ORIGINAL ARTICLE

The impact of rurality on vulvodynia diagnosis and management: Primary care provider and patient perspectives

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Abstract

Objective: The objective of this study was to better understand how rurality impacts the knowledge, diagnosis and management of vulvodynia by primary care providers (PCPs) practising in the geographically disparate province of Newfoundland and Labrador, Canada.

Design: This was a qualitative case study using questionnaires and semi-structured interviews with PCPs, compared with semi-structured focus groups and interviews with vulvodynia patients conducted in a previous study phase.

Results: Ten family physicians and 6 nurse practitioners participated. Over half had baseline knowledge that vulvodynia has a relatively high prevalence, but most underestimated the likelihood they would see a patient with vulvodynia in their practice. Three barriers to discussing and managing vulvodynia emerged: (1) discomfort initiating sexual/vulvar health conversations; (2) concerns about protecting patient privacy and confidentiality; and (3) time constraints and building therapeutic relationships. These issues were largely corroborated by previous findings with vulvodynia patients. Rural-informed solutions might include: (1) supporting increased education in vulvodynia and sexual health more broadly, including funding to attend continuing professional education and developing more clinical tools; (2) following practice guidelines regarding standardised initiation of sexual health conversations; (3) incentivising retention of rural providers and extending appointment times by reconsidering fee-for-service structures; and (4) researching a tailored vulvodynia toolkit and the potential advantage of mobile health units.

Conclusion: Rurality exacerbates common concerns in the identification and management of vulvodynia. Acting on recommended solutions may address the impact of rurality on the provision of timely care for those experiencing vulvodynia and other sexual health concerns.

Keywords: Dyspareunia, family physician, fee structures, geographic disparities in healthcare, healthcare administration, nurse practitioner, qualitative case study, qualitative research, rural health, sex education, sexual health, vulvar pain

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Résumé

Objectif: Mieux comprendre l'impact de la ruralité sur la connaissance, le diagnostic et la prise en charge de la vulvodynie par les prestataires de soins primaires exerçant dans la province géographiquement disparate de Terre-Neuve-et-Labrador, au Canada.

Conception: Étude de cas qualitative utilisant des questionnaires et des entretiens semi-structurés avec des prestataires de soins primaires, comparés à des groupes de discussion semi-structurés et à des entretiens avec des patientes atteintes de vulvodynie menés lors d'une phase précédente de l'étude.

Résultats: Dix médecins de famille et six infirmières praticiennes y ont participé. Plus de la moitié d'entre eux savaient au départ que la vulvodynie a une prévalence relativement élevée, mais la plupart sous-estimaient la probabilité de voir une patiente atteinte de vulvodynie dans leur pratique. Trois obstacles à la discussion et à la prise en charge de la vulvodynie sont apparus: (1) la gêne à entamer des conversations sur la santé sexuelle/vulvaire; (2) les préoccupations relatives à la protection de la vie privée et de la confidentialité des patientes; et (3) les contraintes de temps et l'établissement de relations thérapeutiques. Ces problèmes ont été largement corroborés par les résultats obtenus précédemment avec des patientes atteintes de vulvodynie. Les solutions adaptées au milieu rural pourraient inclure (1) soutenir une meilleure formation sur la vulvodynie et la santé sexuelle en général, notamment le financement de la formation professionnelle continue et l'élaboration d'outils cliniques supplémentaires; (2) suivre les directives de pratique concernant l'amorce normalisée des conversations sur la santé sexuelle; (3) encourager la rétention des fournisseurs ruraux et prolonger les délais de rendez-vous en reconsidérant les structures de rémunération à l'acte; et 4) faire des recherches sur une trousse d'outils sur mesure pour la vulvodynie et sur l'avantage potentiel des unités de santé mobiles.

Conclusion: La ruralité exacerbe les problèmes courants liés à l'identification et à la prise en charge de la vulvodynie. La mise en œuvre des solutions recommandées peut permettre de remédier à l'impact de la ruralité sur la fourniture de soins en temps opportun aux personnes souffrant de vulvodynie et d'autres problèmes de santé sexuelle.

Mots-clés: Douleur vulvaire, dyspareunie, santé rurale, santé sexuelle, éducation sexuelle, structures tarifaires, administration des soins de santé, disparités géographiques dans les soins de santé, recherche qualitative, étude de cas qualitative

INTRODUCTION

We know a lot about the barriers to screening and diagnosis of vulvodynia, a surprisingly prevalent condition affecting up to one in four people with vulvas.[1] (While we use the term 'woman' and 'women's health' throughout the manuscript when repeating participants' language, appropriate gynaecological care must respect the gender diversity of people with vulvas. Failure to do so results in poor healthcare outcomes.)[2-4]

There are several reasons to question how the rural context may exacerbate challenges with vulvodynia diagnosis and treatment.[5-7] Smaller, more intertwined communities pose an increased risk of breaching 'internal confidentiality'[8] and this may increase patient discomfort in initiating sexual/vulvar conversations. Rural populations are older,[9] and may be less comfortable initiating discussion of sex. At the same time, primary care providers (PCPs) are less likely to question older adults about their sexual health.[10] Rurality is often associated with fewer opportunities for sexual education,[11] which increases the likelihood people will think pain is normal.[12] Finally, while time constraints are a problem across healthcare settings, rural PCP-to-patient ratios are generally lower than in urban centres, due to fewer PCPs practising in rural areas and lower retention of those providers.[13] In addition, rural family physicians often fill multiple healthcare roles, which may result in having less time for office-based primary care.[14]

Our study looked at rural and small urban PCP attitudes and experiences with vulvodynia, corroborated by patients' experiences receiving diagnosis and care, as part of a three-phase, patient-engaged, qualitative case study in Newfoundland and Labrador, Canada. It compares patients' perspectives on the diagnosis and treatment of vulvodynia (collected in Phase 1) with the perspectives of family physicians and nurse practitioners (collected in Phase 2). Our results offer insights into potential solutions for rural contexts, organised into four strategic pillars – education, policy, practice and research.

METHODS

Phase 1 was a qualitative study of 10 NL patient participants and has been published.[12] Participants were identified through patient records from the pelvic pain practice in St. John's of KB. The clinic is the only specialised one in the province, and patients were invited to participate in a focus group. Three groups were held, running 1–2 h each, and were audio-recorded. A focus group interview guide was used to stimulate patient-generated narratives about the challenges of receiving a vulvodynia diagnosis and treatment. Demographic data and treatment histories were also collected from participants. To enhance validity and increase participant agency, transcripts were returned to their respective group members for comment, as were anonymised summaries of the study as a whole. No revisions were requested. Data were then analysed and independently hand-coded by two researchers using inductive thematic coding.[12]

Phase 2 collected data on PCPs' perspectives on barriers to diagnosis and treatment for vulvodynia. Study information was distributed at two PCP provincial health conferences and to regional health authorities and professional peer groups via newsletters, E-mails and closed social media. Research collaborators carried out secondary, arms-length recruitment. Snowball strategies were also used. Self-selecting individuals were given additional information before providing written consent. Participants first completed a 22-item questionnaire collecting demographic information and baseline knowledge of vulvodynia. Semi-structured interviews were conducted in person or via teleconferencing between October 2018 and April 2019. Interviews lasting 30–90 min were audio-recorded, transcribed verbatim and de-identified.

Transcripts were independently read, emergent ideas tagged and initial codes created. Codes were populated with supporting participant quotations, merged, and collapsed. Codes were synthesised until the authors agreed that the meaning of the codes (meaning saturation) was well described and understandable.[15] Phase 2 PCP themes were compared with Phase 1 patient themes, and areas of overlap identified.

Both study phases were approved by Memorial University's Health Research Ethics Board (Phase 1: HREB #2015.049; Phase 2: #2018.123).

RESULTS

Ten family physicians and 6 nurse practitioners responded to the questionnaire and participated in individual and paired interviews. Twelve identified as women and 4 as men. Ages ranged from 35 or younger (n = 4), 36–45 years (n = 4), 46–55 years (n = 6), to over 55 (n = 1) and no data (n = 1). Years in practice varied: <5 years (n = 6), 5–10 years (n = 3), 11–19 years (n = 3), 20+ years (n = 3) and no data (n = 1). Ten of 16 held university appointments or were university affiliated. Participants practised across the province, with 7 practising in the main urban centre of St. John's, which is home to the only tertiary referral centre and specialised vulvodynia resources in the province. Four more participants were located within 3.5 h of it. Participants practising outside this region reported that their patients had to travel 3.5–12 h by car or, in the case of Labrador on the Canadian mainland, had to travel by air to access resources.

While 56% of PCPs (9/16) reported the prevalence of vulvodynia to be 10% or higher, 94% (15/16) said that they 'rarely' or 'never' see affected individuals. Taking a sexual history was considered a requirement by 75% (12/16) of participants. None were aware that the cotton swab test[16] was the recommended physical examination tool for localised provoked vulvodynia. The majority (15/16) of PCPs were able to list at least one appropriate differential diagnosis for vulvodynia, and half correctly identified some of the treatments often used. The majority (14/16) of participants correctly identified that a multidisciplinary approach to vulvodynia treatment was appropriate. Thirty minutes or longer was considered an appropriate amount of time for a vulvodynia office visit by 81% (13/16).

Three barriers to diagnosis and treatment were: (1) initiating sexual/vulvar health conversations; (2) managing patient privacy and confidentiality and (3) addressing time and educational constraints that limit building therapeutic relationships. Each concern is described and supported with Phase 1 patient data.

Initiating sexual/vulvar health conversations

Primary care provider data

Many PCPs said that it was uncomfortable or inappropriate to initiate a conversation about a patient's vulvar or sexual health in the absence of patient prompting:

> I don't ask a woman who is not offering to talk about her vagina, how her vagina is doing (or) if she's having sex. It wouldn't be really that appropriate. (PCP1)

PCPs speculated that patients may be embarrassed to discuss sexual health concerns for fear of being seen as abnormal.

> I think the biggest challenge is that it's not brought up. Because it's seen as some sort of fault of the woman herself, you know, *there is something wrong with me* [...] And the few times that it has come out, I've always thought to myself, *oh no, I should've asked about this years ago*. (PCP4)

It was evident that PCPs experienced discomfort, even in the context of the research interview, as noted in PCP3's hesitation:

> [Sex] is never an easy thing to discuss [...] So, this is certainly a weakness of mine, I have gotten no proper training, so I would always struggle with a case like this, if someone has pain with-, with-, with sex.

According to PCPs, patients were less likely to initiate conversations about sexual pain when they thought pain was expected.

> If you asked about painful sex, they'll say everything is fine. Like they are just coming in for their regular Pap or mammogram requisition or whatever. And then you are going down through, and you say *any pain in sex?* and they say *yes*. When they had just said everything was fine. I think a lot of women, probably menopausal women, in particular, think it's normal and they think that if they are having discomfort, it's menopause or it's just what happens, and they probably don't present it as a problem. (PCP12)

Gender discordance was another issue.

> I don't see many women with complaints. They don't tell me, at least about sexual problems, to be honest. [...] About three-quarters of our [clinic] providers are women, and they are more likely to go to a woman to speak about those issues, I suspect, than myself [a man]. (PCP16)

Age discordance between PCP and patient also exacerbated disclosure discomfort:

> Sometimes the kids will hold things back because they were embarrassed, you know they were dealing with an older male physician, so they didn't want to discuss some elements of their history. (PCP10)

Pap tests have traditionally been an ideal time for a routine check-in about sexual health, but these occurred less often as screening recommendations shifted:

> We're doing Paps every three years with the new guidelines. [Vulvodynia] is maybe not something that comes up outside of those times if you are not screening for it. (PCP5)

Given the infrequency of a routine opportunity for screening, PCP3 suggested this strategy:

> A little pamphlet that's floating in our bathroom, so it's a little more discreet. Or some way for patients to access a little bit of information which might inspire them to discuss it.

Linking vulvodynia screening questions to another screening visit such as STI testing was suggested as an appealing way to overcome discomfort for both the patient and PCP.

> I think one needs to actually incorporate having direct questions [about sexual/vulvar health], […] I think it would be easy for a woman to answer a direct question. But to just bring it up as a complaint, I don't think they often know, *'is it something that I even talk about to a physician?'*.(PCP4)

Patient corroboration

Phase 1 patient data elicited similar themes. Patients described how it feels inappropriate to raise vulvar/sexual health unless prompted by the PCP, particularly if one believed their pain was 'normal':

> I just thought this is me. This is normal [...] not really realizing that this isn't normal, and that this kind of pain doesn't have to be this way. [...] I need [the doctor] to ask. (Janice [Patients identified with pseudonyms]).

Routine screening questions may normalise sexual health conversations that might otherwise be considered uncomfortable or inappropriate territory when raised by either PCP or patient.

> It's not something you're comfortable bringing up. At least I wasn't. And I didn't know it was an actual problem for a really, really long time […] until it got so hurtful […] if I was asked questions and educated, I think I would have gotten help a lot sooner. (Pam)

Some patients said that they lacked the language to describe the problem, posing a barrier to diagnosis.

> I remember going to my family doctor and not really knowing the words to say, just saying *we are trying to have sex and it's not comfortable, it's very uncomfortable*. But I never would have thought to, or probably even at that point been able, to say, *we can't penetrate*. (Abbey)

Interestingly, patients did not explicitly identify age and gender discordance as a barrier to initiating a conversation. Danielle suggested that such preferences are 'personal depending on the individual' and that she 'really [doesn't] care: Male, female; my doctor is male'.

Managing patient privacy and confidentiality

Primary care provider data

PCPs expressed concern about respecting patient privacy and confidentiality. PCP9 said, 'Sometimes in a small community, it may be uncomfortable [to discuss vulvar pain], because you know people personally, or I know them professionally'. Another said:

> I had some difficulties [discussing sexual health], usually with patients who were young. Because I practise in a rural area, so I had often looked after them since they had been--you know, I delivered them, looked after them, and also looked after their parents. So, sometimes that would be a little uncomfortable, mostly for the patient. (PCP10)

Patient corroboration

Patients discussed similar concerns about access to confidential care.

> I moved to a very small, small, isolated community on the south coast, and like people knew my shoe size by the time I was there for a week! So, the service [internal physiotherapy] was not available, but even if it had been, I would have been like no, not going to expose myself that way. Definitely not. (Abbey)

Addressing time and educational constraints that limit building therapeutic relationships

Primary care provider data

Time constraints in medical training and healthcare are ubiquitous and perennial. Most PCPs reported receiving minimal or no training in vulvodynia and other pelvic pain conditions. As one PCP bluntly stated, 'I have never seen this word [vulvodynia] before in my training' (PCP12). Another explained:

> Even though I do a lot of women's health, I feel like it is a big knowledge gap for me. And in med school, I don't ever really remember learning much about it. I might have had a clinic during my gyne rotation and clerkship and that's probably it. (PCP15)

PCP3 suggested self-study tools, and professional development sessions for improving PCP awareness of vulvodynia.

> An online module would be something I would certainly do if I had the opportunity […] But that should be fairly concise and nothing too long-winded, something straight to the point, right? You know, three, four pages max.

However, many described a lack of time or motivation to address this knowledge gap, since vulvodynia was seen as a niche concern, deprioritised in training as less urgent or prevalent than other medical conditions. PCP6 put it this way: 'I think people might not make the time to learn about [vulvodynia] because it doesn't present that commonly'. PCP1 agreed. 'We got a million different things coming at us all the time. So [vulvodynia] just ends up on the pile of things that you need to learn more about'. These statements highlight misinformation about the prevalence of

vulvodynia and the knowledge required to identify it as the common problem it is.[1]

Even when educated and motivated to address sexual health, time was still 'the biggest barrier' (PCP15). Educational opportunities are also more limited in rural areas, meaning PCPs who would like to deepen their knowledge require more time and resources to do so: 'CMEs [continuing medical education] are always good [for gaining more knowledge of a subject], but location is always a barrier'. (PCP3)

> Any educational opportunity that is within my timeframe that I can avail of, I try to, right? [...] I'm a twelve-hour drive away from […] St. John's, where everything usually takes place […] I'm not going to take off work very easily for that. (PCP8)

Limited time for patient appointments also impedes conducting a sexual health history and working through a differential diagnosis. Building a comfortable relationship between patients and PCPs enabled the discussion of sensitive topics:

> I'm able to interview the patient first and have a therapeutic relationship with them and then they feel more comfortable. So, when they get their Pap, they are not as uncomfortable because we already have a relationship built. (PCP11)

PCPs agreed that it takes time to build relationships and opportunities for disclosure.

> Not everyone will take the time to do a really thorough sexual health history. They don't come in and say they are having *female sexual pain* or whatever. It usually gets revealed some other way. (PCP15)

The diagnostic process takes considerable time: 'I think the other huge barrier is the amount of time it would take, like if I went through that differential diagnosis [...] I think it would take me like five office visits' (PCP6). Several PCPs suggested that a simplified algorithm or flowchart may expedite the process:

> A nice one-page algorithm poster [...] saying *do this, rule out that, work your way through, try this next*, that kind of a thing. (PCP3)

The fee-for-service structure also disincentivises PCPs from taking the time necessary for a sexual health interview:

> [It's] not only lack of time [that is the problem], but lack of compensation. Because these are long interviews and you have to work somebody into telling you this intimate stuff and if at the end of the day you are gonna get 32 dollars out of it, you can't just make a living out of it. (PCP15)

Patient corroboration

Patients also reported that vulvar conditions are under-prioritised: 'women's health issues, in general, have not received as much research or as much funding' (Fay). Fay, in talking with Gabriella, further noted how their family physicians lacked the time to research the topic:

> Gabriella: Maybe part of the problem is [the GP] is not given the time to go and educate himself [...]
>
> Fay: I'm pretty sure there's a reference book somewhere he could have looked in but yeah, again, the time. It's like, *appointment, appointment, appointment*.

Patients described the enormous impact such deprioritisation had on their lives:

> We didn't have a second child because of this [...] By the time it got fixed, I'm 41 now, so by the time we went through [diagnosis and treatment], then it was like now I'm older, the risk of having issues [is greater], and my husband was like *'do you really want to go through that again?'*. (Danielle)

DISCUSSION

We found solutions for improving diagnosis and management of a common sexual health problem through a rural lens are key to building regional capacity through four strategic pillars: education, practice, policy, and research.[17]

Education solutions

Broader-based sexual health education is needed for patients and PCPs. The upstream solution for PCPs is to increase sexual/vulvar health content in medical and nurse practitioner curricula. This supports previous research regarding PCPs' lower comfort levels when assessing sexual

health.[18] Diverse teaching and learning strategies have been shown to improve knowledge uptake.[19] In this situation, curriculum planners might encourage reflective learning when examining gender-role norms.

The effectiveness of standard continuing professional development (CPD) programmes for improving rural PCPs' professional practice and patient outcomes is unclear.[20] CPD modules devised through a rural lens and succinct and accessible resources about sexual/vulvar health may fill knowledge gaps with the benefit of being widely available regardless of scheduling or geography. Funding and paid time off to participate in CPD has also been ranked as extremely important for recruiting and retaining rural practitioners in Canada.[21]

Creative knowledge translation solutions that consider the unique rural practice environment may enhance knowledge uptake and reflective practice that benefits both PCPs and patients.[19] Office tools developed and tested with patient and PCP collaborators may include social media and other awareness campaigns as well as pamphlets or posters for clinic waiting rooms and bathrooms.

Practice solutions

Patients and PCPs agree that initiating conversations about sexual/vulvar health can be uncomfortable. The Society of Obstetricians and Gynaecologists of Canada Sexual Health Consensus Guidelines[22] provide sexual health screening questions, but access is limited to membership or academic affiliation. Developing practice solutions based on these guidelines and tested by local PCPs and patient collaborators may have a greater impact because they have stakeholder buy-in.

The good news is that patients expressed less concern about gender and age discordance than PCPs perceived. The greater barrier to sexual/vulvar health conversations was sufficient knowledge and comfort discussing sensitive topics. According to the SOGC guidelines,[22] patients want their PCPs to initiate these conversations regardless of their own comfort with sexual topics. Our research supports this guideline and further suggests that patients want this regardless of the gender of their PCP. Therefore, it is incumbent upon PCPs to address their knowledge gaps and comfort issues, so they can establish a therapeutic relationship that invites patients to speak about their sexual health concerns.

Further practice solutions to support conversation and diagnosis may include visual aids to explain anatomy to patients and algorithm posters to direct initial diagnosis, investigation, and management of vulvodynia.

Policy solutions

In 2022, the WHO proclaimed that sexual health is a 'fundamental' component of overall health and well-being.[23] The current time-constrained environment and fee-for-service structure disincentivises how PCPs allocate time for comprehensive assessment. Our results add to the ongoing debate about the efficiency and productivity of Canadian physician fee structures.[24] Even if remuneration were sufficient, the amount of time needed might still pose a barrier to PCPs in rural and small urban communities already overburdened by patient volume. Appropriate remuneration, screening tools and blended or stepped care models are potential solutions for maximising time and resource allocation as is more effectively using nurse practitioners in rural communities.[25]

PCPs and patients agree that there is currently no routine trigger for initiating a sexual health conversation since the annual gynaecologic assessment, the 'Well Woman Visit' (the authors recommend moving away from such gendered terminology), was eliminated due to waning evidence in support of annual Pap and breast cancer screening.[26,27] Further research is needed to determine ideal alternative opportunities to initiate a conversation about sexual health that would both provide adequate screening for these concerns while remaining feasible within the busy practice of rural PCPs.

Research solutions

Phase 3 of our research will develop and evaluate a guideline-based 'toolkit' for assessment, diagnosis and treatment of vulvodynia, including local resources created according to practitioner-identified preferences for content and format. An effective toolkit would also provide a common language to address communication barriers.[28]

Partnering with provincial medical and nursing associations to conduct a nationwide survey of PCP awareness of vulvodynia may reveal important gaps in the knowledge about vulvodynia that falls along the rural-northern-urban divide.

Promising research has illustrated the success of mobile health units for addressing the needs of marginalised populations such as Indigenous peoples,[29] immigrants[30] and the elderly.[31] However, research on the effectiveness of mobile sexual health units serving rural and northern communities is sparse. A mobile unit staffed by sexual health and pelvic pain healthcare providers could service small communities on a rotational schedule, similar to the mobile mammography units operating in many Canadian provinces.[32] Our results suggest there may be benefits to a mobile unit to address some of the barriers to rural care, such as the PCP, knowledge gap and internal confidentiality. Further research is needed to determine the feasibility and cost-effectiveness of such a unit, including how many communities would need to be served by a single unit to make it a worthwhile investment.

Limitations

The small sample size limited our ability to conduct a rural/urban comparison or a conceptual analysis or to make claims about how or why differences in PCP perspectives exist. Recruiting patients from the province's pelvic pain clinic ensure that participants met the inclusion criteria but may have biased the sample by excluding patients who were either not yet referred for treatment or who were successfully treated by their healthcare provider. Patients included in the study (1) were at minimum, identified by their PCP as having chronic vulvar pain or discomfort, (2) felt that it was appropriate to bring the concern to their PCP and (3) saw a PCP with sufficient knowledge of the resource to be able to refer the patient out to KB's clinic. Patients who were not referred to the clinic may differ in any of these three aspects. Furthermore, focus group or interview participation is always subject to recall bias and volunteer bias.

CONCLUSION

Corroborating PCP and patient experiences with diagnosis and care of vulvodynia demonstrates how rurality exacerbates concerns about initiating sexual/vulvar health conversations, managing patient privacy and confidentiality, time constraints and building therapeutic relationships. Acting on recommended solutions may address the impact of rurality on the provision of timely care for those experiencing vulvodynia.

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