



Original article

A patient-oriented workshop on sexual pain and endometriosis: Preliminary evidence for improvements in painful intercourse self-efficacy

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ABSTRACT

Objective: Endometriosis-associated dyspareunia can persist after surgical interventions, requiring multidisciplinary treatment including pain education. This study explored the effectiveness of a one-day workshop for improving knowledge, behavioural changes, and self-efficacy.

Materials and methods: Pre-test post-test study of people who attended a workshop on dyspareunia and endometriosis. A pre- and immediately post-workshop questionnaire was used to evaluate the outcomes. A subsection of the Painful Intercourse Self-Efficacy questionnaire was used to assess self-efficacy.

Results: Sixteen people completed both the pre- and post-workshop questionnaires, 12 of which had endometriosis. There were improvements in knowledge on the prevalence, causes and treatments of dyspareunia in endometriosis after the workshop. All participants with endometriosis said “yes” or “maybe” to discussing what they learned with their healthcare provider. Comparing the self-efficacy of the 12 participants with endometriosis between pre- and post-workshop, there was a significant increase in certainty that they could: continue most of their sexual activities (Cohen's $d = 0.61$, $P = 0.007$); keep dyspareunia from interfering with their relationship (Cohen's $d = 0.77$, $P = 0.023$); make small-to-moderate reductions (Cohen's $d = 0.48$, $P = 0.021$) and large reductions (Cohen's $d = 0.56$, $P = 0.034$) in their dyspareunia by using non-surgical methods.

Conclusion: Disseminating information about dyspareunia at a one-day workshop was associated with improved knowledge and self-efficacy.

1. Introduction

Endometriosis is a chronic, systemic disorder that occurs when endometrial-like cells grow abnormally outside the uterus and affects approximately 190 million people worldwide [1]. Endometriosis-associated deep dyspareunia (pain with deep vaginal penetration during intercourse) affects half of people with endometriosis and is associated with negative impact on sexual quality of life, physical and emotional health, as well as self-esteem [2,3]. Thus, management of dyspareunia and sexual function is crucial to improve the quality of life for patients with endometriosis.

Deep dyspareunia in endometriosis has a multifactorial origin and can be resistant to standard endometriosis treatments; therefore, a multidisciplinary approach that encompasses pain education, physical therapy,

and psychological therapy may be needed [4]. A prospective cohort study of deep dyspareunia showed that interdisciplinary interventions (including pain education workshops on topics such as sexual pain, the sexual response cycle, and the genital and pelvic floor anatomy) were associated with a reduction in the severity of deep dyspareunia after 1 year [5].

Studies have found that teaching specific knowledge and skills, in addition to reinforcing positive behaviors, can increase the perceived ability of chronic pain patients to manage their pain and function [6]. A systematic review evaluating the effectiveness of pain neurophysiological education at facilitating knowledge about chronic pain was conducted and found significant improvements in catastrophizing and knowledge of pain after the intervention [7]. Therefore, education may play a key role in the complex long-term management of patients with chronic pain.

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There is evidence from randomized controlled trials that supports the use of a single, intensive, full-day educational workshop for disseminating health-related information [8,9]. For example, a randomized controlled trial by Horrell et al. showed that a one-day psychoeducational self-confidence workshop for people with depression was clinically effective at improving depression, reducing levels of anxiety, and increasing self-esteem at 12 weeks follow-up [8].

Pain self-efficacy is confidence in one's own ability to manage pain. Evidence has demonstrated a relationship between lower self-efficacy and higher pain severity in multiple pain populations, including those with chronic pain and provoked vestibulodynia [10–12]. In a population with provoked vestibulodynia, greater sexual self-efficacy was associated with better sexual functioning while lower sexual self-efficacy was associated with higher self-reported thermal pain rating at the forearm and higher self-reported pain-pressure at the vulva [13]. Additionally, self-efficacy was associated with increased psychological comorbidities and disability [10,11]. Enhancing belief in ability to manage pain and self-efficacy is an important contributor to improving pain intensity, function, and mood [6]. The above evidence indicates the importance of improving self-efficacy in managing dyspareunia.

We developed a one-day workshop for endometriosis-associated dyspareunia, in collaboration with patient partners, for the primary outcome of self-efficacy. The aims of this study were:

- to measure the knowledge gained and intent for behavioral changes after attending the workshop;
- to measure the impact of this workshop on self-efficacy, using self-reported pre- and post-workshop questionnaires.

2. Materials and methods

This was a pre-test post-test study of people who attended a workshop for endometriosis and dyspareunia in Vancouver, BC. Ethics approval was granted by the UBC Children's and Women's Research Ethics Board (H19-00533) and all participants provided informed consent.

2.1. Participants

People with endometriosis, their friends, and families, and all interested individuals were invited to attend this workshop. The workshop invitation was shared by flyers put up in a tertiary endometriosis center, as well as through the center's newsletter. Additionally, members of the public were invited through community placed flyers and social media platforms (e.g., Twitter). Workshop attendees were given the option of participating in the research study to complete questionnaires pre- and post-workshop. Attendees were included in the research study if they completed both the pre- and post-workshop questionnaires and were ≥ 18 years old.

2.2. Design of the workshop

This workshop was designed according to the principles of patient-oriented research. Patient-oriented research engages patients as partners and focuses on patient-identified priorities with the goals of improving patient experiences, health outcomes and the health system [14,15]. Using this framework and the guiding principle of engaging patients as equal partners throughout all aspects of the research, we developed a workshop that addressed patient-identified priorities and that was accessible to people with endometriosis, ultimately improving health outcomes [14]. The patient partners involved in this study were from our Endometriosis Patient Research Advisory Board (PRAB). The role of the PRAB members were to support this project at each stage including as knowledge user leads on the grant application, as well as defining workshop objectives that were patient-informed, identifying speakers, providing input on study design and workshop materials, and leading the creation of a plain language summary report and its dissemination on social media. In-person, bimonthly PRAB

meetings were used to plan the workshop and identify feasibility issues and barriers that may arise, including low attendance due to the chronic pain population or location chosen. Consequently, the workshop was free and included breakfast and lunch, as well as garden access. Additionally, the workshop was recorded so people who were unable to attend in person (e.g., due to disabling pain, living outside of Vancouver) were able to access it.

In recognition of Pain Awareness Month, the one-day workshop (9am–6pm) was held on Saturday September 21st, 2019 at VanDusen Botanical Garden in Vancouver, BC. The workshop was funded by a Michael Smith Health Research BC Reach Award (\$10,000). With 120 expected attendees, that is approximately \$83/person which included: the venue costs, breakfast and lunch, botanical garden access, resource pamphlets, workshop booklet, and the link to the recorded lectures to re-watch on their own time. Please note that the fees also include costs associated with the planning of this workshop such as patient partner honorariums.

2.3. Contents of the workshop

The learning objective for the workshop was to disseminate research findings and describe the etiologies and self-management tools for endometriosis-associated dyspareunia. The workshop included a multidisciplinary team of speakers with expertise in endometriosis and dyspareunia. The first presentation was led by a clinical psychologist and discussed the rationale and latest evidence for mindfulness for dyspareunia, as well as guided the audience through a mindfulness exercise. A gynecologist at the tertiary endometriosis center reviewed the pathophysiology of dyspareunia in endometriosis, including peripheral and central factors, and discussed potential treatment options. After a yoga break, the *Living with Endometriosis* session began and included three presentations:

- a women's sexual and mental health advocate, coach and speaker, described her story about living with dyspareunia and how she became an advocate and research participant;
- a Canadian-Certified Counsellor/Registered Clinical Counsellor and a Registered Physiotherapist/Fellow of the Canadian Academy of Manipulative Physical Therapy together discussed the role of partners in managing dyspareunia;
- a Registered Physiotherapist with special interest in pelvic health talked about managing dyspareunia with physiotherapy. Lunch followed this session.

Next was a keynote presentation by a researcher from Pain BC (an organization aimed at supporting people in pain, educating health care providers about managing pain, and improving systems that impact people in pain) who has an interdisciplinary background in education and pain management. They described the programs offered by Pain BC that support people in pain, and the importance of advocating for your health was emphasized. The last presentation in the workshop was given by two members of the BC Support Unit (an organization that supports patient-oriented research) who are involved in patient engagement and knowledge translation. Together, they gave a presentation introducing patient-oriented research and led a group discussion about priorities for endometriosis research and care. The workshop ended with a mix and mingle which allowed for 1:1 interaction between attendees and speakers, and the attendees were given tickets to tour the botanical gardens after the workshop was complete.

The workshop also featured 7 trainee posters – created for a public audience – which were displayed throughout the workshop. This gave trainees the opportunity to practice their ability to communicate findings to patients who participate in and are affected by their research, and gave the workshop attendees an opportunity to see what endometriosis and dyspareunia research is currently being done.

2.4. Measures

Online pre- and post-workshop questionnaires were used to assess study outcomes: knowledge gained, intent for behavioral changes, and

self-efficacy. The pre-workshop questionnaire was sent after people registered to attend the workshop and the post-workshop questionnaire was sent immediately after the workshop.

Knowledge questions assessed on the pre- and post-workshop questionnaires included: *sexual pain is present in what percent of women with endometriosis* (10%, 30%, 50%, 100%; correct answer is “50%”), *causes of sexual pain in endometriosis include* (the endometriosis tissue, the cervix/uterus, the bladder, the pelvic floor muscles, all of the above; correct answer is “all of the above”) and *treatments for sexual pain in endometriosis may include* (medications/hormones, surgery, physiotherapy, psychological therapy, medications/hormones and surgery, all of the above; correct answer is “all of the above”). These questions were categorized into correct answer or not.

Intent for behavioural change question included: *if you have suspected or diagnosed endometriosis, will you speak to your health care provider about what you learned?* (Yes, No, Maybe).

Self-efficacy was measured using a subscale of the Painful Intercourse Self-Efficacy Scale (controlling pain during intercourse) [12], on both pre- and post-workshop questionnaires. Participants indicated their perceived certainty to achieve goals in pain management for penetrative sexual activity, for 5 questions each rated from a scale ranging from 10 (very uncertain) to 100 (very certain) [12]. A study of people with provoked vestibulodynia identified good internal consistency for the total score (Cronbach alpha = 0.88) and subscales (Cronbach alpha ranging from 0.76–0.88) [12].

2.5. Statistical analysis

Descriptive statistics were used to describe the study population. Using paired bivariate analyses, we examined if there were significant improvements in knowledge (McNemar Test), and in the Painful Penetration Self-Efficacy Scale scores (paired samples *t*-test), between pre- and post-workshop. Effect sizes were calculated with Cohen's *d*. Significance was $P < 0.05$. IBM SPSS Statistics 24 used for the analysis. Missing data were excluded on a pairwise basis (i.e., per analysis).

3. Results

3.1. Study sample

Thirty-five people attended the workshop, of which 16 people completed both the pre- and post-workshop research questionnaires and were included in the analysis. A comparison between the study cohort and the people who completed the pre- but not post-workshop questionnaire was performed (Supplementary Table 1) and no significant differences were identified. The mean age of this cohort was 36 ± 8 years (range 23–52 years) and 68.8% (11/16) identified as White. Sixty-nine percent (11/16) had been diagnosed with endometriosis, 6.3% (1/16) had suspected endometriosis, 6.3% (1/16) was a partner of someone with endometriosis, and 18.8% (3/16) were “other” which included allied health care providers or other gynecological conditions.

3.2. Educational and behavioral outcomes

Of the total cohort ($n = 16$), 62.5% (10/16) of participants said that they strongly agreed and 37.5% (6/16) said they agreed with the question “*did you learn new information?*”. Of the people with endometriosis, 83.3% (10/12) said “yes” and 16.7% (2/12) said “maybe” to the question “*will you speak to your health care provider about what you learned?*”. All the participants said they would feel comfortable using the tools discussed in this workshop and the tool that the majority of people said they would use was physiotherapy.

Knowledge questions on dyspareunia and endometriosis were asked on both pre- and post-workshop questionnaires and the number of correct responses was compared using a McNemar test. For the question “*sexual*

pain is present in what percent of women with endometriosis”, the proportion of correct answers increased from 0.31 (5/16) pre-workshop to 0.81 (13/16) post-workshop ($P = 0.039$). For the question “*causes of sexual pain in endometriosis include*”, the proportion of correct responses increased from 0.63 (10/16) pre-workshop to 1.0 (16/16) post-workshop. For the question “*treatments for sexual pain in endometriosis may include*”, the proportion of correct answers increased from 0.69 (11/16) pre-workshop to 1.0 (16/16) post-workshop.

3.3. Effects of the workshop on self-efficacy

Of the people with endometriosis ($n = 12$), there was a significant increase in certainty from pre- to post-workshop to: “*continue most of your sexual activities?*” (40.7 ± 27.3 vs. 59.2 ± 33.4 , Cohen's $d = 0.61$, $t(11) = -3.34$, $P = 0.007$, Fig. 1A); “*keep pain during penetration from interfering with your relationship?*” (28.6 ± 26.2 vs. 54.3 ± 39.5 , Cohen's $d = 0.77$; $t(10) = -2.69$, $P = 0.023$, Fig. 1B); “*make a small-to-moderate reduction in your pain during penetration by using non-surgical methods?*” (47.9 ± 31.9 vs. 63.0 ± 31.2 , Cohen's $d = 0.48$; $t(11) = -2.69$, $P = 0.021$, Fig. 1C); and “*make a large reduction in your pain during penetration by using non-surgical methods?*” (38.6 ± 32.7 vs. 56.7 ± 31.6 , Cohen's $d = 0.56$; $t(10) = -2.46$, $P = 0.034$, Fig. 1D). A similar but non-significant trend was seen for the question “*how certain are you that you can decrease your pain quite a bit?*” (38.6 ± 29.0 vs. 49.4 ± 35.6 , Cohen's $d = 0.33$; $t(10) = -1.00$, $P = 0.34$).

4. Discussion

In this pre- and post-workshop study, participants demonstrated improvements in knowledge of dyspareunia and endometriosis, intent to discuss what they learned at the workshop with their health care provider (intent for behavior change), as well as a significant increase in their certainty for four items of the Painful Intercourse Self-Efficacy Scale. This included increases in certainty that they could continue most of their sexual activities, that they could keep pain during penetration from interfering with their relationship, and that they could make small-to-moderate and large reductions in their pain during penetration by using non-surgical methods. These findings provide preliminary evidence to suggest that a one-day workshop was able to provide people with the information and tools necessary to feel more confident in improving their pain at the completion of the workshop.

A systematic review of studies examining chronic musculoskeletal pain populations indicated that there was low quality evidence of a small effect of psychological interventions in improving self-efficacy [16]. Additionally, in a study of people with chronic musculoskeletal pain and depression, including a pain self-management education program into the intervention plan improved self-efficacy [17]. Similarly, our study identified an improvement in self-efficacy after a one-day workshop intervention that included pain self-management education. This study provides preliminary evidence to support a pain education program, including self-management tools, to be included in the treatment of people with endometriosis-associated dyspareunia to improve pain self-efficacy. Improvement in self-efficacy may then facilitate improvements in pain in individuals with endometriosis, which is especially important for those whose pain is not completely alleviated by standard endometriosis therapies. A one-day educational workshop is a relatively low-cost method (approximately \$83/person) to disseminate knowledge on the pathophysiology of dyspareunia and self-management tools to improve people's self-efficacy and may ultimately improve their pain.

Strengths of this study include the multidisciplinary nature of the workshop, the multiple resources delivered to attendees, and the use of a standardized questionnaire for self-efficacy with penetration during sexual activities. Another strength was the involvement of patient partners in the development of the workshop, thus providing a workshop

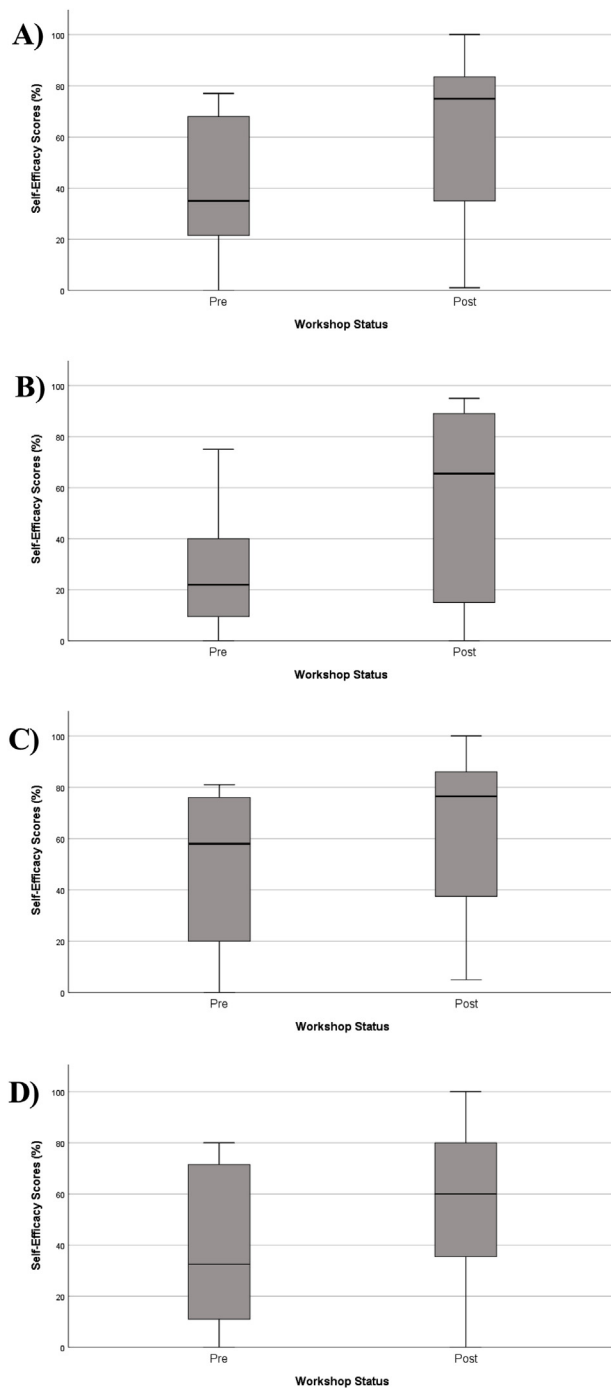


Fig. 1. Percent self-efficacy (certainty) at pre- and post-workshop for: A) *continuing most of your sexual activities?* B) *keeping pain during penetration from interfering with your relationship?* C) *making a small-to-moderate reduction in your pain during penetration by using non-surgical methods?* D) *making a large reduction in your pain during penetration by using non-surgical methods?* There was a significant difference between the groups: A) $P = 0.007$; B) $P = 0.023$; C) $P = 0.021$; D) $P = 0.034$.

that reflected the needs of people with endometriosis and dyspareunia and was delivered in an understandable way. A limitation of this project was the low participation rate of registrants, which may reflect the severity of endometriosis symptom burden or low commitment related to free registration. Future work could consider online, asynchronous workshops to enhance accessibility, as well as a form of commitment (e.g.,

registration fee returned upon arrival) to enhance in-person participation. People with suspected or diagnosed endometriosis were included in this study, although it should be noted that people may experience dyspareunia without endometriosis and thus this study did not collect data from that group of people. Additionally, long-term follow-up data were not collected in this study and limits the interpretation of the long-term effectiveness and retention of information. Although patient partners from a tertiary endometriosis care center were collaborators on this project, community patient voices beyond the PRAB could provide a diverse perspective on this study. Also, no control group was included in this study. Due to these limitations, no definitive conclusions can be drawn from this study, although the preliminary findings show promising results about the effectiveness of a one-day workshop.

Future research on dyspareunia and endometriosis education for patients should be developed with patient partners, specifically ensuring demographic diversity of the patient partners, such as in ethnic background, through outreach to communities of Black, Indigenous, and people of color. A randomized controlled trial could be done to evaluate the effectiveness of the workshop at improving knowledge about dyspareunia in endometriosis and self-efficacy at managing pain, as well as to assess the effectiveness of the educational format, where endometriosis participants receive a health education workshop or the same information in a different format. Research is also needed to determine whether improvements in self-efficacy after an endometriosis educational intervention persist in the long-term, and result in improvements in pain and quality of life. In conclusion, this study explored the change in self-efficacy and educational outcomes of a one-day workshop on endometriosis and dyspareunia. Our preliminary evidence identified improvements in self-efficacy for managing pain with penetration. We propose that disseminating educational information on the pathophysiology of dyspareunia and self-management tools in a one-day pain education workshop could be a method to improve patient self-confidence and thus pain.

Disclosure of interest

The authors declare that they have no competing interest; however, CA has affiliations with Abbvie Inc (board membership), Ferring (board membership) and Hologic (travel support), and MB has affiliations with Abbvie Inc (royalties and consulting fees), Baxter Inc (royalties) and Ferring (funding or grants).

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Authorship contributions (CRediT)

Natasha Orr: conceptualization, data curation, formal analysis, funding acquisition, investigation, methodology, validation, visualization, writing – original draft, writing – review and editing. Jessica Sutherland: conceptualization, funding acquisition, writing – review and editing. Endometriosis Patient Research Advisory Board: conceptualization, writing – review and editing. Alice Huang: writing – original draft, writing – review and editing. Kate Wahl: conceptualization, methodology, writing – review and editing. Heather Noga: conceptualization, funding acquisition, methodology, project administration, writing – review and editing. Lori Brotto and Ciana Maher: funding acquisition, methodology, writing – review and editing. Mohamed Bedaiwy, Christina Williams, Catherine Allaire: funding acquisition, resources, writing – review and editing. Paul Yong: conceptualization, data curation, formal analysis, funding acquisition, methodology, resources, supervision, validation, writing – original draft, writing – review and editing.

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Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at <https://doi.org/10.1016/j.jeud.2023.100027>.

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Jessica Sutherland is a communications professional and student in the Technical Writing Program at the British Columbia Institute of Technology. She is also a charter member of the Endometriosis Patient Research Advisory Board and is most interested in translating research findings into accessible resources for patients and medical professionals.



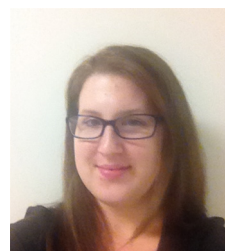
The Endometriosis Patient Research Advisory Board at the UBC Endometriosis and Pelvic Pain Laboratory is a group of people with endometriosis from the BC Women's Centre for Pelvic Pain and Endometriosis who are committed to supporting research projects. For example, the Patient Research Advisory Board contributes to defining research objectives, supporting the design and execution of projects, and ensuring project results are meaningful and understandable to the patient population.



Alice Huang is a MD Candidate at UBC and was involved in central sensitization in the context of endometriosis for her FLEX project. She previously completed a BSc in Microbiology and Immunology at UBC and worked in medical genetic and virology research. She has an interest in education and sexual and reproductive health.



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