

“I wish I knew then what I know now” - pain science education concepts important for female persistent pelvic pain: a reflexive thematic analysis

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Abstract

Pain science education (PSE) provides people with an understanding of “how pain works” grounded in the biopsychosocial model of pain; it has been demonstrated to improve outcomes in musculoskeletal pain conditions. Preliminary evidence suggests PSE may be effective for female individuals with persistent pelvic pain, but how the content of PSE needs to be modified for this group remains to be determined. A reflexive thematic analysis of qualitative data was performed to identify PSE concepts that female individuals with persistent pelvic pain consider important and why. Twenty individual, semistructured interviews were conducted with adult females who had engaged with PSE and had self-identified as having “improved” pelvic pain. Most participants had been diagnosed with endometriosis (n = 16). Four themes were generated capturing PSE concepts considered important by female individuals with “improved” pelvic pain: (1) “A sensitised nervous system leads to overprotective pain” validated their pelvic pain as being real; (2) “Pain does not have to mean the body is damaged (although sometimes it does)” provided reassurance that pelvic pain does not mean their condition is worsening; (3) “How I think, feel, and ‘see’ my pain can make it worse” enabled participants to find optimal ways to manage their pain; and (4) “I can change my pain... slowly” provided hope that pelvic pain can improve and empowered them to pursue pain improvement as a viable goal. This study generated 4 PSE learning concepts that were important to female individuals with improved pelvic pain and may be incorporated into PSE curricula for female individuals with pelvic pain.

Keywords: Pelvic pain, Chronic pain, Consumers, Pain education, Qualitative, Pain management

1. Introduction

Persistent pelvic pain (herein referred to as “pelvic pain”) is an umbrella term for conditions often accompanied with symptoms suggestive of gynaecological, lower urinary tract, bowel, sexual, and pelvic floor dysfunction.²⁸ Although the aetiology remains unclear, biological, psychological, and social factors are believed to contribute to pelvic pain.^{2,38,86} Most guidelines recommend biomedical interventions, including surgery and medical management,⁴⁸ yet these interventions are associated with sub-optimal outcomes. For example, 20% to 40% of people experience the same or worsening pain following laparoscopic

endometriosis,^{1,84} and up to 50% require repeat surgery.⁷² Guidelines rarely recommend treatments that address psychosocial contributions to pelvic pain,⁴⁸ which may explain why people have poor clinical outcomes. Further investigations are warranted into biopsychosocial approaches to pelvic pain management to improve clinical outcomes.

Patient education is a critical component of pain management.^{25,77} Pain science education (PSE) aims to reconceptualise people’s understandings about “how pain works” and provide a rationale for a biopsychosocial approach to pain management.⁵⁶ Established PSE curricula target specific learning objectives^{40,42,58} to shift misconceptions about pain that underpin suboptimal behavioural and treatment choices.^{31,44} In line with conceptual change theories, PSE has evolved from didactic forms,⁵⁷ to contemporary education that target sustained learning about pain biology and management.⁵⁵ Pain science education is routinely recommended as a first-line intervention for persistent pain.^{31,44} Some studies suggest that PSE has limited long-term benefit for people with persistent back pain, in particular when given didactically (eg, seminars and lectures).^{15,85} However, the benefit of PSE increased when combined with active and functional goal-directed strategies^{4,6}; PSE has demonstrated clinically important benefits for people with musculoskeletal pain, including reduced pain, catastrophising, and disability.^{15,47} Furthermore, a recent network meta-analysis of psychological treatments for chronic low back pain found that pain education provides the most sustainable clinical benefits.²⁷

There is some evidence to suggest that PSE could also have an important role in the management of pelvic pain: in a preliminary

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clinical trial, pelvic floor physiotherapy in conjunction with PSE demonstrated improvements to pain intensity and pelvic pain impact scores compared with physiotherapy alone⁸; a case series has also shown PSE in conjunction with pelvic floor physiotherapy had improvements on pain intensity, coping, catastrophising, and symptoms in those with pelvic floor muscle pain⁴⁵; and a pre–post study demonstrated improved knowledge following a PSE seminar in those with pelvic pain.²⁹ These preliminary studies have adapted PSE learning objectives from extensive work in musculoskeletal persistent pain^{13,55,56} on the basis of clinical expertise. Considering the important differences between pelvic pain and persistent pain conditions, including etiology, symptoms, sociocultural context, and implications,^{52,82} further tailoring the content of PSE for persistent pelvic pain would seem a critical step towards better care.

Pain science education content has substantially changed on the basis of extensive input from consumers who have improved or recovered from various types of persistent pain.^{40,42,55,58} Whilst some people with pelvic pain have provided their voice on important PSE concepts,⁴² there is yet to be a study that investigates their experiences explicitly. Delivering educational content that consumers value is important because it promotes “personal relevance”—a critical component of engaging consumers in conceptual change in general¹⁸ and in PSE in particular.^{36,68} In this study, we aimed to identify PSE concepts that female individuals who have improved or recovered from pelvic pain consider important for their improvement and why.

2. Methods

2.1. Study design

Our qualitative study used semistructured interviews to capture rich and nuanced experiences of female individuals with pelvic pain who had engaged with PSE. Our reporting accords with the Standards for Reporting Qualitative Research⁶¹ and the consolidated criteria for reporting qualitative research (COREQ).⁸⁰ Our study protocol was registered before data collection at Open Science Framework on October 12, 2021 (<https://osf.io/tgrz6/>). Ethical approval was granted from the University of South Australia Human Research Ethics committee (no. 203392).

2.2. Participants and recruitment

Using purposive sampling, 20 adult females who self-identified as having “improved” pelvic pain were recruited for this study. Participant inclusion criteria were as follows: (1) a previous diagnosis of pelvic pain relating to a benign gynaecological and/or urological condition (eg, endometriosis and bladder pain syndrome) by a health professional; (2) self-reported that they had engaged with some version of PSE (as confirmed by the primary author through phone call or email before partaking in the interview by confirming they had an understanding of PSE “target concepts”^{40,55}); (3) living in Australia; (4) self-identified as having “improved” pelvic pain (determined by the Likert scale question before partaking in the interview—“How is your pelvic pain now compared with when you were first diagnosed?” Scale rating: much worse, a little worse, the same, a little better, and much better); and (6) proficient in English. Participant exclusion criteria were as follows: (1) having pelvic pain associated with pregnancy, pelvic infections, or tumours; (2) assigned male at birth; and (3) currently younger than 18 years.

Participants were recruited through social media (Instagram, Facebook, and Twitter) and select private pelvic health

physiotherapy clinics that facilitate PSE (Table 1 summarizes the full recruitment strategy). Of the 167 potential participants identified (Fig. 1), 53 participants were deemed eligible and 20 of those participants were purposively recruited for a spread of different ages and pelvic pain diagnoses. Demographic characteristics of the participants are summarized in Table 2.

2.3. Procedure

An open-ended interview guide was developed using a framework for semistructured interviews³⁰ and guidance from published qualitative studies that investigated experiences with pain management^{3,24,36} or with PSE^{17,46} (see File S1, supplemental digital content, <http://links.lww.com/PAIN/C18>). The interview guide was piloted in 3 phases to refine and ensure relevancy of questions. First, the guide was evaluated by the primary research team for sequencing and wording of questions. Second, we sought external assessment by an expert in semistructured interviews to refine wording of questions and their order. Last, 2 pilot interviews (not included in the final data analysis) were conducted with female individuals experiencing pelvic pain to test the appropriateness of interview questions, duration of the interview, and feasibility of the interview process.

Potential participants completed an online eligibility survey (hosted on REDcap; Vanderbilt University, Nashville, Tennessee) that explained the purpose and procedure of the study and sought written informed consent. Participants who met the eligibility criteria were contacted by AKM through email or telephone to confirm eligibility, specifically regarding their engagement with PSE. Once eligibility was confirmed, participants were instructed to complete a demographic survey (hosted on REDcap; Vanderbilt University, Nashville, Tennessee) (see File S2, supplemental digital content, <http://links.lww.com/PAIN/C18>) and book a suitable time for a one-on-one interview (hosted on Setmore.com). Participants chose either a face-to-face (at the University of South Australia Clinical Trials Facility) or online (through video conferencing software Zoom) interview; all chose to have an online interview.

Using the semistructured interview guide, participants were asked to describe what pain science concepts were important for them to learn when managing their pelvic pain condition and why these concepts were important (interview questions 4–9). For context, participants were also asked to share how they engaged with PSE (interview questions 10–15). These data were analysed by content analysis (full methods are outlined in File S3, supplemental digital content, <http://links.lww.com/PAIN/C18> and are summarized in Table 3).

Table 1
Participant recruitment strategy.

Recruitment strategy	Source
Social media	<ul style="list-style-type: none"> Melbourne Endo sisters (Facebook group) Endo Support SA (Facebook group) Managing endometriosis in Australia (Facebook group) Research teams' personal social media profiles (Instagram and Twitter)
Private physiotherapy clinics	<ul style="list-style-type: none"> Pelvic Floor Health, Walkerville, SA, Australia Aware Women's Health, North Adelaide, SA, Australia Flex Rehabilitation Clinic, Norwood, SA, Australia

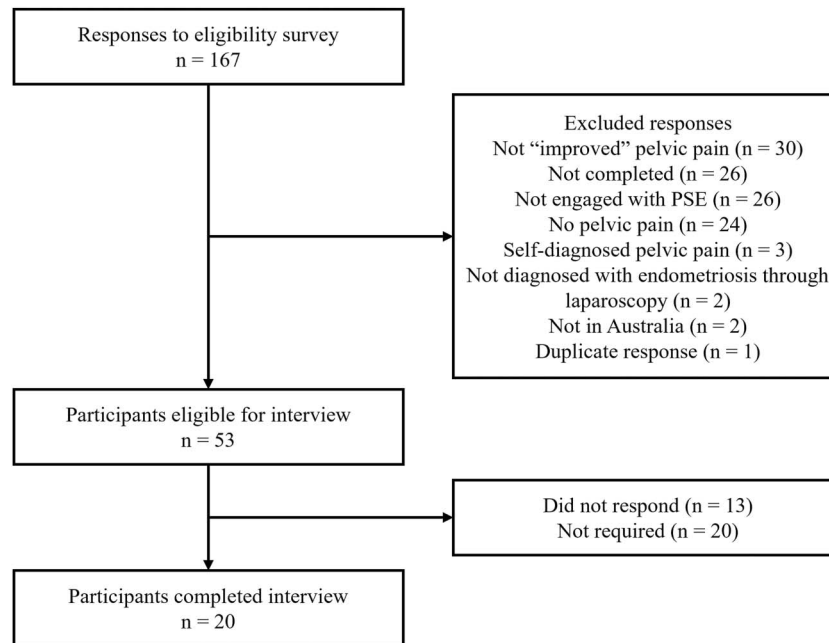


Figure 1. Flowchart of participant recruitment. PSE, pain science education.

All interviews were conducted by AKM from September 2021 to February 2022 and audio recorded using Zoom software (San Jose, California). The average duration of the interviews was 50 minutes. Participants were reimbursed with an AUD\$30 gift card for their time.

2.4. Data analysis

Demographic survey data were analysed in Microsoft Excel using descriptive statistics. All audio recordings were transcribed verbatim by OutScribe transcription services⁶³ (Littlehampton, South Australia, Australia) and checked for completeness by AKM.

Qualitative data pertaining to PSE concepts were analysed using Braun and Clarke's method for reflexive thematic analysis.^{11,12} The theoretical flexibility of thematic analysis allowed for a critical realist ontological perspective, which considers reality as independent from our thoughts and observations of it, but mediated by language and culture.¹¹ This approach allowed us to generate the most important PSE concepts for female individuals with pelvic pain from the data, whilst contextualising their experiences within the wider sociocultural meanings attached to pelvic pain. We assumed a contextualist epistemology, whereby knowledge becoming truth is contextually situated and dependent on the perspectives of the researcher.^{9,11} Therefore, the researcher's subjectivity, experiences, and perspectives are harnessed for the generation of knowledge, rather than being contained to reduce bias.¹¹ For context, the research teams have research and clinical backgrounds in physiotherapy, psychology, neuroscience, and medicine and have published in the fields of chronic pain, pelvic health, and PSE. Two authors also have lived experience of pelvic pain.

The primary researcher first became familiar with the data through conducting the interviews, listening to audio recordings, and rereading interview transcripts. Thematic analysis was conducted with a primarily inductive approach, whereby codes and themes were generated from the data. Both semantic and latent features of the data were considered throughout the

analysis.⁹ The initial coding process was performed on NVivo software (QSR International, Burlington, Massachusetts) using a recursive approach, whereby codes were developed, returned to, and revised. Codes were then clustered into an initial set of themes and subthemes. These themes and subthemes were then collaboratively reviewed among the authorship team to develop a richer, more nuanced reading of the data¹⁰ and construction of the final themes. Frequency of themes, interrater reliability, and consensus among team members were not sought because they are at odds with our contextualist epistemology and assumptions of thematic analysis methodology.^{10,62} Rather, we adhered to quality criteria relevant to reflexive thematic analysis.⁹ The final themes are presented alongside supporting quotes to produce a logical and meaningful story.¹⁴

3. Results

Four themes were generated to capture PSE concepts important for female individuals with pelvic pain, including: (1) a sensitised nervous system leads to overprotective pain; (2) pain does not have to mean my pelvis is damaged (although sometimes it does); (3) how I think, feel, and "see" my pain can make it worse; and (4) I can change my pain... slowly (**Fig. 2**). A prominent feature across the data was that people valued similar PSE concepts despite having varied pelvic pain diagnoses. However, there was diversity in how participants made sense of PSE concepts in relation to their individual experiences of pelvic pain.

Theme 1: A sensitised nervous system leads to overprotective pain

The first theme captures the importance of participants learning about changes to their "pain system" (P47, endometriosis) that occur with pelvic pain. All participants spoke about the role of the brain and nervous system in pain. One participant described nerves to be like "roads" (P22, bladder pain syndrome and chronic pelvic pain syndrome [CPPS]) for signals to travel from the body to the brain. They stated that the brain determined

Table 2
Participant demographics.

Demographic	n (%)
Age, y	
18-25	6 (30)
26-35	8 (40)
36-45	5 (25)
46-55	0 (0)
56-65	1 (5)
Gender	
Woman	19 (95)
Genderqueer	1 (5)
Highest level of education	
High school	1 (5)
Diploma or Vocational Education and Training certificate	1 (5)
Bachelor's degree	13 (65)
Postgraduate study	5 (25)
Region of residence	
Urban	18 (90)
Rural	2 (10)
Remote	0 (0)
Pelvic pain condition*	
Endometriosis	16 (80)
Chronic pelvic pain syndrome	8 (40)
Adenomyosis	4 (20)
Bladder pain syndrome	2 (10)
Vulvodynia	2 (10)
Dysmenorrhoea	2 (10)
Pudendal neuralgia	1 (5)
Multiple pelvic pain diagnoses	12 (60)
Pelvic pain duration	
<12 mo	0 (0)
1-3 y	4 (20)
4-6 y	4 (20)
7-9 y	3 (15)
>10 y	9 (45)

* More than 1 could be selected.

the level of threat or danger to an individual. In this context, pain was described as a protective mechanism.

Pain is to do with threat, and the body perceiving threat, and signals getting sent to your brain through your central nervous system. (P95, endometriosis)

Some participants made clear distinctions between acute and persistent pain. Acute pain was associated with protection from actual physical threat and tissue damage—that it is “*the body's response to being... hurt, you've been damaged, you're in danger*” (P1, endometriosis). Conversely, persistent pain was portrayed as an overprotective response to what the brain perceived to be threatening (whether actually threatening to the body or not).

Pain is pretty much always a protective mechanism, but your brain can't differentiate between what's like a real threat and what it thinks is a threat. So, it will essentially set up like this sensitisation process in which it's always going to keep thinking that like you're in danger, so it needs to protect you. (P6, vaginismus)

Many participants described how persistent pain becomes overprotective. Some attributed this to physical changes to the

Table 3
Pain science education delivery methods.

Themes (%)	Categories	Frequency (%)
Self-directed learning (90)	Books	15 (75)
	Social media	7 (35)
	Websites	6 (30)
	Academic publications	3 (15)
	Videos	2 (10)
Health professional (85)	Physiotherapist	13 (65)
	Gynaecologist	6 (30)
	Pain specialist	6 (30)
	Psychologist	6 (30)
	General practitioner	2 (20)
	Exercise physiologist	1 (5)
	Chiropractor	1 (5)
	Dietician	1 (5)
	Acupuncturist	1 (5)
Visual aids (55)	Diagrams	11 (55)
	Models	3 (15)
Pain course/workshops (30%)	Pain program	4 (20)
	Workshop	4 (20)
Education institutions (20%)	University	2 (10)
	Vocational training	1 (5)
	School	1 (5)
Social network (10%)	Friends	2 (10)
	Family members	1 (5)
Technology (10%)	Virtual reality	1 (5)
	Apps	1 (5)

brain and nervous system that “*the whole central nervous system has actually changed and adapted to how it senses pain and... therefore feeds back to you how you experience your pain*” (P44, endometriosis). Whilst for others, the mechanism underlying overprotective pain was the nervous system becoming hypersensitive to different stimuli and thus “*perceiving it to be worse than it is*” (P151, endometriosis). One participant used a metaphor of a car alarm to describe this phenomenon, suggesting that “alarms” in the body can be triggered without any apparent justification.

When one thing goes off, it's like a bunch of car alarms, so when one little organ is like, “Oh my god, I'm in pain,” everything else is just like, “Oh my god, oh my god, oh my god.” They're freaking out basically. So, that causes the whole-body mechanisms of the nausea, the pain, the depression. (P151, endometriosis)

Some participants described that hypersensitivity could be a long-term consequence of persistent pain. For example, one participant described that the brain is “*always going to keep thinking that like, you're in danger, so it needs to protect you*” (P6, vaginismus). Other conceptualisations likened pain system hypersensitivity to be “*like cement,*” or “*permanently in shit, something's wrong mode*” (P93, endometriosis). One participant described persistent pain as an automatic process due to hypersensitivity:

With chronic pain, it starts from you are actually sore, maybe there is some damage to your body, and when that happens all the time, you begin to perceive any signal, just neurological signal, from within that typical area as pain..., it's a bit like a snowball, the more that gains track, the bigger it gets and the more automatic that becomes. (P1, endometriosis)

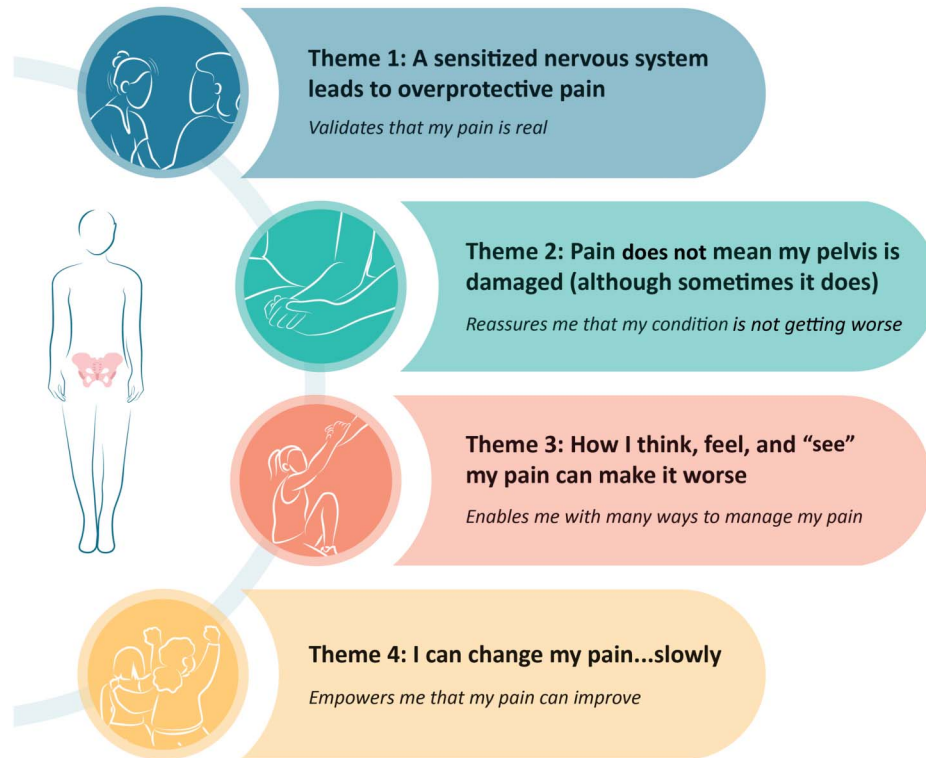


Figure 2. Important pain science education concepts for female individuals with persistent pelvic pain.

Female individuals with pelvic pain described that they valued learning about the biological mechanisms of pain because it validated that their experience of pain was real. That is, learning about how the brain and nervous system change with persistent pain provided an explanation for why they experience it. For many participants, this validation of their pain was particularly significant because it contrasted with prior dismissive comments from healthcare professionals such as “*I think you’re fine*” (P22, bladder pain syndrome and CPPS). Receiving no explanations for their pelvic pain after seeing multiple professionals led participants to describe feeling responsible for their own pain.

It was relief in that I’d been dismissed for so long, and to finally have people that were, “This is a thing,” as opposed to me thinking, “It hurts, and I don’t know.” Like you start to think, “Is it just me? Am I overthinking it?” So, it was good to have that. (P40, CPPS)

Some participants highlighted challenges they faced learning about the role of the brain in pain. Similar to their experiences of feeling dismissed by healthcare professionals, participants thought they were being told their pelvic pain was merely “all in their head,” implying that it was imaginary. However, after gaining an understanding of the biological mechanisms underlying persistent pain, participants described how they shifted the blame for their pain from themselves to their brain and nervous system.

“[The physiotherapist] showed me this picture of the brain with pain and the brain without and said ‘okay actually there’s these physical changes that have occurred in the brain’... It just made sense. All of a sudden, I’m like, ‘Oh my god it’s not me, it’s not my personality, there’s physical changes going on all this time’.” (P152, endometriosis)

Taken together, the theme “a sensitised nervous system leads to overprotective pain” describes how female individuals with pelvic pain conceptualised “how persistent pain works.” Learning about the biology of pain provided validation of their pain experience—pain is a real thing.

Theme 2: Pain does not have to mean my pelvis is damaged (although sometimes it does)

The second theme captures the value that female individuals with pelvic pain placed on learning that their pain inadequately reflects the physiological state of their pelvis. Many participants described how pain does not indicate tissue damage to the pelvis or something “*medically wrong*” (P84, endometriosis). In reference to Theme 1, one participant described how her hypersensitive nervous system was responsible for her feeling pain even without tissue damage, demonstrating a potential shift in conceptualisation of her pain being something purely biomedical towards one that encompasses contemporary pain pathophysiology and neuroscience (Theme 1). This knowledge seemingly alleviated the self-blame she placed on herself for having pain, a belief that is commonly held by people with pelvic pain.⁶⁰

I think having the knowledge of the nervous system and how [nociceptive] pain can be this ongoing thing. It doesn’t have to mean that there is something attacking my body or impacting me right now, but it can be set off by other things. That knowledge helps you not be so hard on yourself.” (P95, endometriosis)

Many participants recalled their previous misconception that pain would only be experienced in the presence of an injury or pathology. For one participant, the misunderstanding that pain must indicate tissue damage was a key contributor to a poor

quality of life. Now harnessed with this new knowledge, she described feeling a sense of agency and control over her pain—something that she did not previously have.

I suppose my understanding of it back then was everything was very physical. So, I thought my control of that situation is out of my hands. It's what my body's doing, and that's the way it is... And in that time, that affected a lot of my, yeah, ability to get to work and everything like that. So, that wouldn't have been as impacted if I knew everything that I did now." (P1, *endometriosis*)

Participants described how the belief that pain must relate to tissue pathology was reinforced by health professionals in the process of getting a diagnosis. One participant expressed how, due to the absence of demonstrable tissue damage, doctors showed little concern about her pain. She expressed a disconnect between herself as a patient and healthcare professionals; the lack of interest by healthcare professionals on conditions that do not have a pathological component led to her feeling dismissed and frustration caused by diagnostic uncertainty.

"The OBGYN's only interested if you're pregnant, have PCOS, or endo. Like that's all they really care about, and if you don't have those three things it's like too hard. And it's like your whole research is in the pelvic region, like you should be fine with that, like you should be able to be more helpful than they are. Because that was very frustrating... I remember when I came out of surgery and she was like "you don't have endo", I just started crying, and I was like "what do I have?" (P6, *vaginismus*)

Participants found it important to learn about the poor relationship between pain and pathology because it reduced their worry and fear about potential tissue damage to their own pelvis. For those with pelvic pain in the absence of tissue pathology, learning this concept reassured them that their pain "*is like a real thing*" and that it is okay to feel pain "*without a [biological] cause*" (P6, *vaginismus*). For others, the reassurance they developed through learning that pain doesn't equal tissue damage was further emphasised through their descriptions of gradually returning to meaningful activities—seemingly a mindset shift from "I can't" to "I can." Participants also described that pain could be felt despite there being no damage to the pelvis, which alludes to the notion of "sore but safe" (a phrase used in PSE resources⁸⁸). One participant explained how knowing about the brain's role in pain was useful for reconceptualising it as a protective mechanism, rather than a marker of tissue damage. As such, she was able to reassess and change her behaviour from what she thought to be "*minimis(ing) damage*" (P47, *endometriosis*) (ie, limiting movement) to that which was more in line with her goals and priorities.

I've learnt that pain doesn't equal damage, so that's been really important because when I thought pain equalled damage, I did everything I could to minimise pain, because I wanted to minimise damage. But I've learnt that that's not what's happening; that pain is the protect mechanism of the brain... I was scared of doing yoga, and now—because I would hurt sometimes - and now I'm like, I'm back at yoga regularly. (P47, *endometriosis*)

Although it was important to understand that persistent pain and pathology do not always relate, many participants with endometriosis described that it was important to be aware that

pain could *sometimes* be a sign of tissue damage or pathology. Participants emphasised the importance of recognising endometriosis as a cause of pelvic pain because receiving their diagnoses was a poignant moment that validated many years of pain and suffering.

It's a feeling of relief (to get an endometriosis diagnosis) ... yes, I'm not insane, yes, this is something. Everyone that was telling me that it was in my head or it's just IBS or it's stress or whatever is just wrong... it was very validating. (P94, *endometriosis*)

For those with endometriosis, learning the concept that pain and tissue damage inadequately relate also reassured them that pain did not indicate a relapse or worsening of their condition. For example, one participant described feeling relief after being told that her pain post laparoscopy was real "*but it's not endo*" (P51, *endometriosis*). Whilst another participant explained that pain did not indicate endometriosis progressing, rather her hypersensitive nervous system made her experience more pain than necessary.

"I went and saw the pain specialist... She said, "You have pain in your uterus. You're very swollen and inflamed, and there's lots of inflammation." But she said, "The pain you have... It's actually becoming more heightened every time you experience pain." (P19, *endometriosis*)

Extending on this, one participant suggested that it was especially difficult for people with endometriosis to understand that pain does not always indicate damage. She explained that people find it difficult to understand pelvic pain does not always mean there is endometriosis because the biomedical model of pain is so integrated into not only the experience but also the conventional management of endometriosis.

"I think it's such a hard concept in endo because everyone thinks if you've got pain it's because you've got endo there, and if you have your endo chopped out, you're going to not have pain anymore. We know that that is entirely not the fact at all anymore and there's no evidence to support that." (P44, *endometriosis*)

Taken together, the theme "pain does not have to mean my pelvis is damaged (although sometimes it does)" describes how female individuals with pelvic pain conceptualise the poor relationship between pain and tissue pathology and the importance this learning has on reassuring them that pain does not mean further damage to the pelvis.

Theme 3: *How I think, feel, and "see" my pain can make it worse*

Building on Theme 2, in that pain is not merely influenced by tissue damage, this theme captures the importance that participants placed on learning how pelvic pain can be influenced by many things, namely psychological factors. Frequently, participants described how unhelpful thoughts made pelvic pain worse. That is, "*if you expect pain*" (P68, *endometriosis*), and fixate on pain, it would be amplified. One participant described how focusing on pain made it worse and that this was not an indication of damage to the body.

"So how you think about pain matters... if you focus on it or whatever, it's probably going to feel worse... just because you're doing something and you're in pain doesn't mean

you're actually going to hurt your body necessarily.” (P84, *endometriosis*)

Similarly, some participants noted how words about pain could influence their pelvic pain. The phrase “trigger words” was used by participants to articulate emotive phrases used to negatively describe their pain, for example, “my sacrum being crushed backwards into my spine” (P44, *endometriosis*). One participant described how these “trigger words” could contribute to pain and make pain worse. As such, she would actively rephrase the language she used when conceptualising and describing her pain, inferring that this was something that could be harnessed to manage her pain.

“We looked at my trigger words which I think were, ‘This is going to go on forever’. ‘I have this the rest of my life’. ‘This hurts so bad’. ‘I’m in so much pain’. Then we had to look at shaping them to other things so that if I didn’t exercise, or if I started feeling cramps, my brain didn’t automatically go to those trigger words and then start that, ‘Oh, there’s pain. Let’s make it worse.’” (P19, *endometriosis*)

The medical context of being labelled with a pelvic pain diagnosis and “seeing” medical imaging was also described as a factor that could influence pain. One participant described that the combination of physically “seeing” tissue damage through scans alongside the names of diagnoses that she associated with negative connotations was enough to induce a pain response. These descriptions align with the theoretical “neuromatrix” model of pain—that pain is an output involving multiple systems and is activated by an individual-specific “pain neuromatrix” when the brain concludes that the body is in danger, whether that be actual or potential.⁵³

“If you look at an MRI, the chances of you healing from something chronic lessen because you’ve got physical evidence, and then throw in some really complex names of things... painful bladder syndrome, interstitial cystitis, endometriosis, like they’re all very complex and they’re pretty scary names, like none of it sounds like rainbows and lollipops—pudendal neuralgia, pudendal nerve entrapment—like it sounds really fucking hectic, and it sounds scary, so your brain’s like ‘oh my god, this is really, really bad, we’re in a bad way here, like holy shit, bunkers down, like, can’t do anything.’” (P58, *bladder pain syndrome and pudendal neuralgia*)

Participants conceptualised that the nervous system held a central role in explaining how psychological factors can influence pain. Linking to Theme 1, they described stress and anxiety as factors that increase pain by “*making the nervous system excited*” (P84, *endometriosis and vaginismus*). As such, the brain perceives that something is physically wrong and requiring action, such as reduced activity, as inferred by the quote below:

“I can see like the link with anxiety there, if like it’s making you anxious and you have pain, you’re less likely to do it because you think that there’s something physically wrong, which is just like a protective mechanism, but kind of a protective mechanism on steroids.” (P6, *vaginismus*)

For some participants, learning about the psychological influences on pain was important, but it was initially challenging. They first perceived it as invalidating, implying that their pain was “all in their head” and therefore not real. Many participants

reported being diagnosed with comorbid mental health conditions and felt saddened to think that they inadvertently contributed to their own pain.

I felt sad because knowing, or feeling like there probably was somewhat of an anxiety component as well, there were parts of me that were like, “Did I cause all this though? Have I contributed to it in part because of being anxious?” (P40, *CPPS*)

Learning that there was a range of contributors to pain was important for participants because it enabled them to find optimal ways to manage their pain: “*there are so many different ways of managing [pain]*” (P7, *endometriosis*). Participants described using various strategies to reduce pain, including exercise and movement, mindfulness, cognitive reframing, and breathing practices, which they said acted directly on their hypersensitive nervous system.

“You like work on your deep breathing, so you’re really like trying to dampen that sympathetic nervous system response.” (P6, *vaginismus*)

Participants described that the value of learning how pain can be influenced by psychological factors was that it provided the context for *why* certain pain management strategies may be helpful. They emphasised a critical aspect was the pairing of education with self-management strategies. Merely learning about the multifaceted nature of pain in isolation would be disempowering because they also needed strategies to use their understanding to improve their pelvic pain.

A lot of the education was paired with action which was really helpful because I think if she had just given us a huge amount of information on, this is what’s happening, this is what’s wrong, this is why it’s like that, I think the information could have been dis-powering. (P68, *endometriosis*)

Similarly, discussing only self-management strategies without learning why they are useful would be “*disrespectful*” (P58, *bladder pain syndrome & pudendal neuralgia*). Some participants highlighted that they would have been reluctant to adopt any self-management strategies without education because those strategies seem counterintuitive to their previous biomedical understanding of pain management.

“If you don’t understand how pain works, all the different suggestions seem, ‘How does that make sense... You’re asking me to exercise... moving hurts, exercise hurts. Why is this your suggestion?’” (P1, *endometriosis*)

Taken together, Theme 3 describes how female individuals with pelvic pain valued learning how pain is influenced by many things, particularly psychological factors, thus allowing participants to find other ways to better manage their pain.

Theme 4: I can change my pain... slowly

Theme 4 describes the importance of learning that pelvic pain can change and improve over time, albeit slowly. Some participants highlighted that pain is “*not a permanent state*” (P94, *endometriosis*) and that it could be changed for the better.

“Just because I’m feeling pain at the moment, that doesn’t mean it’s going to last.” (P1, *endometriosis*)

Participants drew on their understanding of “how pain works” (Theme 1) to explain the biological mechanisms for how pain improves. The process of changing one’s pain was said to involve “rewiring” the nervous system and “retraining” the brain, referring to the concept of bioplasticity.⁵⁴ One participant also likened the brain to “a lump of Play-Doh” that can be “*reshape(d)*” (P94, endometriosis) to demonstrate its plasticity. Some participants found comfort in labelling their pain as “neuroplastic”—if their pain system had changed to become hypersensitive, then it could just as well change to become less sensitive.

“My pain is not structural, I believe it’s neuroplastic which is massive, and I can see a way out through the pain reprocessing stuff.” (P58, bladder pain syndrome and pudendal neuralgia)

To describe how they implemented strategies to change their pain, participants tied together the concept of bioplasticity with their active role in managing their pain. Participants said that using active pain management strategies unique to their pain experience directly resulted in the neurophysiological changes required for an improved pain experience.

“Medication wasn’t the answer... but changing my way of thinking around how pain works and knowing that I can turn down my experience of pain is what helped me.” (P11, endometriosis)

Learning that pelvic pain can change and improve was important to participants because it provided a sense of hope and optimism that pain “*wasn’t a forever thing*” (P68, endometriosis). Facilitating hope through understanding that pain can change seemed to be the catalyst for empowering participants to persevere with their pain management strategies, even when their motivation was low. Not only were participants hopeful for change, they were also empowered to make the change because they were armed with the required knowledge and tools.

“There is a lot of reassurance from learning about [pain] and empowering like if you understand what’s happening to your own body you don’t feel so out of control.” (P68, endometriosis)

With a sense of hope and empowerment, participants described feeling more in control of their pain. Some participants described how they now put the onus of rewiring and retraining their pain system onto themselves rather than health professionals. For one participant, she described herself as the “healer” of her pain, and this was a seemingly critical component for how she applied her understanding of how pain can change.

“I kept seeking other people to be the amazing healer in my life, and what I found through this ‘Explain Pain’ journey is that it has to be me. I have to be the one who is the magical healer of myself, and that’s been quite a revelation.” (P47, endometriosis)

Although participants found benefit in learning about the modifiability of their pelvic pain, they also stressed that this process was slow and arduous—it was “*the hardest thing to do*” (P47, endometriosis). Some participants reported feeling frustrated by previous “quick fix” pain management strategies that did not improve pain in the long-term. One participant highlighted the challenge of maintaining motivation to continue working on herself and implementing

behaviours to help reduce her pain and emphasised the necessity for persistence.

“[Changing pain] a slow process, so you can’t just like go from, you know, “I validate my pain all the time and I worry about it all the time to like it’s fine, whatever.” You can’t just stop that overnight.” (P84, endometriosis and adenomyosis)

Another participant described how people with endometriosis may find it difficult to apply the concept that pain can change to their experience of pain. They attributed these challenges to the pathological component of endometriosis-associated pain, coupled with societal misconceptions that pelvic pain cannot improve.

“People think that I’m this sick now, it’s only going to get worse because again, endo is a recurrent disease. So, they just assume that there’s no way out of it and I think, a lot of people also assume that after their surgery, that is as good as it gets.” (P94, endometriosis)

One participant firmly believed that her pelvic pain would never improve completely. She described decades of dismissal and trauma associated with her pelvic pain and significant grief for the life they may have had if her pain had been taken seriously by health professionals. They highlighted that learning about how pain can change needed to be done with sensitivity because “*some people don’t get to improve*” (P152, endometriosis).

“I don’t know that I will sort of be pain free ever... I deal with grief and the loss of what I can and can’t do in my life every day and that’s how I manage it. I’m not expecting myself to get to a point where I’m better or I’m not struggling.” (P152, endometriosis)

Taken together, the theme “I can change my pain... slowly” describes how it was important for female individuals with pelvic pain to learn that pain can change over time (albeit slowly) because it provided them with hope and empowerment that with perseverance, their pain can improve.

4. Discussion

This study aimed to identify PSE concepts that female individuals with pelvic pain consider important for their improvement and why. Four themes were generated using reflexive thematic analysis to represent important PSE concepts. The first theme captured how learning about the biological mechanisms of persistent pain was important for female individuals with pelvic pain because it validated their pain as real. The importance of validation is not new—people with persistent pain frequently report their desire for validation and recognition of their pain.^{49,81} Validation of pain may be particularly poignant for female individuals with pelvic pain because of the extensive history of prejudice and dismissal of their pain, particularly by healthcare professionals.^{65,87} In this study, participants described feeling dismissed when they were told their pain was “all in their head”. That learning “how pain works” legitimises and makes sense of pain experiences^{65,76} aligns with care priorities identified by a broader cohort of consumers with persistent pain.⁷⁵ Providing a biological explanation for persistent pain may be particularly validating for people who have previously blamed themselves for their pain.^{35,67}

Female individuals with pelvic pain valued learning that pain does not always indicate damage to their pelvis (Theme 2). The

poor relationship between pain and pathology is well documented across persistent pain states. Regarding pelvic pain, for example, there is no correlation between the stage of endometriosis and associated pain and symptoms,^{19,83} and pelvic pain can exist without identifiable tissue damage (eg, vulvodynia).^{37,66} Participants, particularly those with a diagnosis of endometriosis, also emphasised, however, the importance of acknowledging pathological contributors. Many qualitative studies have highlighted “the power of the visible”⁴⁹; a pathological explanation of pain often legitimises the experience and provides a sense of control,^{7,26,49,82} although this likely reflects the dominance of a structural pathology understanding of “how pain works,” rather than a more contemporary biopsychosocial understanding. Participants in this study frequently expressed that understanding that pathology is just one contributor to their pain, rather than the singular cause, was itself validating. That is, although previous studies have found that female individuals with pelvic pain seek reassurance through a diagnosis of pathology through laparoscopy and ultrasound,^{50,65} this study suggests that learning that increased pain does not mean worsening or undetected pathology is itself reassuring.

Participants valued learning that pain can be influenced by a variety of factors, notably their thoughts, feelings, and the language used to describe their pain (Theme 3). Understanding the biopsychosocial model of pain has been routinely endorsed as a key PSE concept for other pain populations,^{20,39,51,55} particularly because PSE provides a biological explanation for why psychosocial (eg, psychological therapy) and self-management strategies can be effective. Female individuals with pelvic pain strongly emphasised the need to couple PSE with practical strategy advice—one without the other was seen as meaningless and disempowering or disrespectful. This supports the notion that PSE interventions should be delivered as one component of a multimodal treatment approach rather than in isolation.⁵⁶ Certainly, PSE combined with other active interventions has been demonstrated to have greater efficacy on reducing pain and disability than one component alone,^{15,47} and a recent network meta-analysis suggested that combination imparts the most sustainable improvements in people with low back pain.²⁷ One qualitative study has highlighted the frustration people with persistent pain felt following pain education in the form of a single written article: they were left pondering what to do about it³⁵ (one might also doubt the likelihood of sustained learning with such an approach). Young adults with persistent pain have also described that learning about the biological link between stress and pain empowered them to engage in self-management strategies.⁴¹ There seems a compelling argument that integrating education about psychosocial and active self-management interventions with the biological justification for those interventions may well assist with their uptake and ultimately improve outcomes.

Female individuals with pelvic pain valued learning that their pain can change and improve over time (Theme 4), aligning with the wider concept of bioplasticity.⁵⁴ Understanding the bioplastic nature of the pain system is a common learning concept in PSE interventions.^{13,40,55} To conceptualise bioplasticity, participants used easily accessible metaphors, such as “rewiring” or “retraining” the brain and nervous system. Similar metaphors have been used by clinicians to explain other complex pain states.^{21,40,88} Metaphors about pain have also been demonstrated to have therapeutic value, particularly for self-efficacy and empowerment.⁷⁸ In this study, understanding that pain can change provided hope, empowerment, and agency over pain.^{40,42} This may be particularly so for those without a pelvic pain diagnosis nor obvious pathological contributor or when

removing a pathological contributor (eg, endometriosis) has not fully ameliorated symptoms.

The 4 themes generated here share similarities to concepts valued by people with other persistent pain conditions. For example, PSE concepts iterating that persistent pain is over-protective, pain does not equal tissue damage, and pain is influenced by many factors have been said to be important to learn for people with musculoskeletal pain conditions^{42,67,79} and complex regional pain syndrome.⁵¹ These concepts are also similar to those in existing PSE resources,^{13,55} which is not surprising given that participants learned through these resources (eg, Explain Pain¹³) and no curriculum has been empirically developed for pelvic pain. Given the similarities, existing PSE resources may be beneficial for female individuals with pelvic pain. In particular that despite the variability in how participants learnt PSE, these concepts were routinely described as being important to learn by participants. However, female individuals with pelvic pain did value some distinct concepts. Participants emphasised the importance of learning that pain can be an indicator of tissue pathology, which may be because they report dissatisfaction with clinicians who dismiss tissue pathology and feel validated when a pathological diagnosis is attributed to their pain.^{73,74,76} This concept differs from those used in existing PSE resources, which describe how pain is *not* equal to tissue damage.⁴⁰ Commonly, PSE resources describe learning about the disproportionate relationship between pain and tissue *injury*.^{13,55} Female individuals with pelvic pain may not find this concept relevant because their pain is not due to an injury but rather in relation to pathology (eg, endometriosis), their menstrual cycle,⁷⁰ or neuroimmune factors.⁶⁶ This emphasises the importance of developing PSE curricula with consumers to ensure personal relevance, a key factor for promoting engagement with education interventions.^{36,68}

Interpretation of this work should consider its strengths and limitations. We lodged our protocol before data collection, a step now recommended in pain research⁴³ and clinical research more broadly. We purposively sampled from a wide volunteer pool to ensure age representation. However, despite aiming to achieve diversity in our sample through recruiting from pelvic pain clinics and social media, our sample was relatively homogenous. That is, most of the participants were aged 35 years or younger, had at least a bachelor degree, lived in urban areas, and had a diagnosis of endometriosis. Further studies encompassing a more diverse cohort are necessary to ascertain the broader applicability of our research findings. Our sample was also predominantly WEIRD (Western, Educated, Industrialised, Rich, and Democratic),²³ which also applies to much previous research into PSE⁶⁴ (although there are exceptions^{22,59,71}) and pelvic pain more broadly.¹⁶ We limited demographic data collection to minimise participant burden, but considering the increasing recognition of social determinants in both chronic pain outcomes^{32,34} and health education outcomes,³³ this represents a potential shortcoming. Clearly, conceptualisation and application of PSE needs to consider individual circumstances.^{5,69} We also did not aim to standardise the “dose” and delivery methods of PSE recruited participants had engaged with because we wanted to understand how female individuals with pelvic pain are currently engaging with PSE in clinical practice. We acknowledge that how participants engage with PSE would influence what content was taught and subsequently the concepts they find important. Finally, it would also be helpful to learn from female individuals with pelvic pain who engaged with PSE but did not improve and with others who did not engage with PSE and did improve. The participants in this study had all participated in some version of PSE as part of their care. Our study design does not allow for any

conclusions that their improvement were a direct result of that intervention, but equally, we cannot presume that participation in other interventions may result in different learnings that are also linked to recovery. Further investigation of these matters should lead to a deeper understanding of barriers to, and enablers of, recovery for female individuals with pelvic pain.

Future research may use the concepts generated in this study as a basis for developing a PSE curriculum for female individuals with pelvic pain. The development of such curriculum may also integrate concepts valued by clinicians who deliver PSE, which should also be further investigated (ie, what expert clinicians think to be important PSE concepts for pelvic pain), as well as how PSE should be delivered. Whilst this study investigated people who have “improved” pelvic pain, it would be pertinent to test a PSE curriculum in a clinical trial to determine its efficacy on clinical outcomes. It would also be helpful to learn from those who do not find benefit from the PSE curriculum so it can be further modified and optimised. These investigations align with educational and care priorities identified by consumers and clinicians,^{39,41,51,58,73} as well as research priorities highlighted in national endometriosis guidelines.^{61,70} The current work also provides a suitable platform for consumer-led and codesign studies, in which female individuals with pelvic pain are “fully engaged” in the research process, including intervention development.

5. Conclusions

We generated 4 themes that capture pain science concepts most valued by female individuals with improved pelvic pain. These results provide a starting point for developing PSE curricula for female individuals with pelvic pain. Further research with more diverse samples, including expert clinicians, and codesign of PSE resources is required.

Conflict of interest statement

A. K. Mardon has been reimbursed by professional organisations for travel costs related to presentations of research on pelvic health at conferences. K. J. Chalmers has received speaker fees for lectures on physiotherapy and pain. Professional bodies have reimbursed her for travel costs related to presentations of research on physiotherapy and pain at scientific congresses. R. Parker receives payment for lectures on pain and rehabilitation. Professional bodies have reimbursed her for travel costs related to presentation of research at scientific conferences and meetings. R. Parker is a director of the Train Pain Academy, a not-for-profit educational organisation. R. Parker has no conflicts of interest related to this work. G. L. Moseley has led a research program developing, testing, and implementing pain science education programs. Professional and scientific bodies have reimbursed him for travel costs related to presentations of research on pain education at scientific conferences/symposia. He has received speaker fees for lectures on pain and rehabilitation. He receives book royalties from NOIgroup publications, Dancing Giraffe Press and OTP for books on pain education. He has received support from Institutes of Health, California; AIA Australia; Reality Health' Connect Health, United Kingdom; and Kaiser Permanente. H. B. Leake has received speaker fees for talks on pain. The remaining authors have no conflict of interest to declare.

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