I’m in Charge, But Not Always in Control: A Qualitative Exploration of Women’s Beliefs and Knowledge About Their Pelvic Pain

a1798869

This thesis is submitted in partial fulfilment of the Honours degree of Bachelor of Psychology (Advanced) (Honours)

[Name removed for anonymity]

School of Psychology

The University of Adelaide

September 25th, 2023

TOTAL WORDS: 6895

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Abstract

Beliefs and knowledge about pain can influence how an individual approaches pain management. At present, beliefs and knowledge that women hold about their pelvic pain have not been investigated; therefore, treatment approaches may not be targeted at current patient understandings. Exploring such beliefs and knowledge may help inform and subsequently improve treatment outcomes by allowing for more tailored content to be delivered. This study aimed to fill this gap in the literature by identifying beliefs and knowledge that women hold about their pelvic pain, guided by the Common Sense Model. Semi-structured interviews (*n*=12) were conducted with questions relating to the identity, cause, consequence, control, and timeline beliefs that participants hold about their pain. The transcribed interviews were analysed using an Interpretive Description Framework, which is a qualitative approach that aims to develop clinically applicable knowledge. Participants tended to report a biopsychosocial understanding of pain; however, many participants described their own pain experience in a way that was more aligned with the biomedical model of pain, suggesting incongruence in pain understandings. Pelvic pain was perceived to be disruptive of life, both at present and into the future, with predictability of pain varying over time. Participants valued their ability to take charge of their pain management, highlighting bodily autonomy and being proactive in treatment approaches. This approach to management did not provide total control over participants’ pelvic pain. This study provides recommendations for clinicians, especially in terms of providing pain science education and equipping patients with helpful representations of their pain.

Key Words: Pelvic pain, Common Sense Model, Patient perceptions, Health knowledge, Qualitative research

Declaration

This thesis contains no material which has been accepted for the award of any other degree of diploma in any University, and, to the best of my knowledge, this thesis contains no material previously published except where due reference is made. I give permission for the digital version of this thesis to be made available on the web, via the University of Adelaide’s digital thesis repository, the Library Search and through web search engines, unless permission has been granted by the School to restrict access for a period of time.

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September, 2023

Contribution Table

ROLE	ROLE DESCRIPTION	Student Researcher	Internal Supervisor	External Supervisor	Additional Team Member 1	Additional Team Member 2
CONCEPTUALIZATION	Ideas; formulation or evolution of overarching research goals and aims.	X	X	X	X	X
METHODOLOGY	Development or design of methodology; creation of models.	X	X	X	X	X
PROJECT ADMINISTRATION	Management and coordination responsibility for the research activity planning and execution.		X	X		
SUPERVISION	Oversight and leadership responsibility for the research activity planning and execution, including mentorship external to the core team.		X	X		
RESOURCES	Provision of study materials, laboratory samples, instrumentation, computing resources, or other analysis tools.					
SOFTWARE	Programming, software development; designing computer programs; implementation of the computer code and supporting algorithms; testing of existing code.					
INVESTIGATION	Conducting research - specifically performing experiments, or data/evidence collection.	X				

VALIDATION	Verification of the overall replication/reproducibility of results/experiments.			X	X	
DATA CURATION	Management activities to annotate (produce metadata), scrub data and maintain research data (including software code, where it is necessary for interpreting the data itself) for initial use and later re-use.					
FORMAL ANALYSIS	Application of statistical, mathematical, computational, or other formal techniques to analyze or synthesize study data.	X	X	X	X	
VISUALIZATION	Visualization/data presentation of the results.	X				
WRITING – ORIGINAL DRAFT	Specifically writing the initial draft.	X				
WRITING – REVIEW & EDITING	Critical review, commentary or revision of original draft		X	X	X	X

[ACKNOWLEDGEMENTS]

[Removed for anonymity]

1. Introduction

1.1 Background

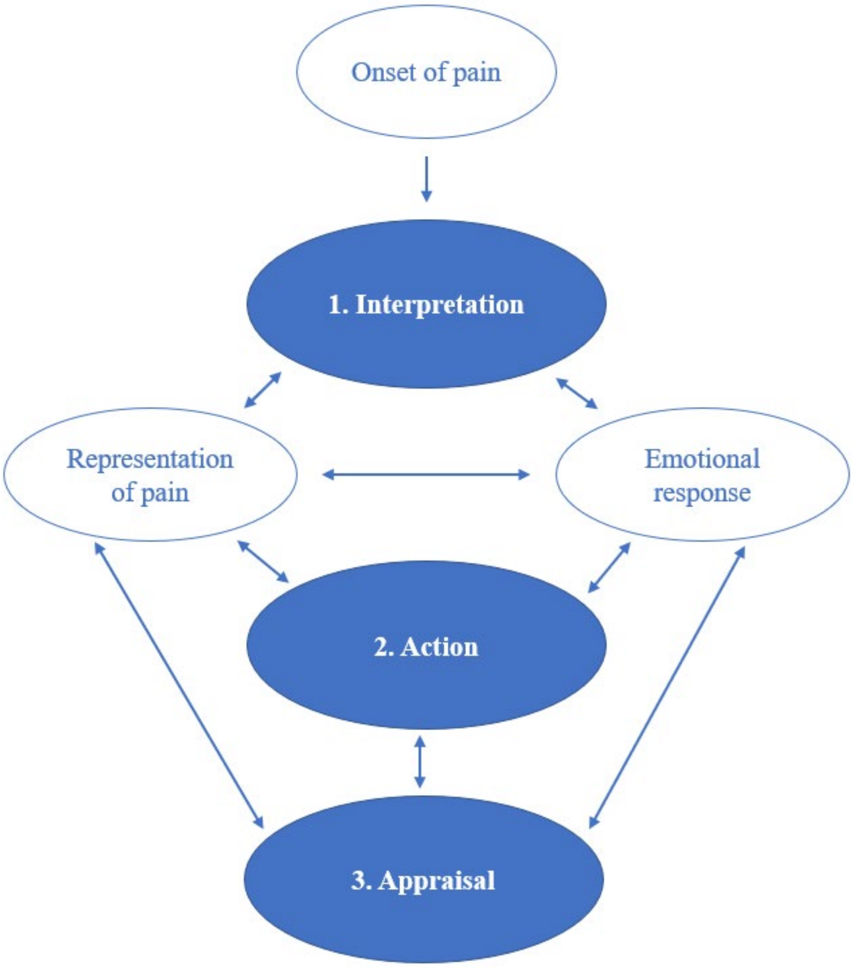
Persistent pelvic pain (herein referred to as pelvic pain) is an umbrella term for a range of conditions, which involve persistent or recurrent pain lasting >6 months in the pelvis or structures related to the pelvis (Merskey & Bogduk, 2011). Endometriosis, adenomyosis, and dysmenorrhoea are all conditions associated with pelvic pain in women (Evans, 2015), and it is estimated that up to 25% of women will experience pelvic pain in their lifetime (Ahangari, 2014). Pelvic pain is often debilitating and can result in decreased productivity (Schoep et al., 2019), as well as absenteeism and presenteeism from work and education (Armour et al., 2020). Productivity-related costs have been demonstrated to have the biggest financial impact on women with pelvic pain, accounting for approximately 75% of total condition-related costs (Armour et al., 2019a). Individuals with pelvic pain may also experience social consequences, such as isolation from friends and family, and avoidance of intimacy (Chalmers et al., 2017; Mellado et al., 2016). Pelvic pain also has a psychological impact, with the prevalence of depression and anxiety symptoms being significantly higher in people with pelvic pain than in the general population (Siqueira-Campos et al., 2019).

1.2 The Common Sense Model

The Common Sense Model (CSM) describes how beliefs can influence pain. The CSM outlines the interplay between an individual's interpretations, actions, and appraisals of their condition, whilst also considering their emotional responses and cognitive representation of their pain (see Figure 1) (Bunzli et al., 2017). An individual's representation of their pain consists of a series of 'common-sense' beliefs, including one's understanding of what the pain is (identity), what caused the pain (cause), the associated consequences of the pain (consequences), how the pain can be controlled (control), and the expected duration of the pain (timeline) (Leventhal et al., 2016). The CSM poses that an individual's representation of their pain influences how their pain is perceived, and how they respond to pain behaviourally and emotionally. The model is therefore useful for understanding how individuals make sense of their pain, which in turn influences management behaviours (Bunzli et al., 2017). Previously, the CSM has been applied to various pain populations including people with hip (de Oliveira et al., 2020) and back pain (Bunzli et al., 2017) to explore how patients make sense of their pain.

Figure 1

The Common Sense Model



Note. This figure demonstrates the CSM. When individuals experience the onset of pain, they initially form an interpretation of the pain based on their perception of symptoms and the social context. Next, they form a representation of pain based on a series of beliefs and respond to the pain emotionally. Individuals then engage in actions based on the representations and emotional response. Finally, the effectiveness of actions are appraised and the model is continually updated. Adapted from (Bunzli et al., 2017).

Whilst the CSM has not explicitly been applied to women with pelvic pain, previous research has investigated how women describe the onset of pelvic pain, how they interpretate their condition, and how they respond emotionally to their pain and diagnosis. Women’s interpretations of pelvic pain is in part linked to social understandings that menstrual pain is ‘normal’ (Armour et al., 2021). In addition to this, studies have consistently found that when women present to healthcare settings for their pelvic pain, they often feel dismissed (Hawkey et al., 2022; Young et al., 2015). The feminisation of pain can also be considered in this interpretation, as women’s pain is often viewed as emotional and taken less seriously (Hawkey et al., 2022). In terms of emotional responses, women have described feeling validated when they were provided with a diagnostic reason for their pain, and subsequently hopeful for treatment options (Toye et al., 2014). However, with varied levels of success with treatment, women with pelvic pain are also likely to engage in catastrophic thinking about their condition, and experience high levels of depression and anxiety (Till et al., 2019). The actions women take regarding their pelvic pain are also known. Research has suggested that many women with endometriosis engage in self-management strategies to take action over their condition (Armour et al., 2019b); however many of these strategies have no significant effect on symptoms (Mardon et al., 2023). Medication is also a common treatment action for dysmenorrhoea, with one study suggesting that young women predominately use over the counter medications, and approximately one third use an oral contraceptive to manage their pain (Armour et al., 2021). Despite these understandings, the literature is yet to identify the representations that women hold about their pelvic pain. Gaining this understanding will strengthen the applicability of the CSM in a pelvic pain context and may allow for more tailored treatment approaches.

1.3 Pain Science Education

Pain science education (PSE) is an established form of education aimed at improving someone’s understanding about pain in line with contemporary pain science. PSE is underpinned by conceptual change theories, in that rather than adding to one’s knowledge, it addresses misconceptions held about pain (Moseley & Butler, 2015). By reconceptualising their understanding about pain, individuals can begin to view their pain as an over-sensitive response from their nervous system, rather than a measure of tissue damage or injury (Louw et al., 2016). Consequently, this shift in perspective encourages individuals to participate in health promoting behaviours such as exercise and health care utilisation (Louw et al., 2016). Understanding people’s beliefs about pain has enabled the development of PSE interventions tailored to persistent pain conditions. For example, Darlow et al. (2018) found that people with osteoarthritic knee pain held the misconception that their knee pain was due to ‘wear and tear’ in their joints and subsequently stopped engaging in exercise out of fear of making their pain worse. A PSE resource has now been developed to specifically target this misconception and help people with osteoarthritic knee pain re-engage with exercise (Stanton et al., 2020).

A current barrier to delivering effective PSE in people with pelvic pain is an absence of information about what people currently know and believe about their pelvic pain. Without understanding what people with pelvic pain believe and understand about their pain, PSE resources are unable to target potential misconceptions. Such knowledge may refine current education approaches to be more appropriate for the population, and thus improve clinical outcomes.

1.4 Rationale

Despite the body of evidence regarding people’s beliefs about different persistent pain conditions, there is a gap in the literature regarding the beliefs and knowledge held by women with pelvic pain. This study was designed to address this gap through the aims listed below.

1.5 Aims

This study aimed to explore the beliefs and knowledge that women hold about their pelvic pain. Through the lens of the CSM, representations of pelvic pain were analysed. As such, this study sought to answer the research question, ‘how do women with pelvic pain perceive and understand their pain?’.

2. Methods

The study was approved by the University of Adelaide Human Research Ethics Committee [number removed for anonymity]. A protocol was prospectively registered on Open Science

Framework [hyperlink removed for anonymity] on [date removed for anonymity]. The study is reported in accordance with the Standards for Reporting Qualitative Research (see Appendix 1) (O’Brien et al., 2014). Participants provided informed consent prior to participating in the study.

2.1 Study Design

This study used an Interpretive Description framework, which aims to answer research questions in a clinically useful manner (Thorne et al., 1997). As such, the analysis drew on clinical understandings of pelvic pain in relation to the CSM to construct themes from the data, with an overarching goal of informing clinical practice.

Semi-structured, individual, video-recorded interviews were used to allow for rapport-building and privacy during the interview, which is desirable when discussing potentially sensitive topics (Dempsey et al., 2016). Semi-structured interviews have previously been used for numerous investigations into pain beliefs, with populations including people with hip pain (Haber et al., 2023) and knee pain (Wallis et al., 2019).

2.2 Participants and Recruitment

2.2.1 Inclusion Criteria

Eligibility requirements included being assigned female at birth, aged ≥18 years, having persistent pelvic pain lasting ≥ 6 months, ability to communicate in English, and having access to the internet and Zoom video conferencing software (Zoom Video Communications, 2023). Participants were excluded if they had persistent pelvic pain associated with pregnancy, infection, or tumours.

2.2.2 Recruitment

Participants were recruited by purposive sampling using the criterion-i strategy (Palinkas et al., 2015) to allow for a diverse range of perspectives to be captured, with attempts made to account for age, level of education, socioeconomic status, employment, relationship status and diagnosis. The intended sampling quotas are listed in Table 1.

Table 1

Sampling Quotas

Demographic Measure	Categories of Participants
Age	≥1 person in each category: 18-29, 30-39, 40-49, 50-59, >60
Level of education	≥1 person in each category: Not completed high school, completed high school, diploma/certificate/other, Bachelor’s Degree, Masters/PhD
Socioeconomic status	≥1 person in each quartile of the Index of Relative Socio-economic Disadvantage (IRSD) (Australian Bureau of Statistics, 2023)
Employment	≥1 person in each category: unemployed, <10 hours/week, 10-35 hours/week, >35 hours/week
Relationship status	≥2 people in each category: single, in a relationship, de facto/married
Diagnosis	No more than 6 participants with endometriosis as their only condition

2.2.3 Sample Size

Based on previous studies of a similar nature (Darlow et al., 2018; de Oliveira et al., 2020) we initially aimed to recruit 12-16 participants for this study. Recruitment was undertaken with the intention of the exact number of participants being determined when our targets for purposive sampling were met and when the research team agreed that themes constructed would not be influenced by the inclusion of additional participants.

2.3 Procedure

Recruitment materials were advertised on social media and in pelvic health physiotherapy clinics. QR codes and URL links on recruitment materials directed interested participants to an online eligibility survey, hosted on the Qualtrics platform (Qualtrics, 2023). An information sheet was provided at the beginning of the eligibility survey, and participants were required to give consent via a checkbox before proceeding to the survey. The eligibility survey screened participants according to the inclusion and exclusion criteria, and demographic information was collected for participants selected for an interview.

Once participants had completed the eligibility survey, those selected were invited via email to participate in a one-on-one interview online. Interviews were conducted between July and August, 2023, by the student researcher, who is a female Honours (Psychology) student. The student researcher had experience in interviewing through tertiary level training and volunteer experience. The student researcher did not have a prior relationship with any of the participants. Participants were informed of the student researcher's academic background and the goals of the research via the participant information sheet. Those selected for an interview were required to provide written or verbal consent prior to commencing the interview.

The interview guide was informed by the CSM and followed a semi-structured format adapted from a previous study of pain beliefs (de Oliveira et al., 2020). Prior to conducting interviews, the interview guide was piloted with a member of the research team who has lived experience with pelvic pain to ensure the transferability and appropriateness of questions in a pelvic pain context. The interview guide was also piloted on the first two participants, with the research team discussing the quality of these interviews; however, no major changes were made. Aspects of the guide, such as the wording of questions and the order of delivery, were slightly modified when deemed necessary in the context of each interview.

Participants were advised that interviews would last approximately 60 minutes. Interviews were conducted online via Zoom software (Zoom Video Communications, 2023). The interview was audio recorded for transcription purposes. Recordings were digitally transcribed using Descript (Descript, 2023) and checked for completeness by the student researcher in preparation for analysis. Participants were offered the opportunity to review their transcript prior to analysis to add or correct any information recorded.

2.4 Measures

2.4.1 Eligibility Screening and Demographic Information

The eligibility survey was used to identify participants who met the eligibility criteria, whilst also collecting demographic information. Information obtained from the survey included first name, email address, phone number, age, sex assigned at birth, gender, postcode, level of education, employment status, relationship status, diagnosis of pelvic pain, nature of pain, intensity of pain, duration of pain, previous engagement in pain science education, concurrent conditions, and Pelvic Pain Impact Questionnaire (PPIQ) score (Chalmers et al., 2017). The PPIQ is a self-reported measure of the impact of pelvic pain on women. The score consists of the aggregate of eight items, scored from 0-4 of a Likert scale. As such, the highest possible score is 32, indicating maximum impact score (Chalmers et al., 2017). Two supplementary items that assess the impact of pelvic pain on tampon use and sexual activity are also included in the scale; however, they are not scored due to being inapplicable for some users (Chalmers et al., 2017).

2.4.2 Pain Knowledge and Beliefs

In the semi-structured interviews, participants were asked to describe their beliefs and knowledge about their pelvic pain. Interviews were guided by the CSM to explore how people make sense of their pain, with open ended questions corresponding to the five belief dimensions and appraisals of emotional and behavioural responses. The full interview guide can be found in Appendix 2.

2.5 Data Analysis

Survey data were exported from Qualtrics (Qualtrics, 2023) to Microsoft Excel (Microsoft Corporation, 2023) for compilation and analysis. All audio recordings from the interviews were transcribed verbatim using Descript (Descript, 2023). Data were analysed by the student researcher with input from the research team.

An Interpretive Description framework was used to guide data analysis (Thorne et al., 1997). This framework combines a deductive and inductive analytic approach, and considers both theoretical and clinical knowledge (Thorne et al., 1997). As such, the CSM domains were considered when coding the data; however, 'open' inductive coding was also used to capture other content relevant to the research question. The Interpretive Description framework has an interpretive naturalistic perspective, and poses that there are shared realities that are subjectively constructed through human experience (Thorne et al., 2004). Furthermore, the perspective presupposes that individuals are influenced by the object of enquiry and vice versa (Thorne et al., 2004). Finally, the naturalistic orientation suggests that theory is grounded in or emerges from the data (Thorne et al., 2004). This framework has previously been applied in the context of pain beliefs, yielding meaningful findings (Bunzli et al., 2015).

The following five steps were taken for data analysis: deductive and inductive coding of each transcript; intrasubject analysis- salient coding; intersubject analysis- search for patterns between participants; identification of emerging themes; and interpretive discussion of findings (Bunzli et al., 2015).

Open coding of all transcripts was conducted by the student researcher using NVivo software (QSR International, 2020). A second member of the research team also open coded a transcript to check the consistency of codes. After initial open coding of the first six interviews, the authorship team met to discuss the initial set of codes. Codes were critically examined to ensure their relevance to the topic of pelvic pain beliefs and/or knowledge. Once authors were in agreeance on the codes, they were compiled in a ‘code book’, for comparison with subsequent interviews. The codes that were the most relevant to pelvic pain related beliefs were considered to be ‘salient codes’. The full list of salient codes was determined through discussion amongst the co-authors. Next, extracts were grouped by codes. These groups were checked again by the co-authors to ensure that they continued to follow the research question. When viewing the grouped extract codes, patterns were examined by the student researcher, who aimed to define and construct themes. Again, the research team discussed the themes and ensured their adherence to the research question. A third member of the research team then recoded a transcript to check the applicability of the themes. Finally, the meanings of the themes were discussed and interpreted through a clinical lens. The authors considered the following question in this interpretation: ‘How may this finding inform current treatment approaches for pelvic pain?’ Final themes are presented narratively, supported by quotes selected to represent a range of participants.

Data analysis began at the time of the first interview and took place concurrently as further interviews were conducted. Data collection continued until the authors agreed that including additional participants would not alter the main themes constructed and that the research question could be answered in a clinically meaningful manner. Due to time constraints, participants were not asked to provide feedback on the final results.

To ensure rigour, an audit trail was kept throughout the project. This included notes about potential topics of importance throughout the data collection process, as well as decisions in the coding and theme generating stages. Reflexivity was considered when analysing the data by taking note of any personal experiences or viewpoints that may have influenced the author's interpretation of the data. For example, the student researcher is a female psychology student who is an emerging academic. Having a foundational understanding of psychological concepts may have influenced her analytic interpretations. The rest of the analytic team consisted of three academics: a male psychologist with experience in pain research, a female physiotherapist with expertise in pelvic pain, and a female physiotherapist with expertise in qualitative methods and health belief theory. Whilst these varied backgrounds may have influenced the interpretation of data, the range of perspectives may have allowed for a wider range of explanations to be considered.

2.6 Data Management

Data collected from the eligibility survey was identifiable for the purpose of contacting eligible participants to arrange an interview. All identifiable information was stored on a password protected file until the interviews had been completed. After each interview was conducted, the associated name and phone number was deleted. Email addresses of participants were kept briefly to enable participants to have the opportunity to review their transcript. Once the participant had reviewed their transcript, their email address was also deleted, unless they indicated that they would like a copy of the final manuscript. In this instance, their email address was retained for this purpose and was deleted once the manuscript had been emailed to them. Each transcript was assigned a pseudonym to ensure confidentiality of participants during data analysis and in publication.

3. Results

3.1 Overview

The eligibility survey yielded 83 responses, with 34 being eligible for an interview. Of those eligible to participate, 22 were invited for an interview, however, seven did not respond and three were unable to attend an interview due to scheduling conflicts. As a result, a final sample of 12 participants were interviewed and included in this study. No repeat interviews were conducted. All participants completed the eligibility survey, from which demographic data was collected (see Table 2). Of the intended sampling quotas presented in Table 1, quotas were met for socioeconomic status, relationship status and endometriosis. No participants reported being aged 50 years or above, not completing high school, or being unemployed, so quotas for age, education level, and employment were not met.

Table 2

Demographic Data

Characteristic	**Number of participants (%) (n= 12)**
Gender	
Female	12 (100)
Age (years)	
20-29	6 (50)
30-39	3 (25)
40-49	3 (25)
Education	
Completed high school	1 (8.3)
Diploma/Certificate	2 (16.7)
Bachelor’s degree	8 (66.7)
Masters/PhD	1 (8.3)

Socioeconomic status (IRSD)	
1st Quartile (most disadvantaged)	2 (16)
2nd Quartile	2 (16)
3rd Quartile	2 (16)
4th Quartile (least disadvantaged)	6 (50)
Employment	
<10 hours/week	3 (25)
10-35 hours/week	3 (25)
>35 hours/week	6 (50)
Relationship status	
Single	3 (25)
In a relationship	6 (50)
Married/De facto	3 (25)
Diagnosis	
Endometriosis	4 (33.3)
Endometriosis and other pelvic pain	6 (50)
Other pelvic pain	1 (8.3)
Undiagnosed	1 (8.3)

Note. IRSD = The Index of Relative Social-economic Disadvantage (Australian Bureau of Statistics, 2023)

The eligibility survey also provided descriptive information about clinical characteristics, as demonstrated in Table 3. Participants were given the option of choosing their own pseudonym or having the research team to assign one for them. The PPIQ scores ranged from 12 to 32, indicating that medium to high impacts of pain were experienced by participants. A range of diagnoses were captured within the sample, with endometriosis being the most frequently reported. Three participants had previously participated in pain science education.

Table 3

Clinical Characteristics

Pseudonym	Diagnosis	Mode of diagnosis	Nature of pain	Severity of pain	Duration of pelvic pain	PSE	PPIQ
Alex	Endometriosis, Polycystic ovarian syndrome (PCOS), Dysmenorrhoea	GP, Obstetrician / gynaecologist, Physiotherapist	Combination	8	10 years	No	24
Maggie	Endometriosis	Obstetrician / gynaecologist	Constant	2	5 years	Yes	14
Lily	Endometriosis, Vulvodynia, Vaginismus, Dysmenorrhoea	Obstetrician / gynaecologist	Constant	3	5 years	No	12
Barbara	Endometriosis, Dysmenorrhoea	Obstetrician / gynaecologist	Combination	8	>10 years	Yes	24
Rose	Endometriosis, Adenomyosis	Obstetrician / gynaecologist	Constant	4	3 years	Unsure	18
Maisy	Endometriosis	Obstetrician / gynaecologist	Combination	7	9 years	Unsure	21
Alice	Endometriosis, Dysmenorrhoea	Obstetrician / gynaecologist	Combination	4	>10 years	Yes	20
Janine	Endometriosis	Obstetrician / gynaecologist	Combination	2	6 years	No	21
Sally	Dysmenorrhoea, Prolapsed fibroid	Obstetrician / gynaecologist	Constant	8	2 years	No	32
Belinda	Endometriosis	Obstetrician / gynaecologist	Combination	9	>10 years	No	15

Taylor	Not diagnosed	Not diagnosed	Cyclical	10	3 years	No	17
Olivia	Endometriosis, Vulvodynia, Vaginismus, Dysmenorrhoea	GP	Combination	8	>10 years	No	14

Note. PSE = Pain Science Education, PPIQ = Pelvic Pain Impact Score (Chalmers et al., 2017).

The outcome of the analytic process is displayed in Table 4. The knowledge and beliefs that participants hold about their pelvic pain were grouped into three themes that were derived from the data:1) BIOpsychosocial view of pelvic pain, 2) I’m in charge, but not always in control, and 3) pelvic pain makes my life predictably unpredictable.

Table 4

Analytic Process

Themes	Categories	Codes
BIO-psychosocial view of pelvic pain	Biological factors	Pain comes from the brain Hormones Immune system Nervous system Food and diet Exercise Sleep
	Medical language	Surgical findings Findings from scans Imagery of condition Pain connected to specific body parts
	Anatomical understanding of endometriosis	Endometriosis diagnosis No correlation between severity of endometriosis and pain Perceived correlation between medical findings and pain experienced
	Psychological factors	Stress Negative mood Positive mindset Acceptance
	Social factors	Chronic pain not understood Stigma Women’s issue Understanding that period pain is normal

Themes	**Categories**	**Codes**
I'm in charge, but not always in control	Necessary diagnosis	Need diagnosis for pain to make sense Need diagnosis to treat condition Hope associated with diagnosis Self-advocacy
	Medical hesitancy	Non-invasive options Hesitancy towards medication Bodily autonomy Negative healthcare experiences
	Preparing for pain	Preparing for pain Being proactive Medicating before pain starts
	I'm doing all the right things	Doing the right things Sleep Exercise Diet Relaxing
	What did I do wrong?	Guilt It's my fault
Pelvic pain makes my life predictably unpredictable	Opting out of life	Missing out Debilitating Can't drive Stay home Absenteeism and presenteeism

Themes	Categories	Codes
	Short-term predictability	Menstrual cycle as predictor of pain
	Future consequences	Future planning Career opportunities and decisions Decisions about having children Fertility and conception Pain is unpredictable Pain is forever Anxiety about condition

3.1 BIOpsychosocial View of Pelvic Pain

The first theme related to a biopsychosocial view of pain, with an emphasis on the biological aspects. When describing their understanding of pelvic pain, most participants reported that they understood that pain is complex and is the result of numerous factors interacting. Participants described biological, psychological, and social contributors, which is in line with the widely recognised biopsychosocial model. Despite explicitly stating this understanding, many participants appeared to have conflicting beliefs as evidenced by the language they used to describe their knowledge and beliefs. Participants tended to use language aligned with the biomedical model, suggesting a potential conflict between their explicit knowledge of the biopsychosocial model with implicit beliefs about the biomedical model. This was demonstrated through anatomical understandings of pelvic pain, as well as an understanding of treatments that directly target medical findings. This theme captures participant understandings of what their pelvic pain is, and what causes it. Therefore, the theme aligns with the ‘identity’ and ‘cause’ domains of the CSM.

The biopsychosocial view of pain was broadly discussed by various participants. In describing her understanding of pain in general, Maisy explained her understanding of the many factors that contribute to experiencing pain:

> It's so many different systems, so many different inputs are all contributing to the response of pain, and those responses then influence our inputs and continue to alter that cycle, continue to alter our response and our output of pain. (Maisie)

When describing the perceived cause of their pain, many participants described complex aetiologies. When explaining her vaginismus diagnosis, Lily described multiple factors that she believed contributed to the condition: “From my understanding it's a, you know, involuntary tightening of the muscles around the vagina, um, for various different reasons, psychological, physical, you know, past trauma and all that kind of thing.” (Lily).

3.1.1 Biological Understanding

In terms of biological underpinnings of pain, many participants identified the brain and nervous system as playing significant roles in their pain: “There are lots of neural pathways involved, so it's not really the lesion. The pain is being originated from a lot of other sources, so your nervous system is greatly affected.” (Belinda).

This understanding of the nervous system often led participants to the belief that the persistent nature of their pelvic pain was due to increased sensitivity over time.

> I guess from my understanding, like, over time, having frequent pain, then that becoming chronic pain, and then your body sort of like, um, responding to that sort of sensitization level of, like, having my body sort of maybe reacting more dramatically and more intensely than what it needs to because it's kind of always on like high alert of like something's wrong when it might just be sort of, you know, my usual body being my body. So, yeah, definitely noticing that like my pain has gotten worse and I've become sort of, I don't know, I don't know if I'd say my pain tolerance is lower but it just kind of feels like it's like I'm more sort of sensitive and like it's, it gets worse, the more prolonged it has been. (Barbara)

Some participants also noted that their increased sensitivity had resulted in pelvic pain when they were experiencing an unrelated health issue.

> It makes sense to me in the way that I get why my brain sends signals to my pelvic region, but I don't get why in that, in an instance like that where I can have a completely unrelated health issue, it would then interpret, like, I get why it would up-regulate my nervous system, I don't get why I would then go, okay, well that, it, that automatically equals pelvic pain, you know? (Maisy)

Another participant noted the role of hormones in her pain, particularly in relation to changes with menopause.

> I'm 42 now, um, and hopefully in the next few years that come, my hormones will, you know, calm themselves down a little bit. And hopefully that would, um, that would, that would cause the pain to decrease as well. (Rose)

The role of inflammation in pain was another significant biological understanding of pain, with participants viewing it as a causal factor.

> I personally believe that it's due to inflammation. I get a lot of heat in the area. I've got swelling. I'm continuously bloated for up to two weeks for this period. And yeah, pain also. I personally don't know why I'm inflamed during this period. (Alex)

Some participants demonstrated coherency beliefs by explaining how they could manage their inflammation through diet. Rose discussed how removing dairy from her diet had a drastic impact on her inflammation: "Cutting dairy out of my diet really helped with my inflammation levels, which helped to take everything down a few notches and make it more manageable. Um, that was really huge actually." (Rose).

Food and diet were perceived as both a cause of pain and a method of management. Participants typically identified 'unhealthy' food groups as influential for their pain. Lily described her difficulties with diet when travelling: "It's kind of flared out because I'm not on my normal diet. So I'm eating, you know, more takeaway and like pizza and, um, you know, not enough vegetables and fruits. So I think that definitely flares it up." (Lily).

Sleep was identified as a crucial factor to manage for many participants. Whilst feeling exhausted was consequence of pain for many participants, it was also seen as a causal factor. This seemed to form a perpetuating cycle, especially when the pain experienced was so severe that it impacted on sleep. The only way to break this cycle was to have a quality sleep, which was often difficult to do.

> I know that if I sleep well, I can manage pain on a day to day basis, but once that balance gets thrown out, it gets a lot harder. Um, and, uh, yeah, like, oh, if I have a bad day, then by 8 or 9 o'clock at night. I'll be unable to manage my own pain to the point I can get to sleep. So I'll be

> awake until like, 2, 3 or 4 in the morning. Um, and then that has a bit of a snowball effect for the next few days, few days. (Rose)

Participants expressed differing beliefs about how exercise influences their experience of pelvic pain. Some participants found value in an active lifestyle for managing their pain, describing it as a necessary aspect of control.

> Exercise definitely makes it better for me. Um, I always try and exercise regularly, whether that be like the gym or, um, you know, walking or yoga. Um, that always makes it better. Um, when I don't exercise, you know, when I, you know, I've been sick or whatever. Um, I feel like that's when it kind of flares up a little bit. (Lily)

Other participants felt as though they needed to 'give up' more strenuous forms of exercise to manage their pain, or to avoid making it worse.

> I loved going to the gym and I was really getting into reformer pilates and I was really building up, um, a lot of strength and, um, you know, trying to, yeah, see if, um, that would help with anything around my pain in that area, but it was becoming progressively worse. So I had to give up that. (Sally)

Some participants identified that the intensity of exercise was a deciding factor in whether it would be beneficial or exacerbating for pain severity: "Exercise is a really funny one. Because it can help sometimes and it can also make it worse, depending on quite how, um, stimulating it is." (Janine).

3.1.2 Medical Language

All participants reported having at least one scan or surgery to explore a diagnosis, which often provided them with a biological explanation for their pain. Participants generally used specific anatomical language when describing the body parts of interest in medical findings:

> The laparoscopy found, um, I think it was, maybe it was definitely, like, right, maybe left ovarian fossa, right ureter, right and left utero sacral ligaments, um, probably pouch of

> Douglas, I think, um, yeah, so, you know, stage 2, but I was kind of, like, obliterated with it, if that makes sense, you know, they kind of just found it all over the place, really. (Maisy)

Despite being able to label the specific body parts affected by their pelvic pain condition, some participants generalised this pain to their uterus. This was generally in the context of control, with the removal of the uterus via a hysterectomy being seen as a form of management: "If I could just not have a uterus, that would be nice. That's a complicated thing." (Barbara). Another participant discussed the potential removal of her uterus when describing her experience of deciding whether to have a hysterectomy: "Logically, it makes sense to not have a uterus if it's causing you trouble." (Rose). These beliefs reflect the biomedical model, suggesting that pelvic pain is confined to the uterus, and that surgical removal would provide a cure.

When describing medical procedures, some participants viewed surgery as a way of 'cleaning' their pelvic area: "In the first surgery, all they did was clean out, um, the, the muck, I guess, from the, um, from the cyst that had exploded." (Rose). This is a logical treatment progression from the anatomical identity participants held, which is further evidence of a biomedical understanding. Other participants described how their organs were 'connected' or 'stuck together': "I had adhesions that were kind of like connecting my uterus to my abdominal wall." (Barbara). The use of medical jargon was therefore also involved in the representations of pelvic pain.

3.1.3 Anatomical Understanding of Endometriosis

When discussing conditions more generally, participants continued to have a high-level understanding of the anatomical identity of their diagnosis. Participants with endometriosis typically understood that their condition involves endometrium tissue growing outside of the uterus, with many specifying areas of the body in which this tissue can be found:

> I understand that it's endometriosis, endometrio- endometrium tissue that grows outside of the uterus, um, can develop lesions and adhesions, um, that, that, um, are triggered at the time of a period and can cause pain, inflammation, swelling, bloating, um, and that this tissue can

> exist in many places in the body. Um, the tissue can, has been found in the brain, in the eyes, in the lungs, in the diaphragm, can grow on muscles. (Alice)

Most participants with endometriosis also described that they understand that pain is not directly correlated with the stage of endometriosis.

> With the level of staging, we know that endometriosis, uh, is staged from minimal to severe and the type of pain does not correlate with the staging at all. So someone with stage four may have minimal pain and someone with, you know, stage one or two can experience excruciating pain. (Belinda)

This belief contrasts with the view of some participants, who suggested that medical findings provided a direct explanation for the pain experienced. For example, Rose described her perception of her adhesions: "basically everything's just stuck and, um, I definitely could feel that, I could feel the adhesions." (Rose).

3.1.4 Psychological Understanding

Participants identified psychological factors that were involved with their pain, which also exemplified 'emotional responses' in the CSM. Stress was perceived to be a major contributor to pain, with many participants reporting that they had noticed a causal relationship. One participant described how her stress resulted in tension, which in turn lead to pain:

> If I'm stressed, um, that will hugely impact things. Um, I think that I can feel that when I'm stressed, I'm going through my day and I'm holding on to so much tension like I can feel um, that my pelvic floor is like, even more tense than usual, um, and that will inevitably lead to pain, especially, yeah, if I'm going to try and have sex, um, that's not going to work. (Olivia)

Some participants described a cyclic relationship between pain and mood, as they understood their pain to negatively influence their mood, which in turn influenced their pain:

> I find that it's kind of a two way street, you know, and that like, if I'm feeling like if I'm in like a depressive rut or whatever, or if I'm anxious, that can perhaps influence my pain, but then

> the opposite as well, you know, if I've got the pain, that can make me feel quite low and then can make me feel anxious of, but why am I having this? Why is my pain back? Like, why am I having this really bad flare? And I'm not stressed. I'm not, you know, whatever. Why is this pain here? Why did I wake up in pain? Which can then probably make the pain worse as well and make my mood worse too. So, yeah, it's just this cycle that just keeps going and going and going. (Maisy)

Adapting a positive mindset was viewed as a method of control in terms of breaking this cycle relationship. Participants discussed how having a positive mindset was important for the management of pain: “I find like if I can be in like a good headspace and, and like, and then the pain comes on and I can sort of keep like a somewhat positive attitude around it, it's obviously better.” (Barbara).

Taking things a step further, some participants described how they had reached a point of acceptance of their pain.

> I think I'm probably going to have it for a very, very long time, if not forever, but I'm kind of, as weird as this sounds, I'm kind of accepted that, and I'm kind of okay with that, you know? And I think it's just about, I just, I need to continue to manage it the best that I can. (Maisy)

3.1.5 Social Understanding

The social context played a role in the participant’s interpretations of pain. Most participants described their onset of pain being around the time they first started menstruating, with many describing that they previously thought their pain was normal. Some described social influences who reinforced this belief.

> I had another friend who also had quite severe period pain. And I don't know uh, whether that was very helpful because I thought, you know, period pain was normal and what I was experiencing was quite normal because the two of us would, would kind of, I suppose, relate to each other over, over our pain. (Alice)

Some participants expressed that they often did not feel understood by the general population due to the stigma around chronic pain conditions: “There's a lot of stigma around chronic pain and, you know, being someone that is in pain and trying to communicate that to people who don't understand.” (Barbara).

Other participants also suggested that their difficulties navigating pelvic pain were due to their condition being a ‘women’s issue’. A key idea within this belief was that society does not care about women’s issues: “Let's be honest. It's a women's issue, so no one really cares.” (Lily). One participant also spoke about her beliefs about the medical community’s view on female conditions: “Women's pain in general, it hasn't really been studied. You know, medical research is about, you know, um, you know, white men. So there’s, you know, intersectional issues there too.” (Alice). Another participant discussed how she felt as though women were encouraged to be ‘strong’ and to put up with their pain:

> We are always told to be strong. There's nothing wrong with us. You know, we are women and that that's all right. Women experience pain. Like, no, no, that's not all right. You're just like any other human being. And pain is not normal. It's your body telling you something is wrong. (Belinda)

3.2 I’m in Charge, But Not Always in Control

The second theme constructed from the data was ‘I’m in charge, but not always in control’. The concept of being in charge relates to belief that participants needed to self-manage their condition. This was due to holistic biopsychosocial understandings and mistrust of medical professionals. Participants felt as though it was necessary to receive a diagnosis and have an in-depth understanding of it. The concept of being in charge also encompasses hesitation towards medical interventions, emphasising the value of bodily autonomy.

Although participants felt in charge due to using numerous strategies to self-manage their condition, this didn’t always mean they were in control of their pain levels. This reflects the ‘control’ domain of the CSM and demonstrates a CSM ‘action’.

3.2.1 Necessary Diagnosis

Participants placed a high level of value on receiving a diagnosis for their pain. As a diagnosis typically provides an anatomical explanation for pain, this demonstrates an area where participants held beliefs that were aligned with the biomedical model. One participant described the necessity of receiving a diagnosis for proceeding with the treatment and subsequent management of her pain:

> I think in my head, until I have a diagnosis, I don't know what's going on. So that causes a lot of issues and it's something I know that I'm going to have to put up with for the rest of my life until we do find something to help me. (Alex)

Other participants described receiving a diagnosis as being a relieving and validating experience, highlighting the value of understanding the reason for their pain:

> Once I discovered that it wasn't normal, it was like, well, I know I need an answer to it. You know? And so getting an answer to that was like a, was a relief and it was a, it's not in my head, it's a, there is something wrong here that can then be managed, you know, and I'm, and I'm not back at square one again. (Maisy)

Self-advocacy was crucial for many participants when they were seeking a diagnosis for their pelvic pain. Participants expressed the frustrations they felt, especially regarding the need to be vocal about their symptoms to numerous professionals before feeling listened to:

> I had to fight so hard for someone to listen to me and even still with a diagnosis, I still feel at times like unheard and unsupported. I think that really does play into, um, the mental health around pain. I think the connection with, like, not being believed and not listened to and not having adequate support makes it really hard. (Janine)

3.2.2 Medical Hesitancy

Participants often expressed hesitancy to engage in medical interventions such as medication and surgery. Exploring alternative options before committing to medications or surgery was common amongst participants. Participants were eager to see if conservative management would be beneficial in hopes of delaying or avoiding invasive options altogether. They typically held negative beliefs about medical treatment approaches, likely due to fears of side effects or iatrogenesis: "Piling drugs in every day and, you know, getting things cut out of you is a pretty drastic option. Um, so let's think about the other things that we can do that are a bit easier." (Rose).

Autonomy was also important in making medical decisions. One participant shared her experience of deciding not to have a hysterectomy, thus keeping the option of having children open.

> I ended up deciding not to have the hysterectomy because I just wasn't ready. Like I haven't had children and I know I probably won't ever now. Um, but it was just mentally not something I had had a lot of time to prepare for. (Rose)

Negative healthcare experiences were common amongst most participants, with many reporting feeling dismissed or not heard. This led to a belief that patients are the expert in the management of their condition. As a result of this, one participant explained her hesitancy towards presenting at hospital:

> I rarely present at hospital for my pain, um, only because I know in that clinical setting, I'm probably not going to get, um, the care I can provide myself in the comfort of my own home. Um, and again, those places are cold. Um, you know, the level of stress and anxiety also, you know, medical gaslighting that you can often get. (Alice)

3.2.3 Preparing for Pain

Participants valued the importance of being proactive in preparation for pain. With many participants experiencing cyclical pain associated with periods, they had experiential knowledge of their pelvic pain. This knowledge allowed participants to predict the timing of pain, and when they should engage in preventative strategies to help manage their pain. This typically involved practical arrangements such as limiting commitments and filling prescriptions.

> In a practical sense, a lot of it would be just like scheduling and being like, I'm not going to commit to social things this week, um, making sure that I've got all my meds available to me and all my scripts are filled. (Barbara)

Other participants found it helpful to take medication in anticipation of pain: "I take a pain med, then it's going to stop in the tracks. But if I don't take a pain med, it will progress till the day the periods begin." (Belinda).

3.2.4 I'm Doing the Right Things

Many participants discussed managing their condition by targeting factors that were perceived to be both causal and within their control. These factors were typically biological in nature, and included sleep, exercise, and diet. Taylor described her approach to these controllable aspects: "I feel like I do the things, like I get enough sleep, and I eat well, and I exercise, and you know, lifestyle things, I feel like I'm doing all the right things." (Taylor). Sally reflected this idea of self-management, also highlighting the importance of stress reduction:

> My thoughts are, what can I do through diet and, you know, around mental health and reducing stress and um, you know, working on myself to reduce some of that inflammation in my body to hopefully reduce pain. So I try, I'm trying to think of things that are in my control and that's something that feels more in my control. If I can do things through the things I eat and the things I do and how I treat myself, can that have an impact? Um, yeah. (Sally)

Despite the emphasis on self-management strategies, some participants noted that they believed that pain can only be self-managed to a certain extent:

> I was like, okay, if I do, I see a physio, I get my diet, right. I have all of my meds right. Like, I do everything. Then like, surely something's going to help. And then you kind of, I guess that like impact of realizing no matter like how perfectly you try and tackle this. And if you try and do everything right, no matter what, like, medical practitioners, tell you often there is just like an element to this that you can't do anything about and it's like learning to accept that and, um, process I guess what that means for you is sort of hard. (Barbara)

3.2.5 What Did I Do Wrong?

Due the immense involvement participants had in their management of pain, some felt as though they were at fault when they unexpectedly experienced pain. One participant described their experience with self-blame:

> I appreciate having some data and I appreciate being able to notice some patterns. Um, what I do struggle with is that I feel like the onus is then on me. Um, because I have all the data and I have all the information, so if I have pain, then I start to feel like, well, what did I do wrong? Where did I go wrong? Did I eat something wrong? Have I exercised and done something wrong? Um, yeah, it feels like it's my fault because I'm in charge now. (Olivia)

3.3 Pelvic Pain Makes My Life Predictably Unpredictable

The final theme was the concept of predictability of pelvic pain and its associated consequences over time. Most participants knew their pain could be predictable at times, yet they also reported feeling uncertain about the future due to an inability to predict their pelvic pain long-term. Due to these characteristics, this theme is reflective of the 'timeline' and 'consequence' domains of the CSM.

3.3.1 Opting Out of Life

Many participants described the present-day impacts that they experience due to their pelvic pain. In times of severe pain, participants expressed that they felt as though they were missing out, or opting out of life. "I do opt out of life when pain's really bad." (Janine). Others described the duration of their flair ups and the activities that they feel as though they need to avoid during these periods:

> It can really be debilitating, you know, uh, if I'm having terrible period pain, um, I can't drive a car, I can't, I can't get my body to an office to work, I can't sit in a chair, um, that might last for a day or two, um, lately it's been about three days with pain like that. (Alice)

The debilitating nature of pain was reported to influence whether participants could attend work or be fully present when at work. Taking time off work was a point of insecurity for some participants particularly with fears of judgement from others: "To call in sick all the time definitely affects how my employees might see me or that's what I at least think.” (Alex). Another participant described how she could not function to the best of her abilities at work when in pain: “I get like, um, you know, brain fog. I'm definitely not my best self, most productive self at work just because that kind of affects you know, what's happening in my brain.” (Lily).

3.3.2 Short-Term Predictability

Despite the debilitating nature of pain and its disruption of everyday life, many participants knew when their pain would be present, due to its association with their menstrual cycles. This enabled participants to prepare for pain, as outlined in Section 3.2.3.

> I have very regular periods. So I’m pretty prepped mentally for that sort of, you know, and I know that I, like, I always sort of bleed for seven days. The three days before, uh, going to be bad too. So it’s kind of like those 10 days are very predictable. (Barbara)

3.3.3 Life on Hold

Pain was also described as fundamental consideration when planning for the future. Participants expressed their frustration at this, especially at the notion of their life being ‘on hold’:

> I don’t want my life to be on hold for pain. Um, small things like planning your wedding, trying to plan it so that it’s not on that week where you’re not going to function because who wants to not celebrate their own wedding. (Alex)

In terms of career progression, many participants noted how they have had to turn down opportunities due to their pelvic pain.

> I actually couldn't work full time anymore. I had to reduce down to three days a week. And, um, I had so many lovely career opportunities I could have taken on that I loved. Like I had a really great team I was working in. I was working across two roles, and because of how unwell I was with this pelvic pain, I had to decline a lot of that. (Sally)

Decisions around children were also highly tied to the pain participants experienced. Some participants explained how their decisions around having children were largely tied to their pelvic pain, holding beliefs that they would have limited capacity to look after a child, particularly during times of severe pain or exhaustion:

> There are so few days where I feel energetic and healthy, that I can't imagine those all being taken up with caring for another human, as well as trying to be present and care for children on my bad pain days. (Barbara)

Other participants felt anxious about the idea of managing pregnancy alongside their pelvic pain: “If I've got pelvic pain already, what's it going to be like carrying a baby? And then would I, will I be able to do that? So those worries around the future has become quite big.” (Sally)

3.3.4 Long-Term Unpredictability

The unpredictability of pain was a major point of concern for many participants. This resulted in uncertainty for the future, as well as feelings of stress and anxiety: “When it's... it's beyond the norm, like the, you know, daily, like the predictable, um, and definitely I can feel a bit like stressed or anxious that it's going to keep getting worse.” (Maggie)

Some participants discussed the uncertainty of their pain in relation to menopause, which was often viewed as a possible end point for pelvic pain.

> I think it's going to go on to menopause … maybe till the age of 50. I expect things to be like that, but we also know that endometriosis is not something associated with just the bleeding. And people experience pelvic pain even after they have entered menopause. (Belinda)

Participants also struggled with the fear that their pain was ‘forever’, and that they would continue to experience it for the rest of their lives.

> I panic a little bit because I feel like it's not going to go away. It's not necessarily that I think that I'm catastrophizing that something like really bad is happening to me and that like, I don't know what's going on or that like I need to be in the hospital or anything. It's more just like catastrophizing that it's not going to stop. And so then it kind of gets overwhelming of like,

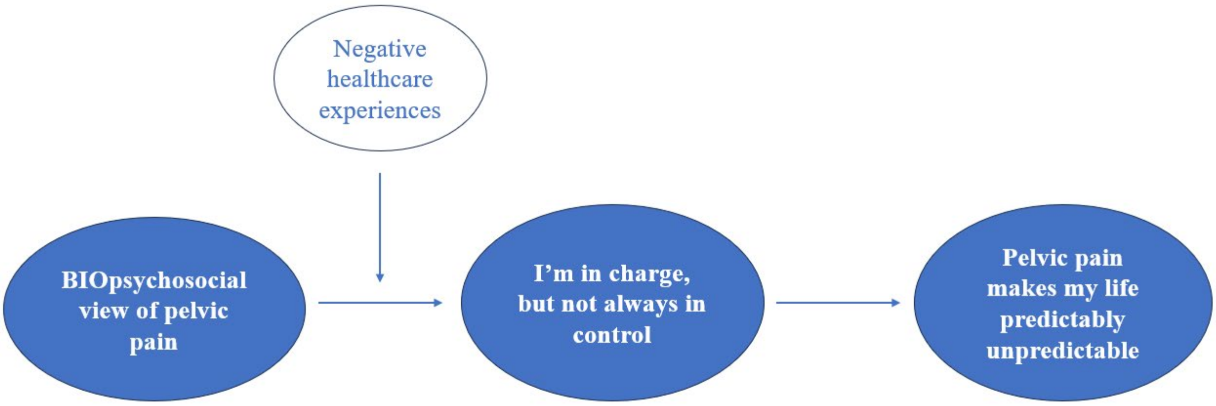
> well, then what does the rest of my life look like if this, you know, I have to deal with this forever kind of thing. (Barbara)

4. Discussion

This study qualitatively explored the beliefs and knowledge that women hold about their pelvic pain. The findings align with the CSM and help explain how women make sense of their pelvic pain. The themes constructed suggest that the representation of pelvic pain involves a pathway of beliefs, as demonstrated in Figure 2. This representation of pelvic pain helps fill the gap in the literature and provides an improved understanding of what women believe and know about their pelvic pain.

Figure 2

The Representation Pathway of Pelvic Pain



Note. This figure depicts the representation of pelvic pain embedded within the CSM. Firstly participants described developing a 'BIOpsychosocial view of pain'. This knowledge, in combination with negative healthcare experiences, led individuals to self-manage their pain, as outlined in the theme 'I'm in charge, but not always in control'. With self-management approaches having limited success, individuals assume the belief that 'pelvic pain makes my life predictably unpredictable'.

The first theme, 'BIOpsychosocial view of pelvic pain', describes the participants' aetiological understanding of pain through the 'identity' and 'cause' domains of the CSM. Participants reported a biopsychosocial understanding of pain, describing pain to be the result of interactions between biological, psychological and social factors (Engel, 1977). Due to this understanding, participants already had knowledge of some of the key concepts of pain science education (Louw et al., 2016). Despite this knowledge, participants seemed to struggle to conceptualise their own pelvic pain within the biopsychosocial model. Instead, participants used language that placed emphasis on ‘biological’ aspects of their pelvic pain, with findings from medical procedures being influential in conceptualising their own pain. This understanding is consistent with the outdated biomedical model of pain, which emphasises nociceptive aspects of pain, whilst disregarding emotional and social influences (Bendelow, 2013). As such, participants demonstrated explicit biopsychosocial knowledge of pain, yet also held implicit biomedical beliefs in relation to their personal pain experience.

Many of the beliefs and understandings about the identity and cause of pelvic pain originated from the diagnostic stage of participant experiences. With many participants reporting medical dismissal and trauma during the early stages of their pain experience, this was influential in shaping their representation of pelvic pain. Similar experiences have been consistently reported in the literature for pelvic pain cohorts (Hawkey et al., 2022; Young et al., 2015). By experiencing feelings of dismissal by health care providers, participants may have felt as though they needed to ‘fill in the blanks’ of their diagnosis and seek further information independently.

The combination of negative healthcare experiences and biopsychosocial understandings of pain which were highly influential in the theme, ‘I’m in charge, but not always in control’. This theme highlighted participants’ self-management of their condition through the ‘control’ domain of the CSM. Beliefs around self-management were often tied to participants’ biopsychosocial understandings, as participants described a holistic approach to managing their pain; however, these beliefs were also influenced by mistrust in health care professionals. This often involved avoiding medical interventions such as surgery due to concerns of treatment ineffectiveness and impacts on fertility. Whilst participants believed that it was necessary for them to lead the management of their condition, they often felt as though they were not in total control of their pelvic pain. Limited success of self-management strategies for pelvic pain has previously been reported in the literature (Mardon et al., 2023); however, only some participants reported scepticism towards these approaches. Some participants held beliefs about their pain management that aligned with aspects of perfectionism (Rudolph et al., 2007). These beliefs involved consistently engaging in numerous self-management strategies, with negative feelings such as self-blame being experienced when pain occurred unexpectedly. In terms of the representation pathway, perceived uncontrollability of pain was linked to consequences of pelvic pain; some of which were described as predictable, whilst others were described as unpredictable.

The implications of pain were captured within the final theme, ‘my pelvic pain is predictably unpredictable’, which aligns with both the ‘consequence’ and ‘timeline’ CSM domains. When considering present-day pain, many participants used experiential knowledge to predict the onset of pain due to its relation to their menstrual cycle. This allowed participants the opportunity to prepare for pain, however many participants still reported debilitating consequences. Using cyclic knowledge to predict the onset of pain was unique to the pelvic pain cohort. Long term consequences were much harder to predict, with future uncertainty being common amongst many participants. Participants did not have a clear understanding of the future of their pain. Participants were hopeful that their pelvic pain would end when they reached menopause; however, they were uncertain of this. The long-term uncertainty of pelvic pain was a major point of frustration, with many participants describing difficulty in planning for the future.

Previous research has used semi-structured interviews and the CSM in other pain populations to understand how individuals make sense of their pain. When compared to other pain cohorts, many findings from this study are unique to women with pelvic pain. A major point of differentiation for many women with pelvic pain is the association between their pain and their menstrual cycles. As previously discussed, this allows for a level of predictability that does not exist in other pain cohorts. Additionally, with periods being associated with the onset of pain, women with pelvic pain may be less inclined to identify external causal factors, which has been previously seen in other studies. For example, previous pain belief studies have found that participants had ‘cause’ beliefs that moving or overusing affected body parts would result in additional damage (Bunzli et al., 2019), but we did not see similar beliefs linking movement with damage in the pelvic pain sample.

Another distinction between women with pelvic pain and other pain populations is attitudes towards surgery. For example, a study using the CSM found that people with hip pain held 'control' beliefs that surgery would be necessary to cure their condition (de Oliveira et al., 2020). This was not the case for women with pelvic pain, with many viewing surgery as a treatment option with unpredictable outcomes. Concerns regarding fertility after surgery also played a major role in committing to surgical treatment, with participants highlighting their value of bodily autonomy.

Several limitations were noted within the study. Firstly, due to the interviewer's psychological background, they were not familiar with some specific surgical approaches and medical treatments that were discussed by interviewees. This may have limited the number of probing questions asked. It is also important to acknowledge that the interviewer approached the interviews with their own biases, and the interpretations of findings were influenced by the biases of the research team. However, interviewer and interpretation biases were minimised through research-team wide discussions about the results. The study was also limited in terms of the diversity of the sample, with several sampling quotas not being met. Overall, the results suggested a high level of understanding of medical concepts, which is likely to due to high levels of education and socioeconomic status captured within the sample. Despite attempts to include a range of diagnoses through purposive sampling, most participants reported having a diagnosis of endometriosis. Whilst this did not allow for a wide range of conditions to be included, it did provide a realistic snapshot in terms of prevalence, as endometriosis is most common cause of pelvic pain (Hickey et al., 2014). Future studies may aim to further the literature by exploring the beliefs and knowledge of women with specific diagnoses, or women who experience pelvic pain without a diagnosis.

In terms of theoretical implications, whilst this study aimed to depict the representations women hold about their pelvic pain, it was apparent that other aspects of the CSM should be explored further in a pelvic pain context. Although this study also provided some preliminary data on women's interpretation of their pelvic pain, emotional responses and actions, the 'appraisal' aspect of the CSM remains unclear in a pelvic pain context. This should be explored in future studies to better understand the health behaviours of women with pelvic pain.

There are numerous practical recommendations that can be made of the bases of the results of this study. Representations of pelvic pain may be improved if health care providers provided a diagnostic explanation to help patients make sense of their condition. It was clear that this cohort valued knowledge about their condition and felt as though a thorough understanding of their pain was required to progress with treatment. This clarity may empower individuals in the management of their condition. Providing clearer information upfront may also limit some of the conflicting beliefs that were demonstrated in this study.

The findings also suggest that pain science education approaches may be improved by personalising the delivery of content. Whilst this pelvic pain cohort demonstrated their knowledge of modern pain science concepts, they had difficulty applying this knowledge to their own pelvic pain. Guiding individuals to view their own pelvic pain through a biopsychosocial lens may encourage engagement in a wider range of treatment approaches.

Another important point of change is to improve health literacy at a school-level. Most participants who experienced pain related to their menstrual cycle noted that they believed their pain was normal at its onset. If adolescents were provided with the knowledge to visit their GP if they are experiencing painful periods, early intervention might be possible. Positive strides are already being taken in this direction, with the National Action Plan for Endometriosis aiming to improve awareness and education. This will involve awareness campaigns, early education, improved access to information for individuals with endometriosis and improved awareness and understanding of healthcare providers (Department of Health, 2018).

The findings of this study have highlighted that women with pelvic pain have a complex, yet conflicted understanding of the aetiology of their pain. Although participants held beliefs that self-management was essential, they generally experienced difficulty in managing their condition. Despite often having the ability to predict the onset of pelvic pain, participants could not predict pain long-term and felt uncertain for the future. Providing a clearer diagnostic explanation, as well as framing an individual’s pain in a biopsychosocial context, may allow for a more effective representation of pelvic pain, and consequently improve treatment outcomes.

Support

This study has received no financial support. [Additional team member 2] is supported by the Research Training Programme domestic (RTPd) Stipend as a postgraduate student at the University of South Australia. [External supervisor] is supported by a Leadership Investigator grant to [name removed for anonymity] from the National Health & Medical Research Council of Australia [ID number removed for anonymity]. [Student researcher], [Internal supervisor] and [Additional team member 1] have no financial support to declare.

Conflict of interest

[External supervisor] has received payment for presentations given on pelvic health. [Additional team member 2] has received speaker fees for lectures on pelvic pain. Professional bodies have reimbursed them for travel costs related to presentation of research on pelvic pain at scientific conferences. [Student researcher], [Internal supervisor] and [Additional team member 1] have no conflicts of interest to declare.

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Appendix A

Standards for Reporting Qualitative Research

No.	Topic	Item	Page No.
	Title and abstract		
S1	Title	Concise description of the nature and topic of the study, identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	1
S2	Abstract	Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	6
	Introduction		
S3	Problem formulation	Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	11-14
S4	Purpose or research question	Purpose of the study and specific objectives or questions	14
	Methods		
S5	Qualitative approach and research paradigm	Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/interpretivist) is also recommended; rationale	18-19
S6	Researcher characteristics and reflexivity	Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	20
S7	Context	Setting/site and salient contextual factors; rationale	17
S8	Sampling strategies	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale	15-16, 20

S9	Ethical issues pertaining to human subjects	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	14-15
S10	Data collection methods	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale	17-18
S11	Data collection instruments and technologies	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	17, Appendix 2
S12	Units of study	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	21-24
S13	Data processing	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts	17, 19-20
S14	Data analysis	Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	18-20
S15	Techniques to enhance trustworthiness	Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale	19-20
	Results/findings		
S16	Synthesis and interpretation	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	24-42
S17	Links to empirical data	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	25-42
	Discussion		
S18	Integration with prior work, implications,	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/	42-47

	transferability, and contribution(s) to the field	generalizability; identification of unique contribution(s) to scholarship in a discipline or field	
S19	Limitations	Trustworthiness and limitations of findings	45
	Other		
S20	Conflicts of interest	Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	48
S21	Funding	Sources of funding and other support; role of funders in data collection, interpretation, and reporting	48

Adapted from (O'Brien et al., 2014)

Appendix B

Interview Guide

Stage of interview	Questions
Introduction	Hello (insert name), thank you so much for agreeing to do this interview. My name is (insert name) and I will be here to guide the interview. Give brief rundown of what will be happening: - Relaxed conversation - Ask some questions about your experience of pelvic pain, the things that cause it, things that make it better or worse, and how you control your pelvic pain. - There are no correct answers, we are just interested in hearing your story with pelvic pain - Interview will go for roughly 60 minutes - I will be taking some notes about our conversation during the interview, so if you see me looking down away from the camera that is what I am doing - We will be recording the zoom call for transcription purposes. If you do not wish for your face to be recorded, you are welcome to turn your camera off, so we just have the audio recording - Once the audio file has been extracted the video file will be permanently deleted and all the information will be stored securely - If there is anything you feel uncomfortable answering, let me know - Feel free to stop me any time if you have questions etc. Are you happy to begin?
Identity	Could I please ask for you to give me a brief rundown of your pelvic pain and your experience with diagnosis? - For those with multiple diagnoses: In the online survey, you said you had diagnoses of X, Y, Z. Can you tell me which one impacts you the most and why? - In the online survey, you said you have XX diagnosis. Can you tell me how you got this diagnosis? - Can you explain to me what the diagnosis means? - Have you had any scans or surgeries for your pelvic pain? Can you explain in your own words what these found? Can you explain how these findings contribute to the symptoms (including pain) you experience?
Cause	We are trying to learn more about what women feel is causing their pelvic pain. - Do you know what causes your pelvic pain? - How does pain work? What body parts are involved in your pain? - How predictable is your pain? Do you know when it is likely to be better or worse, and what helps you to predict this? - What sorts of things affect your pelvic pain?
Consequences	- Does your pelvic pain relate to your mood or psychological state? How? Does your mood also relate to your pelvic pain (i.e., does the relationship go in both directions?)?

	- Does your pelvic pain make you fearful or worried about anything?(ask them to describe) - How does your pelvic pain impact your life? - Are there any activities that you avoid because of your pelvic pain? Why? - What do you think would happen if you did XXX (activity/ies mentioned in previous question)? - Do you think that doing XXX (activity) will cause further damage, disease, or pathology in your pelvis?
Control	- How much control do you feel you have over your pelvic pain? - Can you prevent your pain from flaring up? How? - Can you control it once it has flared up? How? - How much control do you feel you have over your response to pain?
Timeline	- For those with constant pain: How long do you expect your pain will last? - For those with intermittent/recurrent/provoked pain: When your pain appears, how long do you expect an episode or flare up to last? - How long do you think you will experience pelvic pain? - How hopeful are you for the future?
Action	- What do you do when you are faced with a situation that you anticipate will make your pelvic pain worse? - What do you think it will take to make your pelvic pain completely better?
Coherency	- How much does your pain make sense to you?
Conclusion	That brings me to the end of my questions. Is there anything else you would like to add? We will be assigning a pseudonym to your transcript for confidentiality when we publish the data. I just wanted to check if you are happy for us to choose a pseudonym for your transcript, or whether you had a name you would like to use? I will transcribe the interview recording when we stop recording. I will send you a copy of the transcribed interview so have the chance to review your transcript. Would you like to be sent a copy of the manuscript when we publish the results from this study? Thank you for taking part in this interview. I really appreciate your time and wish you all the best.

Note. The interview guide was adapted from an example interview guide by Bunzli et al. (2017).