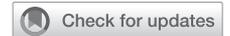


## WOMEN'S SEXUAL HEALTH

# Vulvodynia Viewed From a Disease Prevention Framework: Insights From Patient Perspectives



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## ABSTRACT

**Introduction:** Persons with vulvodynia (a chronic vulvar pain condition) suffer many barriers to diagnosis and treatment, several of which may be exacerbated by the sociocultural and geographical context in which they live.

**Aim:** We drew on the experiences of patients with vulvodynia who were living in small urban and rural communities to learn what they perceived as the major barriers to diagnosis and treatment as well as to probe for possible solutions.

**Methods:** For this qualitative case study, we conducted 3 focus groups with a total of 10 participants, drawn from patients seen at our academic tertiary referral center, with a goal of understanding their lived experience with vulvodynia.

**Main Outcome Measures:** The patient dialogue was coded into themes and temporally grouped to illustrate struggles and victories in diagnosis and treatment.

**Results:** Participants confirmed that healthcare provider knowledge and attitudes as well as system challenges (specialist and allied healthcare provider availability) are major barriers to timely diagnosis. Of novel interest are other factors that exacerbate distress and delay diagnosis such as patients' inadequate knowledge of sexual functioning and sociocultural messages regarding "normal" sexual activity. Our work suggests that a disease prevention framework that includes comprehensive sexual education before or at the onset of sexual activity may be of benefit in reducing the burden of vulvodynia when added to strategies to increase healthcare provider knowledge and improve access to effective treatments.

**Conclusion:** While healthcare provider knowledge and attitudes are often at the forefront of barriers to diagnosis, our study suggests that to minimize patient distress and expedite diagnosis, resources must also be directed to promoting comprehensive sexual health education. **Webber V, Miller ME, Gustafson DL, et al. Vulvodynia Viewed From a Disease Prevention Framework: Insights From Patient Perspectives. Sex Med 2020;8:757–766.**

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**Key Words:** Vulvar Pain; Sex Education; Continuing Medical Education; Health Personnel; Patient Education; Sexual Health

## INTRODUCTION

Vulvodynia is a chronic vulvar pain condition with an estimated point prevalence of 8% and a lifetime prevalence of

10–28% among people with vulvas<sup>†</sup>.<sup>1,2</sup> Localized provoked vulvodynia (LPV) is a subset of the condition that refers to pain localized to a particular part of the vulva and provoked by touch; sometimes caused by superficial contact as with sitting or tight clothes and other times caused by vaginal penetration as with intercourse, tampon insertion, or pelvic examinations.<sup>6</sup> Despite its high prevalence, vulvodynia in general remains widely undiagnosed and untreated with upwards of 40% of persons

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† While all participants identified as women, and frequently spoke of vulvodynia as a women's health issue, we intentionally avoid the term *woman* in general descriptions of vulvodynia. Doing so recognizes that not all people with vulvas identify as women. Failure to acknowledge the presence and needs of trans\*, non-binary, 2-Spirit, and other gender diverse individuals within gynecological practice has a detrimental effect on these patient populations.<sup>3–5</sup>

presenting for care never receiving a diagnosis or treatment.<sup>2,7</sup> Much research indicates that healthcare providers (HCPs) often lack training on the condition, and health systems fail to provide adequate resources.<sup>8,9</sup> Not surprisingly, people suffering from vulvodynia often feel discouraged, their pain ignored or depreciated by HCPs.<sup>8</sup>

Studies conducted in Toronto and Vancouver and focused on patient experiences in the healthcare setting demonstrate the positive outcomes of multidisciplinary teams.<sup>9,10</sup> However, these 2 densely populated urban centers contrast dramatically with the rural geography of Newfoundland and Labrador (NL)<sup>‡</sup>.<sup>11</sup> The results of these studies do not expose the known challenges of accessing health care in rural or small urban settings, and their results cannot be generalized to all of Canada owing to rural/urban resource disparities.<sup>12</sup> This study fills a gap of understanding around the constraints to accessing timely diagnosis and treatment for vulvodynia for dispersed, rural, and small urban populations.

The aim of this qualitative case study was to seek the perspectives of patients with LPV on the barriers to diagnosis and treatment outside of large urban centers, to tailor solutions to their potentially unique needs. It was designed to be hypothesis generating in that we sought solutions that could be validated in subsequent studies. Our analysis supports a disease prevention framework for organizing these solutions.

## MATERIALS AND METHODS

This project was approved by the Health Research Ethics Board of Memorial University, HREB #15.049. Seeking to understand participant experiences of processing their condition,<sup>13</sup> we viewed participant-generated narratives as a valuable and essential source of information for improving the delivery of healthcare services. We interviewed 10 patients in 3 focus groups regarding their diagnostic and treatment journeys. Focus groups were well suited to capture a breadth of experience through the “leveraging of social interaction”.<sup>14</sup> While one-on-one interviews generate in-depth data about individual experience, focus groups can make manifest relevant sociocultural norms and capture “emergent forms of information” such as a range of possible solutions.<sup>14</sup> A recent systematic review of qualitative research for vulvar pelvic pain concluded that focus groups have “the potential to reveal and explain several aspects of chronic pelvic pain.”<sup>15</sup>

### Recruitment

Convenience sampling was used for this study. Participants were identified through patient records from pelvic pain practice of K.B. Patients with a diagnosis of LPV and without other complex chronic pain or comorbid medical conditions were approached via telephone call for participation (n = 42). To be eligible, patients had to be able to communicate in English and

consent to participate. Individuals (n = 22) who signaled an interest in learning more about the study were sent letters of invitation via post or e-mail (based on their preference). The invitations included a cover letter, the consent form, the interview guide, and an opt-in/opt-out form. As vulvodynia is an extremely intimate issue, the ethics board required that participants receive the interview guide in advance, allowing them to decide if they were comfortable discussing the proposed topics. Those who indicated their wish to participate by returning the opt-in form (n = 14) were contacted beginning June 2017. Attempts were made to coordinate focus groups between October 2017 and May 2018. 4 were unable to attend any of the scheduled focus groups. The remaining 10 people participated in 1 of 3 focus groups of 3 or 4 people, divided on the basis of their ability to find a mutually agreeable interview time. Our sample was composed of heterosexual and bisexual female-identified persons between 20 and 50 years of age. At the time of their diagnosis, 8 of the 10 participants were living in a small urban center; the other 2 were living in rural areas.

### Data Collection

Focus groups were scheduled based on shared availability and were conducted in the community room of a local grocery store chain, as these venues offered free parking and an innocuous location in case participants encountered someone they knew in the area. Before beginning, the consent form was reviewed, including the use of audio recording, the importance of guarding each other’s information in confidence, and the assuredness of anonymity in any publications.

Focus groups were conducted by 2 of the research team members (M.E.M. and V.W.). No one but researchers and participants were present in the space. At the time, V.W. (BA, MA, MPH) was a PhD student and research assistant with extensive qualitative sexual health research experience. M.E.M. (BSc, MD, PhD) was working as a postgraduate medical trainee (resident) with experience working in the local medical system. Focus groups opened with introductions, interviewer backgrounds and relationships to the study, and an ice breaker. The interview protocol consisted of semistructured, open-ended questions to minimize predetermined responses and enable emergent themes. Participants were also encouraged to build on one another’s comments. Questions focused on the path to diagnosis, experiences accessing treatment, and the impact of the condition on social and sexual relationships (See [Appendix A](#)).

Focus groups ranged from 75 to 124 minutes (median 81 minutes) and were audio recorded. Researchers made jot notes during the interviews to remind them of issues to explore further with the group. Immediately after each session, interviewers debriefed and made further notes. A written account of demographic data and treatment histories were collected from participants at the end of the focus groups. Participants were offered a list of psychological support services and a \$20 honorarium to defray any costs associated with participation.

‡ The entire NL population of just over half a million people is distributed over 370, 514 km<sup>2</sup>—a landmass roughly 50 times larger than Greater Toronto Area or 200 times larger than Greater Vancouver.<sup>11</sup>

The recordings were transcribed by an independent contractor on the research team, and all identifying information was redacted. To enhance validity and increase their agency over the data collected, participants were sent the transcripts and offered the opportunity to remove or revise any comments. Final anonymized summaries of the findings from their respective focus groups, as well as of the study as a whole, were also sent to participants for their comment. Participants who responded offered no further edits or interpretations.

## Data Analysis

2 members of the research team (M.E.M. and V.W.) independently hand-coded all focus group transcripts. Inductive thematic coding was used, meaning that themes were not predetermined, and then populated with supporting quotes but were developed directly from the data. A theme was any idea, issue, or occurrence that played a role in participants' experience of LPV, for example, discomfort discussing sexuality or HCP disbelief. The independently generated themes were then compared for intercoder reliability and validity. Themes were synthesized, merged, and collapsed until the team members reached consensus on the most appropriate way to capture the relevant issues.

We conducted a second temporal analysis because many of the conversation prompts focused on the journey to diagnosis with participant narratives following a timeline from symptom onset, diagnosis, and, if applicable, some form of symptom resolution. Their various struggles and victories could be viewed along this timeline. In consideration of these 2 analyses, we have grouped the data according to 3 major themes of (i) sociocultural influences, (ii) HCP knowledge and awareness issues, and (iii) challenges to treatment. These themes were framed conceptually using the disease prevention model.

## RESULTS

Through analysis of the transcripts, it became apparent that both the issues faced by participants and the solutions proposed, lent themselves to organization in the disease prevention framework outlined by Teutsch<sup>16</sup> in 1992. Broadly, primary prevention aims to control factors that contribute to the development of a disease, whereas secondary prevention encourages early detection and treatment. Once a person is affected, tertiary prevention entails delivery of services to maximize quality of life and minimize morbidity.

### Sociocultural Influences: Opportunities for Primary Prevention

One recurring theme that emerged from the interviews was that sociocultural norms of silence and discomfort around sexuality impacted people's ability to recognize vulvar pain as a matter of concern. Several participants said they experienced pain early in their reproductive health and/or sexual experiences but

ignored or pushed through it because they assumed it was normal or a sign of some failing or misunderstanding on their part. Moreover, they did not have access to or feel comfortable seeking sexual health information that suggested otherwise.

*[Group 1] Abbey<sup>§</sup>: I could never use a tampon, but my mom never used tampons, [...] I don't even think we had any in the house, so I think I got one from a friend when we went swimming and I just thought, "Oh, I don't know how to use this properly so this is what's happening." So, it was never sort of on my radar.*

*[Group 1] Barb: For the longest time, I thought that inching your way in was how sex [vaginal intercourse] happened, until someone had said to me, "No, that's not the way it is supposed to be."*

*[Group 3] Karen: [If it weren't for my HCP asking about pain during penetration], I wouldn't have a sweet clue what was going on with me and my body. I'd just think that it was the normal, like, you get older, you're with a different partner, it's different sex, maybe his penis is too big, maybe my vagina's too small.*

Presumptions about the role of pain in vaginal intercourse were exacerbated when partners also had misinformed ideas about sex.

*[Group 2] Fay: He [a previous boyfriend] said to me one time, "Don't girls like a little bit of pain with sex?" And like really just didn't understand that yes, maybe, but not that kind, like it's not the kind of pain you want when you're having sex.*

*[Group 1] Abbey: My husband was a virgin when we got together, so he didn't know how it was supposed to work either, right? So, you know, inching our way in and thinking okay, I guess this is how it goes. Yeah, and that took a long time before we realized like no, this is not.*

Some participants mentioned a lack of access to information about sexuality. For example, when asked about the quality of high school sexual education, Janice [group 3] said

*Things like that weren't taught, weren't being discussed. Like, absolutely that's lacking here.*

In the absence of educational resources, mainstream media were cited as a common but problematic source of information about sex.

*[Group 3] Janice: [I thought] other people either don't have the pain or they fake it, you know, on movies and everything else, so maybe this is just what I have to get used to and accept, not really realizing that this isn't normal and that this kind of pain, you know, doesn't have to be this way.*

*[Group 1] Caitlyn: You kind of get caught up in what society, in what all those, the publicity and the imaging and-*

*Danielle: It's not like it is in the movies.*

In addition to a lack of education around genital and sexual wellness, participants alluded to how sex is not something to be discussed openly.

<sup>§</sup> For the purposes of reporting the results, random names were assigned to the participants to protect anonymity while avoiding depersonalizing their experience. Participant responses have been lightly edited for clarity.

[Group 2] Fay: *As far as friends go, um, I've told a couple friends here and there if we've, like reached that point in the relationship, but most of my friends, we don't usually talk too much about the sex stuff.*

[Group 3] Janice: *At the time I was pretty young, I was in my early 20s [...] now I'd probably talk about it very openly in my relationship, but I didn't want to talk about it back then, like that wasn't the dynamic of the relationship.*

This lack of sexual education, and a general social norm of not discussing sexuality in a frank manner, contributed to participants' unwillingness to bring up the subject with their HCPs.

### HCP Knowledge and Awareness Issues: Opportunities for Secondary Prevention

Participants often wished that HCPs had initiated conversation about sexual health and vulvar pain with direct questions.

[Group 1] Barb: *We were having difficulty with penetration, and I never thought to say that, and maybe had I said that I might have gotten somewhere faster [...] [It would be helpful for HCP] to be able to ask the right questions to us who don't know what we are supposed to be saying or how we are supposed to express ourselves.*

[Group 1] Abbey: *I remember going to my family doctor and saying, and not really knowing the words to say, [...] I never would have thought to, or probably even at that point been able to say, "We can't penetrate." Like that would have been so uncomfortable for me.*

[Group 3] Janice: *I didn't really know how to talk about it or how to describe it [...] I need them [the HCP] to ask, because it's not going to be something I'm immediately going to run to and say, like "oh, by the way, when this happens, is this normal?"*

When participants had overcome the difficulty of raising the issue of vulvar pain with their HCP, they were frequently met with what they perceived as dismissiveness.

[Group 3] Haley: *I was totally dismissed with my pain as well in the beginning [...] I was told like, "You can't focus on, don't focus on the pain."*

[Group 1] Barb: *I feel like they [HCP] are almost saying to me, but they are not saying to me, "Well this really isn't that important, you know, I have a patient here who's got a tumor." And I know that's important, yes, and that could be a life or death situation, but I mean this has really impacted my relationship with my husband, right? [...]*

Danielle: *I know it's not life or death compared to a tumor but for people that are going through it is extremely important and it affects everything. It affects your home life, your work life, your emotional; everything, it affects everything. [...]*

Abbey: *It's not kind of life or death, but it is life.*

[Group 2] Edith: *My doctor originally referred me to another gynecologist and seeing her for like a year and a half, she kept saying like, "I don't think there's anything wrong." Our last visit she asked me if it was all in my head. So that was a very horrible experience.*

By contrast, 1 participant had a very positive experience with her HCP, characterized by belief, support, and prompt action.

[Group 1] Caitlyn: *I had gone to the doctor saying, "I am in this relationship, I want to, you know, he's having difficulty penetrating," and he said, "Okay, let's stick you on the waitlist for the gynecologist." That was it. He didn't question it. Which was quite amazing.*

Some participants suggested that their HCPs lacked knowledge about the condition, as well as time or resources with which to educate themselves.

[Group 1] Barb: *I find that most doctors just don't know anything about it.*

[Group 2] Gabriella: *It took a long time to get in and see [the gynecologist K.B.]. I'm thinking a year and half. So in amongst that time, I was tested for STDs, early menopause. My doctor did not have any clue as to what it was, and basically, she [K.B.] was a last resort.*

[Group 3] Haley: *No one can tell you what's wrong with you, and I really thought my life was over.*

[Group 2] Gabriella: *And maybe part of the problem there is [that HCP are] not given the time to go and educate [themselves], you know what I mean? [...]*

Fay: *I'm pretty sure there's a reference book somewhere he could have looked in [...] But again, [HCP don't have time because their schedules] are like appointment, appointment, appointment.*

Many participants identified a gendered element to the treatment of sexual health and pleasure. They felt that sexual health issues having to do with vulvas and largely affecting ciswomen<sup>¶</sup> are taken less seriously than those that involve the penis and largely affect cismen. In a telling moment, Edith [group 2] turned to her infant son sitting in her lap and said: "You're so lucky to have a penis, buddy." This sentiment was evident in how participants perceived their difficulties accessing treatment in a timely manner, an issue addressed in the next section.

### Challenges to Treatment: Opportunities for Tertiary Prevention

Participants generally agreed that receiving a diagnosis, often after a long period of frustration and uncertainty, helped them to move forward by offering hope, validation, and an action plan.

[Group 2] Fay: *It's easier to kind of like gain more knowledge, like google it on the internet and um, just in her [K.B.] knowing about it and she put me on to physio and numbing cream and stuff like that to help manage. I felt a lot better because somebody had*

¶ Cisgendered and the prefix "cis" means that an individual's gender identity corresponds to gender norms associated with the sex that they were assigned at birth.<sup>17</sup> A ciswoman is someone who was assigned female at birth and identifies as a woman, and a cisman is someone assigned male at birth who identifies as a man.

said, like, “Okay, this is what’s wrong with you and this is how we fix it.” So, or not fix it but manage it.

[Group 1] M.E.M. [researcher]: Did actually getting a word, or a diagnosis of something, change your outlook at all about how you experience or feel about the condition?

Danielle: Hope.

Caitlyn: Relief for me, it’s just like this is not just in my head; it’s not just something psychological [...]

Barb: I was, I felt a lot of reassurance, finally someone was taking me seriously. [...]

Abbey: I kind of felt validated I think, like that this is actually really, this is not something that is in my head, this is a real thing and people have heard about it and there might be something that I can do; that this is not normal, this is not what everybody goes through, but maybe there is something that can make sex fun.

Internal physiotherapy was named as one of the most effective treatments by many of the participants as an initial treatment and for continued self-management.

[Group 3] Haley: I went in and saw [the physiotherapist] and she like changed my life. [...]

Janice: It’s crazy what a difference it makes if you just see the right person. Like it’s not about drugs, it’s just about learning how to, to-, that’s all it took.

[Group 3] Janice: [Physio helped with] being able to manage it, because learning those skills through physio, when I felt it come on or I could feel-, I learned to manage it going forward, so it didn’t have to get to that point again. So that was a big help for me.

Unfortunately, while diagnosis and physiotherapy had a positive effect, there are many barriers to receive this care. If symptomatic persons in NL are identified by their HCPs, they may need to travel significant distances for consultation with the province’s only pelvic pain expert (author K.B.) for evaluation, diagnosis, and initiation of treatment. The wait list for her services can be upwards of 2 years. Furthermore, treatments such as pelvic physiotherapy and counseling are extremely limited or unavailable throughout the province.

Participants in our groups had tried 3–6 different treatments with varying degrees of success (Appendix B). Other evidence-based methods for treatment of vulvodynia such as sex therapy and coping strategy counseling were routinely offered but underused. This may be due in part to the many barriers to receive interdisciplinary treatment: long waitlists, lack of appropriately trained experts, limited scheduling and insurance options, and rurality. At the same time, participants reported tremendous benefit in quality of life after initial management by the pelvic pain specialist and internal physiotherapy. Internal physiotherapy empowered participants by giving them some control and agency over their treatment, reducing their distress, and improving their quality of life. There is only 1 part-time practitioner funded by

the provincial health plan, whose services are only available in the capital city of the province. Privately funded therapists in NL have variable levels of training in internal physiotherapy for pelvic pain. Participants perceived this as a lack of care or concern on the part of the health system.

[Group 1] Danielle: The fact that there’s a, there’s like one specialist here, and she can’t get full time hours after wanting them, they obviously don’t see it as being important [...] there was a waitlist as long as your arm, I was trying to go out of province and almost did to get treatment for this, and she wants more hours and they [the Health Authority] won’t give them to her, so obviously they don’t see it as a priority.

[Group 2] Edith: I think my biggest issue is just the wait time to get into the physio. [...] I had to wait like a year to get in, but then I was happy I was in. Like after a couple of weeks I was already seeing some little improvement [...] I can’t see someone privately right now because my graduate insurance is only like \$300 a year so it’s just not an option. [...] I’m a full-time student [...] I don’t know what, like if I’m even going to fit with her schedule. So that will be a barrier if that comes, yeah, for sure.

[Group 1] Abbey: I moved to a very small, small isolated community [...] and like people knew my shoe size, you know, by the time I was there for a week. The service was not available, but even if it had been, I would have been like no, not going to expose myself that way, definitely not.

[Group 2] Fay: I’m up in [an area outside of St. John’s] right now, and I don’t have access to nothing [laughs] but thankfully I’ve kind of been discharged from physio and been able to manage on my own, but if I was in a situation where I couldn’t, I don’t know, maybe I wouldn’t have moved [...] I doubt that outside of St. John’s you would find [a physiotherapist that does this type of work]. [...] Women’s health issues in general have not received as much research or as much funding. The fact that there’s only one physiotherapist that you can get through MCP [the provincial public health insurance], and the waitlist is a year, so that shows like that there is a need for more.

Our study revealed an additional opportunity for tertiary prevention: education that normalizes non-penetrative sex play. Participants reported that they were often confused or surprised when HCPs suggested they engage in “foreplay” activities as an alternative to intercourse. As members of focus group 2 discussed,

Gabriella: When [the gynecologist] said, “You don’t need to have [penetrative] sex,” I thought, what do you mean?

Fay: Yeah, and even if there is intercourse, that warming up [...]. Many women need some warming up anyways, but yeah, for us in particular. It’s definitely knowledge that’s beneficial.

On this particular note, some lamented the lack of resources for their partners, and that having supportive partners’ willing to discuss and try alternatives to vaginal intercourse was invaluable.

[Group 2] Gabriella: Even a pamphlet, I don’t know, for men, or information for the partner of the woman, whatever. I mean,

*because my partner was really good about it and he said, "Okay, let's try this." Well, what if they weren't, you know?*

*[Group 2] Fay: I've learned more about boundaries and communication and things and like what I'm looking for in a male partner, that is open to discuss these things and cares.*

## DISCUSSION

Our research is consistent with the existing literature regarding (i) the experience of attempting to receive a diagnosis for vulvar pain; (ii) the benefits of receiving a diagnosis; and (iii) the barriers to accessing treatment. Notably, participants reported deferring presentation for care or advocating for themselves with their HCP about the significance of their pain because of their (and their partners') understanding of what constituted a "normal" penetrative sexual encounter. While much of the existing literature focuses on diagnosis and treatment, our data highlight that to have a significant and sustained impact on the quality of life of persons with vulvodynia, the condition needs to be viewed within the disease prevention framework of primary, secondary, and tertiary prevention.<sup>16</sup>

Many participants reported a lack of knowledge and comfort in discussing their sexual health. Our findings suggest that providing education and normalizing discussion about sex constitutes an important strategy for primary prevention by educating patients and their partners regarding sexual function and problematic symptoms that should prompt evaluation before they worsen, and normalizing discussion of sexuality to enable patients to feel comfortable seeking evaluation. Familiarizing patients and partners with a breadth of non-penetrative sexual acts also lowers barriers to having fulfilling sexual experiences after symptom onset. This point is discussed in further detail below in the discussion of tertiary prevention.

We understand that advocating for education is broad and complex. However, the United Nations Educational, Scientific and Cultural Organization guidelines explicitly state that sexual education should enable learners to "recognize that understanding their body's sexual response can help them understand their body and can help identify when things are not functioning properly so they can seek help."<sup>18</sup> Similar to us, other studies report that people with vulvodynia are uncomfortable speaking about vulvar pain—be it with HCPs, sexual partners, family, or friends—because of the perceived intimacy of the condition.<sup>19–21</sup> Comprehensive sexual education might better equip all parties—patients, their partners, and HCPs alike—with a level of relative comfort in discussing sexuality and genital sensation.

Our research underscores that sexual education and conversation is needed not only as a form of support or counseling on a vulvodynia diagnosis but long beforehand when youth are first forming their sexual scripts. Educating youth before the onset of sexual activity that pain is not a normal or acceptable consequence of vaginal intercourse may empower partners to seek

earlier medical assistance where pain is persistent. Much research has shown the benefits of sexual education that focuses on the positive aspects of sexuality rather than adverse consequences and that celebrates a breadth of consensual sexual activities.<sup>22–25</sup>

Canadian and international guidelines for sexuality education best practices already call for curriculum that (i) emphasizes sexual consent, communication, and pleasure; (ii) addresses how sociocultural, peer, media, gender, and other norms influence our interpretation and experience of sexuality; and (iii) validates a wide array of sexual behaviors, practices, and identities.<sup>18,26</sup> Sexual education is inconsistent and rarely meets all the suggested criteria, both in Canada and globally.<sup>27</sup> Our study suggests that in addition to whatever other undesirable outcomes such oversight may entail, this also has a negative impact on the early identification of vulvodynia and that delivery of guideline-based sexual education has an important role to play in improving LPV and possibly other pelvic pain condition outcomes.

Secondary prevention strategies are aimed at early detection and treatment. Our study supports previous findings that HCPs have insufficient awareness of and exposure to vulvodynia, thus often have difficulty identifying these symptoms as clinically relevant.<sup>8,28–30</sup> This poses a major barrier to accessing treatment. Research shows that sufferers see an average of 5 physicians before receiving a diagnosis,<sup>31</sup> leading many to report feeling judged, dismissed, or disbelieved by HCPs.<sup>9,10,32–35</sup> This contributes to patients' self-doubt, frustration, despair, wavering confidence in the medical system, and their need to become advocates for their own care.<sup>9,10,36,37</sup> Particularly in regards to health concerns that predominantly affect ciswomen, some suggest that misogynistic ideology encourages HCPs to evaluate certain patients as hysterical, neurotic, or uptight<sup>37</sup> and to provide unhelpful advice.<sup>38</sup> Participants in our study echoed many of these sentiments. Insensitive advice such as "get your mind off of it" or "do not focus on the pain" leaves patients feeling dismissed and that their vulvar sexual health issues are not taken seriously. Participants universally supported increased training for HCPs with respect to diagnosis, treatment, and approach to persons with vulvodynia. Our research also aligns with others<sup>10</sup> about what constitutes a positive experience: HCPs who listen to and acknowledge the pain, admit when it is beyond their knowledge base, and make prompt and appropriate referrals. It is important to acknowledge that dictating increased education for HCPs is not a guarantee of meaningful retention of knowledge or increased positive patient interactions.<sup>39–42</sup>

Several studies note that HCPs may be reluctant or uncomfortable discussing sexual matters or doing pelvic examinations because of their own discomfort or their patient's perceived discomfort.<sup>8,34,43,44</sup> The Society of Obstetricians and Gynecologists of Canada clinical guidelines expect HCPs to create an environment that invites discussion of sexual matters.<sup>45</sup> Such conversations ought to be initiated without patient prompting because patients want their HCP to open such dialogue.<sup>43,45</sup>

Hesitancy on this matter represents an important barrier to diagnosis. Patients should be given the opportunity to discuss sexuality regularly, yet one Canadian survey calculates that only 16% of OBGYN outpatient clinic attendees with sexual health concerns had ever discussed these with their HCP.<sup>46</sup>

Tertiary prevention is aimed at reducing the burden of disease.<sup>16</sup> Our research confirms what others have found that a diagnosis can provide relief because it offers validation, a framework, and the vocabulary for moving forward.<sup>9,10,30,34,35,37,38,47</sup> However, a diagnosis does not guarantee access to treatment. Consistent with previous studies, many of our participants expressed positive responses to interdisciplinary vulvodynia treatment when they could access it, but such treatments were complicated by inconsistent care teams, a lack of specialists in the area, limited access to provincially funded therapists, or coming with a high private healthcare cost.<sup>6,9,36,47,48</sup> In addition, participants in our group suggested that even if such resources were available closer to home, they were unlikely to avail of them owing to the lack of anonymity in smaller communities.

Any recommendation for enhancing vulvodynia treatments must consider the unique challenges of small urban, rural, and remote geography. NL has high annual per capita healthcare costs (\$7,443 compared with the national average of \$6,839).<sup>49</sup> Funding tends to prioritize the high rates of chronic disease,<sup>50</sup> validating a health paradigm that ranks the diagnosis and treatment of life-threatening issues (a downstream approach to health) over preventative strategies that minimize the development or impact of disease and enhance quality of life (an upstream approach to health). As the burden of vulvodynia is underappreciated, all aspects of the condition—sexual education, HCP training, and access to publicly funded validated treatments—are underfunded.

An often overlooked element of the burden of disease is vulvodynia's impact on sexual wellness and satisfaction. To this end, our study contributes to a small but powerful subset of literature<sup>19,20,32,33,38,51–54</sup> that explores how gendered sexual norms influence and exacerbate individuals' subjective experience of vulvodynia symptoms and diagnosis. Participants had been surprised by HCP suggestions that they engage in non-penetrative alternatives to intercourse as a way to enjoy sexual activity without aggravating symptoms. This suggests that the burden of disease could be reduced by using the aforementioned educational resources to challenge sociocultural norms that center vaginal intercourse is the “organizing feature of heterosex,” frame other sexual activities as simply foreplay, and suggest that sexually active people with vulvas should prioritize vaginal intercourse as the goal of sexual expression.<sup>51</sup>

Shallcross et al<sup>33</sup> also conclude that a critique of cisheteronormative and phallogocentric sociosexual narratives is needed to effectively address vulvodynia, in addition to researching effective therapies. Indeed, patients with vulvodynia as participants in Groven et al<sup>38</sup> felt that fostering a broader concept of sexuality

beyond vaginal intercourse enabled them to enjoy a more fulfilling sex life. Several studies have found that patients and their partners are interested in including sex therapy as part of their treatment<sup>9,55</sup> and that more open, cooperative sexual communication patterns between partners is associated with greater sexual and relational satisfaction for both partners, reducing the burden of vulvodynia on the couple.<sup>56</sup>

## LIMITATIONS, STRENGTHS, AND FUTURE RESEARCH DIRECTIONS

### Limitations

This is a small qualitative context-specific project using convenience sampling, therefore we cannot claim population representativeness. Specifically, our sample overrepresents participants who were living in a small urban setting at the time of diagnosis (8 of 10). Focus groups rely on self-reporting, which runs the risk of volunteer and recall bias. They may fail to capture as much depth as individual interviews. No participant offered an exceptional outlier experience during the focus groups; however, there is the possibility that speaking in the presence of other participants may cause some to concede to the majority self-censor or self-aggrandize.<sup>14</sup>

### Strengths

Focus groups are ideal for capturing a breadth of experience, which is useful for hypothesis generation, and practice and policy recommendations.<sup>14</sup> Case studies are beneficial for unpacking how environment and context influence individual and collective experience.<sup>13</sup> This process of contextualization is relevant to research and practice in other locations, regardless of whether they share specific geographic or demographic qualities and characteristics. Our use of hand coding was another strength. Although the use of qualitative data analysis software is popular with some qualitative researchers, there has not been a robust analysis of the impact of software on the validity and reliability of findings, and concerns have been raised that software cannot capture all forms of meaningful data or leads to the overproliferation of codes to the detriment of the bigger picture.<sup>57,58</sup> We assert that when the volume of data is relatively small and manageable (as with this study), hand coding results in quality analysis because it produces a thorough appreciation of the data, as researchers must become intimately familiar with transcripts.

### Future Research Directions

Looking at a single case or phenomenon from multiple perspectives enables a “richer” (albeit not complete) “portrayal of reality.”<sup>13</sup> As such, the second, ongoing phase of this project (HREB #2018.123) involves conducting focus groups with HCPs across the province about their experience, knowledge, and attitudes toward vulvodynia, to determine the type and format of resources they would find helpful. The final phase of this project aims to develop said resources.

## CONCLUSION

The burden of vulvodynia cannot be underestimated, especially for those living in small urban, rural, and remote communities. Our study suggests that an undervalued avenue to reduce this burden is preventative. Primary prevention in the form of a comprehensive sexual education curriculum could enable earlier identification and reporting of problematic pain by patients and their partners. Secondary prevention calls for increasing HCP awareness of the condition itself and encouraging HCP to initiate discussions about sexuality, leading to expedited diagnosis and referral to treatment. Tertiary prevention entails directing sufficient resources toward these treatments to reduce the morbidity of vulvodynia and using education to broaden sexual scripts, enabling those living with vulvodynia and their partners to enjoy alternatives to vaginal intercourse.

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## SUPPLEMENTARY DATA

Supplementary data related to this article can be found at <https://doi.org/10.1016/j.esxm.2020.07.001>.