>

especially to get [partners] to understand that it is not what [sex] you want and what you don't want—it is something physically preventing you.” PVD also deterred participants who were not in a relationship from entering into new relationships: “I have not really wanted to get into a relationship until I get things under control.”

she does not really know what to do with the condition.” Participants often felt dismissed or ignored and some reported that physicians discounted their pain or implied that the pain was “all in their heads”: “I was told either that I'm frigid or that I don't like sex; just learn to accept it, sometimes women just don't like sex.”

psychological distress, and sexual dissatisfaction when compared with controls. White and colleagues¹¹ reported that women with PVD were “highly likely” to have diminished arousal potential, diminished interest in intercourse, and negative feelings toward intercourse. Women with PVD have reported changes in sexual behavior, including decreased frequency of sexual intercourse¹² and a complete inability to engage in sexual intercourse.¹³ PVD may thus have a profound impact on a couple's fertility.

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Question 2: What was your experience with the health care system before the MVP?

Interactions with the health care system were categorized as unhelpful, destructive, or facilitative. The majority of comments were about negative (unhelpful or destructive) interactions with the system rather than positive (facilitative) ones. Most participants attributed these negative experiences to the inability of physicians to recognize and acknowledge the validity of their condition: “The frustration has been the medical community not knowing anything about this condition—misdiagnosing and mistreating it.” “I can't count how many GPs I have been to... about it.”

Some participants described a loss of trust in the medical system and expressed frustration with ineffective treatments: “She just again asked me to keep trying and trying, so I guess

Positive interactions reported by participants focused on physicians listening to their concerns: “[The physician] took the time to listen to me and acknowledged the fact that I feel abnormal, and that I feel pain, and acknowledged the fact that I needed help that was beyond her... scope of knowledge.” Physicians were perceived as helpful when they were supportive and encouraged patients to seek further help for PVD: “It was my family doctor who really pushed for me to... get more help for it.”

Conclusions

Analysis of our interview data established that women with PVD experience psychological distress, sexual dysfunction, and relationship difficulties. Previous research supports these findings. Gates and Galask¹⁰ reported that women with PVD had higher scores on measures of depression,

Participants reported a mixed experience with the health care system. Most women reported negative experiences that they attributed primarily to the failure of both family doctors and specialists to diagnose the condition. Despite increasing media attention^{14,15} and notable efforts by physician and patient organizations,^{16,17} women commented on the “lack of awareness” among physicians about PVD. Like other chronic pain conditions, the diagnosis is clinical and relies predominantly upon the patient's description of her pain. It appears that many health care providers fail to recognize pain at the entrance of the vagina associated with penetration as a classic symptom of PVD.

Reasons for the inability of physicians to diagnose this condition need to be explored further. The opportunity to learn about vulvovaginal diseases is limited in both undergraduate and postgraduate medical curricula. At the University of British Columbia, for example, there is no specific formal instruction around vulvar diseases in the undergraduate curriculum. Vulvar diseases are also not listed as an evaluation objective by the College of Family Physicians of Canada. While “sex” is listed as a priority topic, there is no specific key feature listing sexual pain or vulvodynia.

How physicians can help

Many women interviewed for our study were made to feel that the problem was “in their heads”—in other words, that their pain was not “real” pain in some way. Physicians were perceived as helpful when they validated the woman's pain, acknowledged the problem, and supported the woman in her quest to find help. Our patients' comments reveal that physicians can play a key role in decreasing a woman's psychological distress by listening to her concerns and acknowledging the pain as a real problem.

Women should be counseled that pain with intercourse is not normal. Physicians should be comfortable in explaining that the diagnosis of PVD is a real pain condition. Patient education material can also be very helpful. Our program website (www.myprogram.org) has sections for both health care providers and patients. A public educational forum, *Why Does Sex Hurt?*, can also be viewed. The provision of accurate information alone has been shown to reduce psychological distress and sexual symptoms in women with PVD.¹⁸

Patients should be reassured that the psychological distress and sexual problems that they may be experiencing are a common consequence of PVD. A woman's loss of sexual interest is understandable given the association of pain with sexual activity, and, despite her beliefs, is not necessarily the result of a lack of love for or sexual attraction to her partner. Given the impact of psychological distress in perpetuating the pain of PVD,¹⁹ validating a woman's pain and her feelings can be an important step toward effective pain control.

Physicians can also help by avoiding ineffective treatments, such as prescribing for suspected infectious vaginitis in the absence of positive laboratory results, and by making

general skin care recommendations (avoiding soaps, stopping all over-the-counter topical medications). In some cases, a lubricant and the use of topical lidocaine prior to intercourse may be helpful in reducing sexual pain. However, as noted by Landry and colleagues,⁸ despite approximately 40 treatment studies conducted in the past 15 years, it is currently not known which women will respond positively to an individual treatment; most women with PVD will try many treatment modalities before experiencing any significant benefit.⁹ PVD is a challenging pain condition to treat. Access to physicians who specialize in the treatment of sexual pain is limited; and those physicians often have lengthy wait lists. Thus, primary care physicians and specialists should be familiar with therapies for vestibulodynia (see Box) in the guidelines^{20,21} and patient resources²² that can aid in the management of this condition.

Study limitations

One limitation of our study is that we interviewed women who struggled to obtain a diagnosis and effective treatment, and consequently their views may not represent the typical woman with provoked vestibulodynia who is quickly diagnosed by her physician, understands the diagnosis, and receives effective treatment. However, prior to the introduction of the MVP, one of the authors of this article ran another vulvar pain clinic and the average wait time for that clinic was 2 years. Thus, it is our expectation that a large number of women in BC experiencing vulvovaginal pain are going without specialist care and will have feelings similar to those of our study participants.

Despite these limitations, we believe our study results provide additional support for previous research that shows an adverse effect of PVD

Therapies for provoked vestibulodynia

- Topical estradiol 0.01% cream b.i.d. for 6 to 12 weeks.
- Topical 2% to 5% xylocaine prior to intercourse.
- Early referrals to pelvic floor physiotherapists, psychologists, or sexual counselors to address the secondary health problems that develop (pelvic floor hypertonicity, depression, sexual avoidance).
- 3-month trial of an oral pain adjuvant (such as a low-dose tricyclic antidepressant or gabapentin).
- Surgical treatment (vestibulectomy).

on several aspects of women's lives, and illustrate how difficult it can be to receive a diagnosis and appropriate care. Both primary care physicians and specialists can play a key role in diminishing a woman's suffering by improving their knowledge of and ability to diagnose PVD, by providing accurate information about this condition, and by making timely referrals to experienced treatment providers. Early diagnosis can substantially diminish the adverse effect of PVD upon a woman and her sexual partner.

Competing interests

None declared.

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