# SEXUAL MEDICINE

# WOMEN'S SEXUAL HEALTH

# What Do Patients Want? A Needs Assessment of Vulvodynia Patients Attending a Vulvar Diseases Clinic



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## ABSTRACT

Introduction: Vulvodynia is a chronic pain disorder that negatively impacts the quality of life of affected women.

Aim: The goal of this study was to identify unmet needs among localized provoked vulvodynia patients.

**Methods:** A qualitative needs assessment was performed in a subspecialized vulvar clinic in a single academic institution in Canada. Semistructured interviews were conducted, recorded, and analyzed using the constant comparative method of grounded theory to identify common themes.

Main Outcome Measures: Interviews were conducted until theme saturation was achieved.

**Results:** A diverse sample of 8 patients completed all components of the study. The most prominent unmet needs raised by patients in their interviews were categorized into 3 main themes: (1) challenges related to obtaining a diagnosis of vulvodynia and finding practitioners who are knowledgeable about vulvodynia; (2) challenges related to the current impact of the disease physically, emotionally, and in social relationships with patients' intimate partners; and (3) barriers to adherence with recommended therapy. Solutions recommended by patients include better education of physicians regarding vulvodynia and the development of multidisciplinary programs that provide access to physiotherapy, sex therapy, mindfulness and psychology services on-site, information classes for new patients, and the creation of peer support networks for patients and their partners.

**Conclusion:** A patient-focused needs assessment suggests optimal vulvodynia care requires better education of physicians and a multimodal approach to therapy, ideally with multiple services offered in 1 location.

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Key Words: Dyspareunia; Needs Assessment; Patient Satisfaction; Vulvodynia

# INTRODUCTION

Vulvodynia is a chronic pain disorder defined by the International Society for the Study of Vulvovaginal Disease as "vulvar discomfort, most often described as burning pain, occurring in the absence of relevant visible findings or a specific, clinically identifiable, neurologic disorder."<sup>1</sup> The etiology of vulvodynia is not well understood currently and patient experiences are highly variable due to heterogeneity of the disorder.<sup>2</sup>

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http://dx.doi.org/10.1016/j.esxm.2016.06.003

Vulvodynia exists in up to 16% of the population. Due to the lack of physician awareness regarding vulvodynia, many women seek multiple medical opinions before receiving a diagnosis and starting treatment.<sup>3</sup> Chronic vulvar pain can have a devastating impact on interpersonal relationships, sexual function, mood, and overall quality of life of affected individuals.<sup>4,5</sup>

Pharmacologic treatment alone has not been shown to be effective in vulvodynia treatment.<sup>6,7</sup> However, several recent studies have demonstrated that on-site multidisciplinary care can have efficacy both in the short- and long-term management of vulvodynia.<sup>8,9</sup> A qualitative study by Buchan et al found that women who were already enrolled in or had completed a multidisciplinary vulvodynia treatment program retrospectively identified delay to diagnosis as a key factor in exacerbation of their symptoms.<sup>10</sup> Previous research has not examined if vulvodynia patients who are treated at a centre without such a program would prospectively be interested in engaging in one. Moreover, there is no current literature on whether there are any other needs of vulvodynia patients that are not being addressed by these multidisciplinary models.

Received January 11, 2016. Accepted June 23, 2016.

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At Women's College Hospital (WCH), a weekly half-day clinic for patients with vulvar disorders is offered that involves collaboration between 1 gynecologist and 1 dermatologist. Vulvodynia is one of many problems seen in the clinic. With its current design, the clinic provides care focused on medical and surgical management of vulvodynia, and patients need to be referred off-site for pelvic floor physiotherapy, sex therapy, and psychotherapy. To assess the needs of this group, a qualitative needs assessment was designed.

One of the most well-validated techniques in qualitative research is that of grounded theory. In this method, systematic analysis of textual data allows the researcher to identify patterns of themes. This ultimately leads to development of theories that are "grounded in" the data to better understand and explain the experience of a person or group.<sup>11</sup> Using the constant comparative method central to grounded theory, data is analyzed as it is collected by deriving codes and themes from each transcript as it is produced and comparing these to codes derived from previous interviews in order to organize and refine themes and theories in an iterative process. Data collection continues until analysis of new data no longer invokes new themes or ideas, at which point data saturation is deemed to have been reached.<sup>12</sup> The sample size at which this occurs can vary depending on the sample group and the research topic; however, saturation can be reached after anywhere from 6 to 400 individual interviews, or more than 2 focus groups.<sup>13</sup> The disadvantage to an inappropriately large sample size is the inability to feasibly complete in-depth analysis on each transcript, and therefore important themes can be lost.<sup>14</sup>

This needs assessment study aimed to identify challenges faced by patients with localized provoked vulvodynia with the goal of providing improved care to these patients.

### MATERIALS AND METHODS

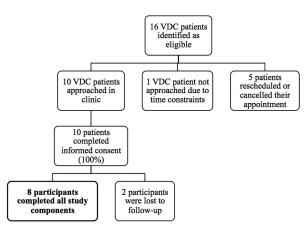
This study was approved by the Research Ethics Board at Women's College Hospital (WCH) (2013-0080-E). A convenience method of sampling was used to recruit eligible participants from the Vulvar Diseases Clinic (VDC) at WCH. To be considered eligible, patients were required to be between 18 and 80 years old, have an established diagnosis of localized, provoked vulvodynia that had been confirmed by a physician in the VDC at WCH, and be capable of communicating in English. Eligible patients provided informed written consent to participate in the study. Each participant then completed a demographic/patient satisfaction questionnaire and underwent a semistructured interview in a private clinic room conducted by a female interviewer whom they had never met before (Author KL), using a preset interview guide of open-ended questions. As data was collected and analyzed, participants were also asked to discuss themes that were emerging in order to confirm or refute developing theories, as is fundamental in the constant comparative method.<sup>12</sup> The interviewer was a medical student who had undergone basic training in qualitative research methodology.

The senior author has an MD and an MSc in health research methodology. Interviews were audio recorded, transcribed, and anonymized. Interviews were not repeated. Field notes were not made after the interviews and transcripts were not returned to the participants for comment or feedback. Descriptive thematic analysis using the constant comparative method of grounded theory was performed on each transcript. Initial descriptive codes were applied to each sentence of the transcript to identify the main idea presented in the text fragment. This was performed by 2 independent investigators; discrepancies between selected codes were discussed and resolved to ensure their validity.<sup>15</sup> Once the transcript was coded, the relationships between codes were defined by themes. Codes and themes were then further described and examples of each were documented. Final themes were corroborated using triangulation with a single semistructured interview with a member of the VDC staff.<sup>15</sup>

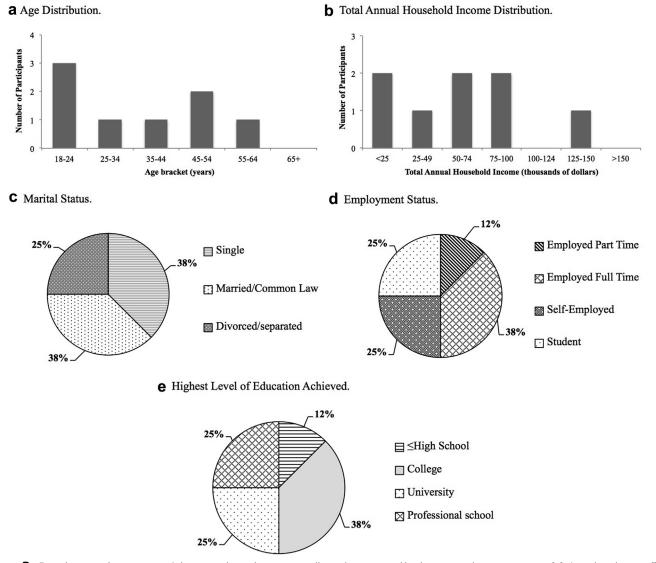
Data collection continued until saturation was reached. Saturation is defined as the point at which the ongoing analysis of new data no longer brings forward any new insights to change or modify the emerging theory.<sup>12</sup> In this study, the developing codes and themes were unchanged by the final 2 interviews and thus, data collection was concluded after 8 interviews.

# RESULTS

Sixteen eligible patients were identified from the VDC clinic list between January 22 and March 19, 2014. Five patients did not attend their scheduled appointment and 1 eligible patient was not approached for participation due to time constraints. All 10 eligible patients who were approached consented to participate. Two participants made arrangements to complete the interviews by phone but ultimately were lost to follow-up. Recruitment continued after these patients were lost to followup, and the point of saturation was determined only when no new information was emerging from completed interviews. The final sample size for this study was 8 participants (Figure 1). Interviews ranged from 15 to 30 minutes.



**Figure 1.** Recruitment flow diagram demonstrating recruitment process from the Vulvar Diseases Clinic from January 22 to March 19, 2014.



**Figure 2.** Distribution of participants' demographic information collected using a self-administered questionnaire. (a) Age distribution (b) total annual household income distribution (c) marital status (d) employment status (e) highest level of education achieved.

Demographic characteristics of the sample are depicted in Figure 2. Overall, the sample captured a diverse group of participants in terms of age, income, marital status, employment status, and educational background.

The main challenges that vulvodynia patients face as a result of their condition could be categorized into 3 overarching themes. These themes along with their associated subthemes and codes are listed in Table 1.

#### Challenges Related to the Initial Diagnosis

#### Difficulty Obtaining a Diagnosis

The path to being diagnosed and referred appropriately for vulvodynia care is difficult for many affected women. One participant noted, "I kept going and going and visiting one [doctor] after another and still none of them had a clue" [005]. Another participant explained, "...you don't know what is going

on, and why you're feeling what you're feeling. And the doctors are telling you that they don't know what's wrong so it's very frustrating" [004]. After several referrals with no success, patients reported feelings of helplessness, and felt their distressing symptoms would never resolve.

Participants also reported receiving many misdiagnoses. One woman described, "It would feel like it was burning, even when there was nothing happening. So, I would go for a swab, and then they'd say 'Oh there's nothing wrong with you' " [006]. Others felt that their physician dismissed their symptoms: "I had decided to go to another doctor. When I opened the medical record I discovered that [my family physician] had made comments... that he thought I was a hypochondriac" [006].

#### Emotional Impact of the Initial Diagnosis

Participants identified differing emotional responses to their initial diagnosis. Six of the women reported a sense of relief that

 Table 1. Semistructured interview themes and codes

	% of transcripts containing the code (transcript count)
Challenges related to initial diagnosis of vulvodynia	
Difficulty obtaining a diagnosis	
Multiple referrals between physicians	63% (5)
Multiple misdiagnoses	50% (4)
Emotional impact of the initial diagnosis	
Relief	75% (6)
Anxiety-provoking	63% (5)
Challenges related to current impact of the disease	
Impact on regular activities	
Ability to have sexual intercourse	75% (6)
Ability to exercise	50% (4)
Choice of clothing	50% (4)
Use of feminine products	25% (2)
Emotional consequences of the condition	
Depression	38% (3)
Isolation	38% (3)
Anger	25% (2)
Frustration	25% (2)
Anxiety	13% (1)
Stress	13% (1)
Impact on Relationships	
Connection with intimate partner	50% (4)
Barriers to adherence to recommended treatments	
Pelvic floor physiotherapy	
Lack of understanding of purpose	25% (2)
Cost	13% (1)
Distance	13% (1)
Medications	
No immediate symptom improvement	25% (2)
Recommended improvements at the VDC to better address challenges	
Pelvic floor physiotherapist on-site	100% (8)
Information class about vulvodynia	75% (6)
CBT and mindfulness provider on-site	63% (5)
Implementation of peer support networks	
Sex therapist on-site	63% (5)
Involvement of intimate partner	50% (4)
Social worker on-site	38% (3)
Engage and educate general practitioners	25% (2)

someone understood the symptoms they had been experiencing. One participant explained, "That was such a relief. That was one of the best days of my life.... [the physician] knew exactly what I am talking about" [005]. Validation of their experience with a medical diagnosis held immense value for these women. A member of the clinic staff emphasized the importance of this, saying "... they're so relieved after they're seen because we validate that, yeah, there is a reason for the pain, and no, it's not in your head." [011]. Conversely, 5 of the women reported that the diagnosis of vulvodynia gave them feelings of anxiety, because they were facing a condition about which they knew very little. A participant described, "I didn't know what it was, what it means... I still know nothing about it" [003]. Many of the women left their appointment with limited knowledge of the condition they were facing; the same patient explained, "[I had] so many questions. About why did I get this? What can I do? Is it going to be better with time when I get the medicine or

To better address these questions, 6 of the 8 participants thought that an information class about vulvodynia and its treatment would be helpful after receiving the diagnosis.

# Challenges Related to the Current Impact of the Disease

#### Impact on Regular Activities

something?" [003].

Participants reported major limitations in their daily activities as a result of the disorder. Four women raised the issue of limitations in choice of clothing. A young patient said, "I find that looser is better. Like I can't wear — like really tight pants is kind of uncomfortable... things like thongs and stuff I just can't wear" [010]. One woman said that her limitations in her choice of clothing are the most bothersome aspect of the disease [004]. Each of the women that raised this issue had developed strategies for minimizing clothing restrictions. Most participants (5, 63%) thought that engaging in a peer support group either online or in person would allow them to share these strategies.

Four women mentioned that they have had to modify their physical activity because of the vulvar pain that they experience. A participant said that the pain limits "... any type of physical activity, so running, bicycling, exercising; anything that has high impact movement, or if you tend to sweat it would get in the way" [004].

#### Mental Health Effects

The participants reported a wide breadth of emotional responses in association with their vulvar pain. One woman said, "... it can cause sometimes stress, ... and like stress that causes you to want to have something to help, so, to cope" [004]. Other women found themselves becoming irritable: "I think it can make me a little grouchy sometimes. I'll find that I'm on edge and I'll think, 'Why am I on edge? Oh, yeah, I have the burning again. So I gotta *not* snap someone's head off" [006]. Three patients said that the pain makes them feel sad and depressed at times, not only because they foresee no end to their symptoms, but also because of the limitations that the pain can impose on their relationships and activities.

Of note, 3 patients discussed the concept of feeling isolated because of their vulvar pain. One woman described, "I don't feel alone in the problem but I kind of do in a way, because there's so many people who, you know, they have no trouble" [008]. In addition to a peer support network, 5 of the women felt that having access to a mindfulness pain management coach or a psychologist would help them to cope with the emotional repercussions of vulvodynia.

#### Impact of the Condition on Intimate Partner Relationships

Six women revealed that they were in long-term relationships. Several of these women emphasized the significant impact of vulvar pain on their relationship with their intimate partner. One woman described this, saying, "... [my husband and I] fight a lot because of this." [003]. These women develop a negative idea of sex and intimacy, and many reported avoiding intimacy with their partners altogether. The participants also described being unable to adequately explain the condition to their partners. This misunderstanding can lead to conflict, putting stress on the relationship:

Well, it's hard when your partner doesn't completely understand, um, what's happening with you. I mean, if there's no obvious physical sign, like some sores or something happening, right, it's really hard to explain to somebody that something is painful... and if you're saying that a lot over time, that it's uncomfortable, after a while, your male partner tends to say, well, you know, "what the hell is wrong?" You know, and "is it something wrong with me?" [006].

The women felt that they needed more help with explaining their condition to their partners, and with developing strategies to foster intimacy during their treatment so that their partners don't feel neglected in the relationship. To address the impact on sexuality and intimacy, 5 of the women suggested that having access to a sex therapist on-site would be immensely helpful.

# Barriers to Adherence to Recommended Treatments

#### Pelvic Floor Physiotherapy

Patients identified 3 main reasons why they were unable to initiate or continue pelvic floor physiotherapy in the community. Some participants had not received adequate explanation of the benefits that pelvic physiotherapy can have in the context of vulvodynia and didn't understand the relevance: "I think [pelvic physiotherapy] might be useful for women who are older, maybe past menopause and they may already have some other issues like incontinence and things like that, or those [pelvic] muscles are not as toned" [006].

Because the service is not currently covered by provincial medical insurance, one of the patients identified cost as a barrier. She indicated, "...for my boyfriend and I financially, we just started working. So my thinking on that was I would like to do it when I have a certain amount saved" [008]. For those without private medical coverage, the expense of pelvic floor physiotherapy can render this valuable treatment inaccessible.

Despite relatively poor uptake of pelvic floor physiotherapy in the community, all 8 participants reported that they would be much more open to attending a set number of private pelvic floor physiotherapy sessions if they were offered on-site.

# DISCUSSION

This study demonstrates that patients with localized, provoked vulvodynia have important social, emotional, and physical needs that are unaddressed in the current model of care at the study center.

Women face delays in diagnosis and expressed a need to be taken seriously and feel validated from the moment they present to a doctor. This is in keeping with previous studies, in which 60% of women were seen by 3 or more physicians before receiving a diagnosis of vulvodynia.<sup>3</sup> Physician education regarding vulvodynia prevalence, identification, and management is a first step in addressing this issue,<sup>16</sup> This was consistent with findings of Buchan et al, in which patients retrospectively identified delay to diagnosis as a major issue in the management of their symptoms.<sup>10</sup>

Women identified that they would be interested in mindfulness, sex therapy, psychology, and physiotherapy to address issues regarding the emotional impact of their disease, issues with their partners, and managing the pain if these services were offered free of charge and on-site at the hospital. Multidisciplinary approaches to vulvodynia management have been previously reported. In 2008, Sadownik et al designed and piloted a program that included comprehensive patient education, group cognitive behavioral therapy (CBT), and pelvic floor physiotherapy to address comparable identified needs among vulvodynia patients at Vancouver General Hospital.<sup>17</sup> Analogous programs implemented in the U.K. and in Sweden have been shown to benefit women with provoked vulvodynia.<sup>8,18</sup> Each of these programs provides both pelvic floor physiotherapy and emotional support.

Women in this study frequently raised concerns about the effects of their vulvar pain on their intimate partners. The impact of vulvar pain disorders on patients' partners is reported to include feelings of guilt, neglect, isolation, frustration, and anger.<sup>19,20</sup> Preliminary reports of couple-centered CBT have demonstrated benefit in reducing psychosexual burden in provoked vulvodynia, emphasizing the importance of including intimate partners in vulvodynia therapy.<sup>21</sup>

Multiple women felt that they would benefit from having sex therapy better integrated into their care. Sex therapists employ evidence-based techniques to augment the patient's ability to cope with the disorder, explore means for achieving pleasure and intimacy aside from intercourse, and enhance support for the couples affected by vulvodynia.<sup>22</sup> Many sex therapists are also certified in CBT, and help to address avoidance behaviors and restore normal function for vulvodynia patients.<sup>23</sup>

Participants in this study expressed a desire to become better informed about vulvodynia. Information classes have been shown to have a positive impact on psychosexual functioning in patients with vulvodynia,<sup>24</sup> and patient support groups are welldocumented to play a role in other chronic pain syndromes.<sup>25</sup> An information class offered to women at the time of diagnosis would allow questions to be answered, and anxieties and fears to be addressed. Peer support groups would allow the sharing of information, experiences, and coping mechanisms to diminish feelings of isolation.

Of note, women did not mention medication side effects as a barrier to adherence with pharmacologic therapy. The reason for this may be that our patients are generally not interested in drug therapy as first-line therapy and often prefer a non-drug approach.

This study is limited in that it was a single-center study, which may restrict its generalizability. However, the challenges faced by patients crossed a wide range of ages, educational backgrounds, and incomes, and are in agreement with much of the previous literature regarding optimal care for vulvodynia patients. Moreover, the small sample size could be seen as a limitation. As is standard in grounded theory, the sample size was not predetermined and was deemed to be reached once saturation was achieved, which in this study occurred after 8 interviews. Finally, the amount of time elapsed from diagnosis to the time of the interview was not taken into account during data analysis. For participants who had been diagnosed with vulvodynia well before data collection, this may have affected their recollection of their reaction to and the impact of their initial diagnosis.

# CONCLUSION

To better address the complex needs of women with localized provoked vulvodynia, centralized multidisciplinary services should be implemented. Current recommendations for vulvodynia care emphasize nonpharmacological interventions as a key pillar of vulvodynia management.<sup>26,27</sup> Integrating physiotherapy, psychotherapy, sex therapy, peer support services, and education classes in a single location is essential in order to provide comprehensive care for these women. Centralization will facilitate access to these services. As these are not currently covered by public insurance plans in Canada, funding would need to be acquired independently to develop a multidisciplinary center focused on providing the best care to women with vulvodynia.

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Conflict of Interest: The authors report no conflicts of interest.

Funding: None.

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- (a) Drafting the Article
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#### Category 3

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