

## SEXUAL MEDICINE

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

Katherine LePage, BSc, MD,<sup>1</sup> and Amanda Selk, MD, MSc, FRCSC<sup>2,3</sup>

### 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.

*Sex Med* 2016; ■:e1–e7. Copyright © 2016, The Authors. Published by Elsevier Inc. on behalf of the International Society for Sexual Medicine. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

**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>

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.

<sup>1</sup>Faculty of Medicine, University of Toronto, Toronto, Ontario, Canada;

<sup>2</sup>Department of Gynecology, Women's College Hospital, Toronto, Ontario, Canada;

<sup>3</sup>Department of Obstetrics and Gynecology, University of Toronto, Toronto, Ontario, Canada

Copyright © 2016, The Authors. Published by Elsevier Inc. on behalf of the International Society for Sexual Medicine. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

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

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

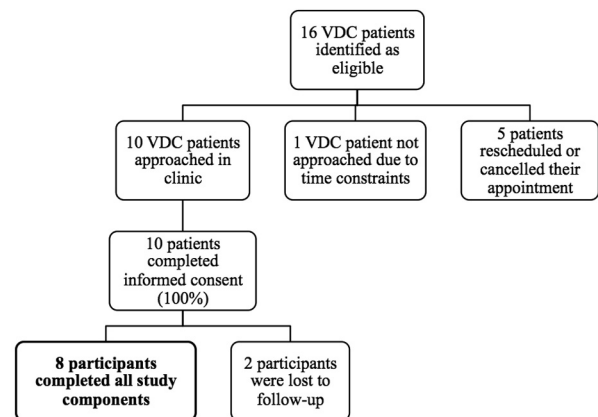
This study was approved by the Research Ethics Board at Women's College Hospital (WCH) (2013-0080-E). A convenience method of sampling was used to recruit eligible participants from the Vulvar Diseases Clinic (VDC) at WCH. To be considered eligible, patients were required to be between 18 and 80 years 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 follow-up, 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.

Download English Version:

<https://daneshyari.com/en/article/8829275>

Download Persian Version:

<https://daneshyari.com/article/8829275>

[Daneshyari.com](https://daneshyari.com)