

## WOMEN'S SEXUAL HEALTH

# Dyspareunia in Their Own Words: A Qualitative Description of Endometriosis-Associated Sexual Pain



Kate J. Wahl, MSc,<sup>1,2</sup> Shermeen Imtiaz, BSc,<sup>2</sup> Michelle Lisonek, BSc,<sup>2</sup> K. S. Joseph, MD, PhD,<sup>1,2</sup> Kelly B. Smith, PhD,<sup>2</sup> Paul J. Yong, MD, PhD,<sup>2</sup> and Susan M. Cox, PhD<sup>1</sup>

## ABSTRACT

**Introduction:** Dyspareunia has been called the neglected symptom of endometriosis and is underexplored in clinical and research contexts. Understanding the physical experience and patient-important aspects of endometriosis-associated sexual pain can help advance valid measurement of this symptom.

**Aims:** The goal of this research was to characterize the physical experience of endometriosis-associated dyspareunia in the words of people affected by this condition.

**Methods:** This was a qualitative descriptive study that included participants with current or previous endometriosis-associated dyspareunia recruited from a data registry. Data collection involved semistructured interviews that began with an open-ended question about dyspareunia followed by prompts related to the nature of sexual pain.

**Main Outcome Measures:** Interviews transcripts were subjected to qualitative content analysis using a priori (pain site, onset, character, radiation, associations, time course, and exacerbating/relieving factors) and emergent themes.

**Results:** A total of 17 participants completed interviews. Mean participant age was 33.3 years and most were identified as white, college-educated, heterosexual, and partnered. Location, onset, and character were important; interrelated features of endometriosis-associated dyspareunia were: (i) introital pain began with initial penetration and had pulling, burning, and stinging qualities and (ii) pelvic pain was experienced with deep penetration or in certain positions and was described as sharp, stabbing, and cramping. Dyspareunia ranged from mild to severe, had a marked psychosocial impact for some participants, and was managed using a variety of treatments and strategies.

**Conclusion:** The endometriosis-associated dyspareunia experienced by participants was heterogenous in presentation, severity, and impact. Our findings have implications for the development of valid patient-reported outcome measures of this symptom. **Wahl KJ, Imtiaz S, Lisonek M, et al. Dyspareunia in Their Own Words: A Qualitative Description of Endometriosis-Associated Sexual Pain. Sex Med 2021;9:100274.**

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**Key Words:** Endometriosis; Dyspareunia; Patient-Reported Outcome Measures; Qualitative Research

## INTRODUCTION

Endometriosis is a gynecologic condition that affects approximately 10 percent of women and is characterized by the growth

of ectopic endometrial-type tissue.<sup>1</sup> More than half of people with endometriosis experience dyspareunia,<sup>2,3</sup> which is classically described as “deep” dyspareunia (ie, pelvic pain with deep vaginal penetration, often in the context of sexual intercourse).<sup>4</sup> This pain is associated with psychosocial sequelae including poorer quality of life,<sup>3,5</sup> lower self-esteem,<sup>6–8</sup> and relationship difficulties.<sup>6,8,9</sup>

Despite its prevalence and impact, dyspareunia is considered a neglected symptom of endometriosis.<sup>10</sup> Clinically, its neglect has been attributed to embarrassment and normalization by clinicians and patients as well as a lack of evidence-based treatment options.<sup>9,10</sup> Although several qualitative studies have highlighted the impact of dyspareunia on the lives of people with

Received May 15, 2020. Accepted October 12, 2020.

<sup>1</sup>School of Population and Public Health, University of British Columbia, Vancouver, Canada;

<sup>2</sup>Department of Obstetrics and Gynecology, University of British Columbia, Vancouver, Canada

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<https://doi.org/10.1016/j.esxm.2020.10.002>

endometriosis,<sup>6–9,11,12</sup> intervention studies are often underpowered for this outcome and its measurement requires further validation.<sup>4</sup>

Patient-reported outcome measures (PROMs) are typically used to monitor endometriosis-associated dyspareunia and treatment efficacy. PROM validity depends in part on whether the measure includes all patient-important aspects of the target concept and whether input was sought from individuals who represent eventual respondents.<sup>13–15</sup> General measures of female sexual function including the Female Sexual Function Index, Female Sexual Distress Scale, and Sexual Function Questionnaire capture sexual pain and are frequently used in endometriosis research; however, these measures may not capture disease-specific dimensions of dyspareunia.<sup>16–18</sup> In contrast, the Endometriosis Health Profile was developed based on the experience of patients with endometriosis but does not measure sexual pain intensity, location, or quality.<sup>19</sup> Other endometriosis-specific PROMs that include dyspareunia have been developed with variable patient involvement,<sup>20–30</sup> with a detailed qualitative description of the physical experience of sexual pain provided in 1 study originally conducted in French.<sup>30</sup> The findings of this study have yet to be confirmed with an English-speaking population. Thus, the aim of this study was to provide a comprehensive account of dyspareunia in the everyday terms that people with endometriosis use to describe their pain. Such data can serve as the foundation for valid PROMs of dyspareunia and yield insights and hypotheses about this symptom for clinical and research audiences.

## MATERIALS AND METHODS

### Design

We used a qualitative descriptive approach, which identifies the fundamental elements of a phenomenon through low-inference interpretation and reporting of participant experiences.<sup>31</sup> The research was guided by a patient research advisory board and approved by an institutional research ethics board (H18-00357).

### Participants and Recruitment

Participants were recruited from the Endometriosis Pelvic Pain Interdisciplinary Cohort data registry ([ClinicalTrials.gov](https://clinicaltrials.gov/ct2/show/study/NCT02911090) Identifier: NCT02911090). The data registry is open to patients attending a tertiary center for endometriosis and captures longitudinal demographic and clinical data. Potential participants were eligible if they consented to be contacted for research, were age of 18 years or older, had clinically suspected or diagnosed endometriosis, reported current or previous dyspareunia alone or with a partner, and could communicate in English—those not meeting all of these criteria were excluded. In accordance with qualitative research guidelines, a minimum sample size of 12 was set and recruitment continued until saturation, the point when additional interviews did not reveal new insights about the experience of sexual pain.<sup>32</sup>

To reflect the demographic characteristics of patients seen at the tertiary center, potential participants were randomly selected from within overlapping subsamples defined by educational attainment, sexual orientation, and ethnicity. KW contacted selected participants by telephone to introduce herself and her program of research, present the study, and screen for eligibility. Interested participants received and returned written study consent forms by e-mail. To reduce sampling bias, 5 attempts were made to contact a potential participant before a subsequent participant was selected.

### Data Collection and Analysis

The interview guide was developed by KW, a graduate student with theoretical and applied training in qualitative methodologies, SC a qualitative health researcher focused on illness experiences throughout the life course, PY a clinician-scientist with expertise in endometriosis, and a Patient Research Advisory Board with lived experience of the condition. KW pilot tested the interview guide and conducted a semistructured telephone interview with each participant. The interviews were conducted after written consent was obtained, a minimum of 24 hours after the introductory call. Interviews began with the question, “Tell me about the pain you experience with sex”; initial prompts related to a priori themes of pain site, onset, character, radiation, associations, time course, and exacerbating/relieving factors. Contemporaneous field notes permitted the identification of additional emergent themes and assessment of saturation. Demographic and clinical data were drawn from the data registry.

The interviews were audio recorded and transcribed verbatim by KW, SI, and ML. KW conducted a qualitative content analysis of the transcripts,<sup>33</sup> using Nvivo 12 software to facilitate the organization and comparison of data.<sup>34</sup> The analysis involved reading the set of transcripts to get a global sense of the data; reading transcripts individually and highlighting words that captured key concepts as codes; sorting the codes into categories based on relatedness; and organizing the categories into meaningful clusters. Automatic coding functions of Nvivo were not used in the analysis.

To ensure reliability of the analysis, SI coded 2 randomly selected transcripts and cross-checked her findings with those of KW. Transcript and analysis checking with the participants was not completed given the low-inference approach to analysis.

## RESULTS

### Participants

Of 36 potential participants we attempted to contact about the study, 17 completed an interview, 7 were ineligible, 5 declined to participate, and 7 were not reached. The average age of the participants was 33.3 years (SD = 7.2, range 23–50). Ethnicity, gender identity, sexual orientation, educational attainment, marital status, parity, endometriosis status, dyspareunia severity ratings, and comorbidities are described in [Table 1](#).

**Table 1.** Characteristics of sample (n = 17) recruited from tertiary care center for endometriosis (2018–2019), qualitative investigation of endometriosis-associated dyspareunia

Characteristic	Mean ± SD, range; n (%)
Age	33.5 ± 7.0, 23–50
Ethnicity	
White	14 [82]
Asian	2 [12]
Other	1 [6]
Female gender identity	17 [100]
Sexual orientation	
Heterosexual	12 [70]
Bisexual	2 [12]
Lesbian	2 [12]
Other	1 [6]
Education	
High school (grades 9–12)	1 [6]
Community college/vocational school	3 [18]
College	9 [52]
Graduate school	4 [24]
Marital status	
Single	2 [12]
Dating	2 [12]
Common law	2 [12]
Married	9 [52]
Separated	2 [12]
Parous	4 [24]
Endometriosis status*	
Clinically suspected	10 [59]
Surgical (visual) diagnosis	1 [6]
Surgical (histologic) diagnosis	7 [41]
Current endometrioma on ultrasound	2 [12]
Current nodule on examination	2 [12]
Deep dyspareunia score	6.76 ± 2.82, 0–10
Superficial dyspareunia score	3.24 ± 3.33, 0–8
Pelvic floor tenderness <sup>†</sup>	2 [12]
Provoked vestibulodynia <sup>‡</sup>	3 [18]
Moderate/severe anxiety <sup>§</sup>	5 [29]
Moderate/severe depression <sup>  </sup>	6 [35]
75th percentile pain catastrophizing <sup>¶</sup>	6 [35]

\*Total > 100% reflects that a patient can fit several classifications.

<sup>†</sup>Unidigit exam not completed for 1 participant.

<sup>‡</sup>Cotton swab test not completed for 8 participants.

<sup>§</sup>Patient Health Questionnaire<sup>26</sup> ≥ 10.

<sup>||</sup>Generalized Anxiety Disorder scale<sup>27</sup> ≥ 10.

<sup>¶</sup>Pain Catastrophizing Scale<sup>28</sup> ≥ 30.

The median interview length was 28 minutes (SD = 13, range 14–72 minutes).

Although 5 participants did not self-identify as heterosexual in the data registry, only 1 explicitly mentioned her sexual orientation in the interview. These participants did not report physical experiences of dyspareunia different from those of other participants; however, the participant who discussed her sexual orientation explained that it was easier to cope with the pain

because vaginal penetration was not essential to her sexual relationship.

## Pain Fundamentals

Among participants, dyspareunia began at different points in the sexual encounter and was described using a range of terms related to pain character and location.

Some participants had difficulty naming the site of their pain and occasionally explained its location in terms of other painful experiences.

*I'm not really not familiar with my biology, the reproductive parts. But the inside. So is it the cervix? Or the uterus? (130)*

*That's really hard to explain, because I can't really pinpoint where it is. It's not on the outside, it's the inside where, if I was pointing at my pelvis, like a couple inches in. (089)*

*The same place I would experience period cramps. (051)*

All participants described pain in the pelvis or pelvic organs, and 7 participants also experienced pain at the vaginal introitus. For example, 1 participant said,

*I have a few different things with pain with penetration.*

This participant went on to clarify.

*I experience the 3 types of penetrative pain so like the penetrative pain in my vagina, and then deep vaginal pain, and I also experience uterine pain with arousal and orgasm. (020)*

Except for 2 participants who reported pelvic pain at orgasm and 2 who reported pelvic pain after intercourse, pain in the pelvis began with deep penetration or certain sexual positions and was associated with sharp, aching, cramping or stabbing sensations. In contrast, pain at the vaginal opening always began with initial penetration and was associated with pulling, stinging, or burning. The frequency of key terms participants used to describe the onset, site, and character of their pain are provided with representative quotations in [Table 2](#).

## Pain Severity

When asked about the severity of their pain, a majority (82%) of participants spontaneously rated their pain as a score out of 10. Participants also described pain severity qualitatively.

*It's not so bad where you're like heeled over, like when you have your period with endo, where you can't move or anything like that, it's not even close to that, it's just, it's more uncomfortable I'd say. (030)*

*I could keep going if I mentally prepared myself but there is also like a side to me that would just want to stop. (033)*

*So, it wasn't the worst pain I'd experienced but it was uncomfortable enough that I would have to stop doing that activity. (043)*

*It wasn't quite at a level I would pass out from the pain, but I would definitely cry quite a bit. (031)*

*The worst pain I've ever felt. Nothing could be done, I can't have people around me, I don't like noises, I just want everyone to just*

**Table 2.** Categories and codes for descriptions of endometriosis-associated dyspareunia among people with lived experience of the symptom, tertiary care sample, 2018–2019

Category	Code*	n <sup>†</sup>	Example [participant ID]	
Onset	At the beginning	7	<i>Right when he like starts to go in</i> [033]	
	Deep penetration	7	<i>It starts as soon as I have deep penetration</i> [109]	
	Certain positions	6	<i>All of a sudden there was an angle that went slightly one or the other, it might be like “Ahh! That hurt!”</i> [097]	
	Orgasm	2	<i>My experiences of it have been that it’s associated with orgasm</i> [020]	
	Afterward	2	<i>For the most part, its cramps afterwards</i> [050]	
Site	Pelvis	7	<i>Very deep in the pelvis</i> [50]	
	Vaginal opening	7	<i>It’s mostly around the vaginal opening</i> [068]	
	Abdomen	5	<i>Up in my abdomen</i> [030]	
	Uterus	5	<i>Right in my uterus area</i> [33]	
	Cervix	4	<i>Inside my cervix</i> [031]	
	Deep vagina	4	<i>The very back end of the vagina and the bottom</i> [097]	
	Ovaries	4	<i>Around where my ovaries are</i> [038]	
	Rectum	2	<i>The rectum area</i> [087]	
	Stomach	2	<i>I feel it right in my stomach</i> [51]	
	Character	Sharp	7	<i>I’m having such sharp pain</i> [035]
		Ache	6	<i>It felt like an ache, that’s what it sort felt like, like a real ache</i> [015]
Cramping		5	<i>A really, really bad cramp</i> [089]	
Stabbing		5	<i>A stabbing pain, I guess you could call it</i> [045]	
Spasm		3	<i>I almost feel like, it’s like a spasm that happens</i> [051]	
Bruise		2	<i>It feels almost like a bone bruise</i> [109]	
Burning		2	<i>It felt like it was burning</i> [031]	
Inflamed		2	<i>Everything is inflamed</i> [051]	
Pulling		2	<i>It feels like my whole insides are being pulled around</i> [038]	
Pulsing/throbbing		2	<i>It’s kind of like pulsing</i> [033]	
Punching		2	<i>It’s like something is punching you</i> [130]	
Stinging		2	<i>It’s kind of like a stinging feeling</i> [033]	
Tense/tight		2	<i>That part of me is still very tense and tight</i> [068]	
Uncomfortable		2	<i>It’s an uncomfortable feeling</i> [087]	

\*All terms used by 2 or more participants are included.

<sup>†</sup>Number of participants who used the term or stemmed word (eg, talk, talking); sum is greater than the total number of participants because participants typically used several terms to identify the site of sexual pain.

*leave me alone. There’s nothing that can be done for it to really go away you know, until it goes away. I don’t know, it’s scary.* (051)

### Pain Impact

Almost all (88%) participants reported having interrupted sex because of pain, and more than half (59%) avoided sexual experiences.

The experience of sexual pain affected the emotional and psychological well-being of some participants.

*It’s hard for me to just deny all the time because I start to feel bad.* (033)

*It would make me feel sort of you know, emotionally kind of discouraged.* (043)

*I feel insignificant, you almost feel broken or something.* (051)

*You feel guilty for having to stop.* (089)

Many participants also reported that the experience of sexual pain impacted their intimate relationships.

*I think my husband was reluctant to approach me for sex because he knew I was feeling ill [...] I’m glad we’ve got a solid marriage and we’ve weathered the storms and we’re ok now. But it was a really tough time.* (043)

*I don’t ever want to have sex, I would be happy to not do it at all, but I have to get myself in the mood. I try once a month to have, you know, that closeness with him even though for me its not pleasurable at all [...]. It has kept me keeping some secrets from my lover, which is not how our relationship normally is.* (038)

*Lately, we just have sex is because we want to conceive [...] we don’t really have sex just because we want to.* (130)

*It got to the point where I was in pain so often from intercourse, that my partner and I basically decided that we just weren’t going to anymore, that it just wasn’t worth me going through the pain [...] It contributed to the end of that relationship.* (031)

For 1 participant who was single, sexual pain affected her willingness to seek out physical intimacy.



*I don't want to watch the horrified faces as I'm suddenly leaping out of bed because I'm in so much pain. (035)*

Some participants had sexual intercourse infrequently or not at all. 4 participants reported that hormonal treatment relieved their pain, but in 1 instance, the treatment also negatively affected sexual desire. Other participants found ways of managing and coping with their pain.

*I have pain with penetration almost all the time, but I am able to accommodate it in a way so it's not severe enough that it stops the experience and I can change a position or stop having penetration and it's fine and I can continue with my sexual experience. (020)*

*We went out and bought that masturbation sleeve and we kind of control the depth just to kind of prevent [the pain] from happening. (051)*

*I just think about noises or him speaking to me and I really just focus on that. I take my mind away from what's actually happening. (033)*

*I've gone to therapy to try to stop myself from feeling guilty right away and just be okay with the fact that we might have to change things up and that's okay. (089)*

*I typically have to take anti-inflammatories for the pain and just managing it, or a hot water bottle, a hot shower, that sort of thing. (109)*

## DISCUSSION

This study described of endometriosis-associated dyspareunia as per lived experiences of patients. Interviews with participants revealed that in addition to the cardinal endometriosis symptom of deep dyspareunia, almost half of the sample experienced pain at the vaginal introitus (“superficial” dyspareunia). Experiences of sexual pain ranged in severity and in some cases had a significant, negative impact that participants sought to manage using a variety of medical, behavioral, and psychological strategies.

An important finding of our study was the pattern of responses indicating that dyspareunia occurred both at the vaginal opening and in the pelvis; the former beginning with initial penetration and having a pulling burning or stinging nature and the latter occurring with deep penetration or certain positions and having sharp, aching, cramping, and stabbing qualities. Clinically, the finding of pelvic pain with deep penetration corresponds with the understanding of endometriosis-associated dyspareunia, whereas the description of pain at the vaginal opening that begins with initial penetration is suggestive of comorbid conditions such as pelvic floor muscle dysfunction or provoked vestibulodynia.<sup>35</sup>

These findings have implications for the development of PROMs for endometriosis-associated dyspareunia. First, current measures that refer to “sexual pain” without distinguishing between pelvic pain and pain at the vaginal opening may capture dyspareunia that arises from comorbid conditions,<sup>36</sup> thereby leading to misclassification of the outcome and potentially biasing the effect of interventions toward the null. Second,

participant uncertainty about elements of their pain suggests that onset- or location-based measures might limit response accuracy; diagrams that highlight relevant anatomic sites could facilitate true responses. Third, although recent clinical trials have used ordinal response options (ie, none, mild, moderate, severe),<sup>19</sup> reporting dyspareunia on a numeric rating scale (0–10) is intuitive for respondents and aligns with recommendations for the measurement of patient-important endometriosis pain symptoms.<sup>22</sup> Finally, PROMs could seek to account for the physical, emotional, and interpersonal dimensions of endometriosis-associated sexual pain as each of these is important from the patient perspective. Such PROMs can lead to improved outcomes through research that characterizes sexual pain in a way that is relevant to patients and centered on their lived experiences. For example, the use of these PROMs in clinical trials may help evaluate treatments which improve symptoms that patients themselves identify as important.

Although the primary aim of this study was to describe the fundamental physical experience of endometriosis-associated dyspareunia, 2 related points of interest emerged. First was the range of strategies participants used to self-manage their dyspareunia, including behavior modification, medication, heat, and cognitive coping techniques, which were comparable with strategies identified in previous research about endometriosis.<sup>37–39</sup> Similarly, the importance that participants placed on the interpersonal effects of dyspareunia aligned with other qualitative work showing that this pain leads to relationship strain and, in some cases, dissolution.<sup>6–9,11,12</sup> Taken together, these findings highlight the potential for patient-oriented endometriosis care that is interdisciplinary and inclusive of partners.<sup>40,41</sup>

A strength of the study was its exclusive focus on and in-depth approach to characterizing the physical experience of endometriosis-associated dyspareunia, which confirmed and extended those of previous work that described this symptom using data from 10-minute French-language interviews about several painful symptoms of endometriosis.<sup>29</sup> Additional strengths were that participants ranged in severity of their self-reported sexual pain and that the sample size allowed for concepts to be supported by a wide range of data resonant with existent literature.

A limitation of this work was that the database from which participants were recruited did not systematically collect data on sexual function, such as desire, arousal, and orgasm, which could have supplemented the qualitative data. While there has been a shift toward clinical diagnosis in practice,<sup>42</sup> it is a limitation of this work that the relationship between endometriosis stage and experience of dyspareunia could not be contemplated because participants were not selected based on surgical diagnosis. It is also relevant that all participants had previously attended a tertiary center where they completed dyspareunia measures and discussed the sexual pain with a care provider—together with high levels of education in the study sample, these earlier clinical interactions may have affected how participants described their

pain. Although the sample was selected to reflect the demographic characteristics of the clinical population, additional work investigating the experience of Black, Indigenous, and people of color is vital to a comprehensive understanding of endometriosis-associated dyspareunia and of the condition in general.

Dyspareunia is a primary symptom of endometriosis, yet has been relegated to a secondary or tertiary outcome in clinical trials research.<sup>22,43</sup> Other studies have established that endometriosis-associated sexual pain negatively affects psychosocial well-being, a finding that the present work reinforced. Notably, this study provided insight into the physical experience of dyspareunia in endometriosis, yielding the methodologic consideration that PROMs for this symptom could include location of pain (pelvic or at the vaginal opening), anatomic diagrams, an 11-point numeric rating scale, and a range of patient-important outcomes. We hope that by providing a comprehensive description of endometriosis-associated sexual pain, this work will be hypothesis generating and will contribute to rigorous investigation of dyspareunia in endometriosis.

**Corresponding Author:** Paul J. Yong, MD, PhD, Department of Obstetrics & Gynecology, BC Women's Center for Pelvic Pain and Endometriosis, University of British Columbia, F2-4500 Oak Street, Vancouver, British Columbia V6H 3N1, Canada. Tel: +1-604-875-2534; Fax: 604-875-2569; E-mail: paul.yong@vch.ca

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

*Funding:* This research was supported by a Canadian Institutes of Health Research Operating Grant (MOP142273) and a Canada Graduate Scholarships – Master's.

## STATEMENT OF AUTHORSHIP

Kate J. Wahl: Conceptualization, Methodology, Investigation, Data Curation, Formal Analysis, Writing – Original Draft, Writing – Review & Editing, Funding Acquisition; Shermeen Imtiaz: Data Curation, Formal Analysis, Writing – Review & Editing; Michelle Lisonek: Conceptualization, Data Curation, Writing – Review & Editing; K.S. Joseph: Conceptualization, Writing – Review & Editing; Kelly B. Smith: Writing – Review & Editing; Paul J. Yong: Conceptualization, Methodology, Writing – Original Draft, Writing – Review & Editing, Supervision, Funding Acquisition; Susan M. Cox: Conceptualization, Methodology, Writing – Review & Editing, Supervision.

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