“A day-to-day struggle”: A comparative qualitative study on experiences of women with endometriosis and chronic pelvic pain

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Abstract
Chronic pelvic pain (CPP) in women is a term that encompasses a range of conditions, including endometriosis, vulvodynia, painful bladder syndrome and adenomyosis. Given the impact on penetrative sex, fertility and potentially motherhood, CPP may also impact on women’s identities as a wife or partner, a mother, and a woman. The aim of this study was to explore similarities and differences in experiences of women with endometriosis and non-endometriosis related CPP. A total of 17 participants aged between 21 and 48 years old participated in three focus groups. Using reflexive thematic analysis three main themes were found: the struggling woman, the unheard
woman and the self-silenced woman. Women, regardless of the cause of their CPP, reported significant impacts on their intimate relationships, fertility, and parenting but those with non-endometriosis CPP often reported greater trouble communicating about pelvic pain in the workplace due to the “taboo” nature of discussing their vulval pain. Many participants described how a societal normalisation of pelvic pain resulted in women silencing their experiences, rendering their pain invisible. While women wanted to resist such silencing through information and support seeking, women with non-endometriosis CPP described fewer avenues to accessing credible informational resources or networks for support.

Keywords
endometriosis, chronic pelvic pain, diagnostic delay, stigma, chronic pain, Australia

Chronic pelvic pain (CPP) in women is a term that encompasses a range of conditions, including endometriosis, vulvodynia, painful bladder syndrome, adenomyosis, and chronic pelvic inflammatory disease (Steege & Siedhoff, 2014). CPP is characterised by intermittent or constant pain below the umbilicus that is unrelated to pregnancy or normal menstruation, and lasts over six months (Kennedy & Moore, 2012). Primary symptoms of CPP include pain either during or in the 24 hours following sexual activity (dyspareunia), painful urination (dysuria), pain during menstruation (dysmenorrhoea), and pain outside menstruation (non-cyclical pain) (Ahangari, 2014; Zondervan et al., 2001). Chronic pelvic pain is highly prevalent, affecting more than one in five Australian women (Pitts et al., 2008). Endometriosis and vulvodynia are two of the most commonly diagnosed CPP conditions in women of reproductive age, with estimated lifetime prevalence rates of around 11% in Australia (Rowlands et al., 2021) and 8–16% for vulvodynia (Harlow & Stewart, 2003; Reed et al., 2012).

CPP is commonly associated with fatigue, anxiety, and depression (Evans, 2012). Many women also report social isolation, difficulties with sexual intimacy, and decreased work productivity (Armour, Sinclair, et al., 2020), all of which contribute to decreased health-related quality of life (Mellado et al., 2016; Zondervan et al., 2001). Given the impact on penetrative sex, fertility and potentially motherhood, CPP may also impact on women’s identities as a wife or partner, a mother, and a woman (Ayling & Ussher, 2008; Hudson et al., 2016; Parton, Katz, et al., 2017). Feminist scholars have argued that the highly feminised and sexualised nature of CPP calls for a feminist disabilities studies approach to research which acknowledges that illnesses such as endometriosis are a significant source of disability and impairment in women’s lives (Jones, 2016).

Despite the severity of symptoms, interactions with health care providers for women with CPP often tend to be unsatisfactory (Moradi et al., 2014), with pain often not being taken seriously or alternate diagnosis such as irritable bowel syndrome being given
The diagnostic delay for endometriosis can be over a decade between first experiences of symptoms and diagnosis (Young et al., 2015). Gendered stereotypes about women and their bodies contribute to these significant delays and misdiagnosis, with women often being constructed as “reproductive bodies with hysterical tendencies” or as “difficult women” if they don’t respond to treatment in ways expected by healthcare professionals (Young et al., 2018, p. 337).

There has been previous research into the lived experience of endometriosis in Australian women (Moradi et al., 2014). However, women with CPP who do not have a diagnosis of endometriosis have received much less attention both in Australia and worldwide (Mellado et al., 2019). Quantitative data from Australia shows that non-endometriosis related CPP has a similar healthcare burden (Armour et al., 2019) and similar impact on women’s social, sexual, and academic lives (Armour, Sinclair, et al., 2020). Previous research also suggests that it is not a diagnosis of endometriosis alone that is most likely to negatively impact on quality of life or mental health but rather the presence of pelvic pain itself (Facchin et al., 2015). This is problematic as women who have experienced a diagnosis such as endometriosis report a greater sense of legitimacy and empowerment to advocate for themselves when interacting with healthcare professionals, family and friends (Cole et al., 2020), while those without a diagnosis for their CPP may lack this feeling of legitimacy in negotiating these relationships.

An important feminist strategy for destabilising the status quo or discomfort around “troublesome topics” is making the private political, and openly talking about such issues (Braun, 1999). Endometriosis advocacy and lobbying in Australia has resulted in the first Australian National Action Plan for Endometriosis (Australian Government Department of Health, 2018), with significant funding being allocated to increase awareness of endometriosis, reduce diagnostic delay and increase treatment options for women with endometriosis. It is therefore possible such approaches could be extended to other chronic pelvic pain related health conditions that have received less attention, despite having significant negative impacts on women’s health and wellbeing. However, little is known about the similarities and differences in experiences of women with endometriosis and non-endometriosis related CPP. Addressing this gap is the aim of this study. This information will allow us to better support women and ensure adequate support and resources exist, regardless of the cause of the CPP.

Theoretical framework

A critical realist epistemological framework (Bhaskar, 2011) has been adopted in this study to enhance our understanding of how gender, the body and identity impact upon women’s lived experiences of CPP. A critical realist approach recognises the materiality of somatic, psychological, and social experience, but conceptualises such materiality as being mediated by culture, language, and politics (Bhaskar, 2011). In other words, materiality is not reducible to discourse, or without meaning unless interpreted discursively; rather, “material practices are given an ontological status that is independent of,
but in relation with, discursive practices” (Sims-Schouten et al., 2007, p. 102). We draw on this approach to acknowledge the material factors experienced by women in this study, for example, pelvic pain, sexual pain and distress. However, we also explore how women negotiate and make sense of such materiality in the context of the discursive constructions of femininity, sexuality and the reproductive body, located in their particular social, cultural and relational contexts (Ussher, 2010).

Materials and methods

Study design

This research was approved by the Western Sydney University Ethics Committee (H12019) in January 2017. This study was part of a larger national program of research which explored the impact of chronic pelvic pain and endometriosis in women in Australia. The quantitative results of the survey component of the study including the cost of illness burden (Armour et al., 2019) and on diagnosis and impact (Armour, Sinclair, et al., 2020) have been published. This article reports on the qualitative component of the study, which utilised focus groups to explore in depth women’s lived experience with endometriosis or CPP.

Participants and procedure

Participants were recruited utilising a number of avenues. Firstly, at the end of the Australian EndoCost survey women were invited to indicate whether they would be interested in participating in a focus group. In addition, the research team’s personal and professional networks were used as part of a snowball sampling strategy to disseminate the invitation to those who did not fill in the survey; this included social media postings by Endometriosis Australia, Pelvic Pain Foundation of Australia, and EndoActive, the three largest support and advocacy groups in Australia at that time, with over 50,000 combined followers on social media.

Three focus groups were conducted between June 2017 and February 2018, one conducted online comprising five women with non-endometriosis related pelvic pain, and two conducted in person in Sydney comprising 12 women with endometriosis. The non-endometriosis group was held online due to difficulties in recruitment in the local area, and a larger sample was able to be reached through offering online participation to women across Australia. The 17 participants were aged between 21 and 48 and, on average, participants were 32 years old.

Face-to-face focus groups took place at a metropolitan location that was convenient to women. This included a library and community centre. Prior to completing the focus group women were provided with written and verbal information about the study, outlining aims and involvement requirements. All participants provided informed consent to participate by signing a consent form. Focus groups were audio-recorded and lasted between 90 and 110 minutes.
Analysis

An adapted version of reflexive thematic analysis was utilised to analyse focus group data (Braun & Clark, 2013; Braun et al., 2019). This approach was adopted to explore patterns of pelvic pain experiences across two different cohorts of women, paying particular attention to similarities or differences across the two groups. All audio transcripts from interviews were professionally transcribed verbatim, and integrity checked for accuracy. Analysis was inductive, with the development of themes being data driven, rather than based on pre-existing research or theory. Firstly, two members of the research team read through all of the focus group transcripts, brainstorming key concepts or descriptive codes that were present in the data. These concepts or “initial codes” were then collapsed and refined through discussion with the broader research team to formulate the coding framework. The coding framework was then uploaded onto the computer software NVivo and the entire data set was coded by HD. This additional step was undertaken to systematically organise data into “bundles” of shared meaning, which would later help to identify data pertinent to a specific issue and tell a narrative across our data set. For example, under an overarching code of “disruptions to life”, data was grouped into concepts around “concerns about fertility”, “impact on intimate relationships” and “family participation”. Being grouped in this way also allowed researchers to unpick similarities and differences across and within the two groups of women. For instance, in the data under the code “concerns about fertility” there were clear accounts of distress associated with infertility across both groups of women. However, it was evident that more commonly women with endometriosis spoke to the difficulties of conception due to scar tissue and experiences with IVF, whereas women in the pelvic pain group spoke more to the mechanics of not being able to engage in the physical act of having sex.

Individually the research team then read all of the coded data and came together to discuss central themes, that is, concepts or similarities across the data (Braun & Clark, 2013). This was done by drawing together coded “blocks of data” into “coherent clusters” of meaning (Braun et al., 2019, p. 855). For instance, in our first theme we talk to issues of work, family life and intimate relationships. What was central to women’s narratives across these domains was a sense of a day-to-day struggle with often taken-for-granted tasks – this informed the overarching theme of “the struggling women”. Through a process of discussion and refinement, using a thematic map, three key central themes were developed from the data, as discussed below. When presenting data, participants are identified as “EP” or “PP”, to distinguish whether women were in endometriosis pain or pelvic pain focus groups. Pseudonyms have been allocated to all focus group participants.

Results

Analysis of data from both women with pelvic pain disorder and endometriosis revealed complementary themes. The results from both participant groups are presented together to compare women’s perspectives across each of the themes below. These include: the struggling woman, the unheard woman, and the self-silenced woman.
Across accounts from women with both pelvic pain and endometriosis, pain was described as “absolutely horrendous” and “agonising”. For many women, “the pain impacts everything you do” (Tara, EP) and “really invades a vast majority of my life” (Elise, PP). However, the areas of life that women most commonly described as being difficult were sexual intimacy, fertility, parenting, and work.

Kate (PP) described her sex life with her husband as a “day-to-day struggle” and that, for her, sex “hurts every time. It’s never been really a super positive experience but I just have to get through it”. Kate’s descriptions of “having to get through it” suggests some participants may engage in penetrative sex, despite experiencing significant discomfort. This is reflective of a “good woman” discourse, one who is self-sacrificing, prioritising (male) partners’ sexual “need” over their own pain (Ayling & Ussher, 2008; Ussher, 2004). Similar sentiments were reflected in Elise’s (PP) account. For her, negotiating painful sex as a newlywed was “one of our biggest struggle[s] just because you go into marriage with these expectations”. Women with endometriosis similarly described sex as “not enticing” due to pain. Amy (EP) told us that “all those years of it hurting, in your brain, [your] automatic response is, ‘No, thank you’”, reflecting previous research which speaks to sexual difficulties experienced by women with endometriosis (Hudson et al., 2016). What is common across both these conditions, and analogous with other sexual difficulties experienced by women (e.g., anorgasmia) is the impact of narrow, largely patriarchal notions of sexual normalcy (Lavie & Willig, 2005) – in this instance that “real” sex must be coital sex. Where women can’t meet this expectation, they are often left feeling isolated, inadequate, undesirable and less of a woman (Ayling & Ussher, 2008). For example, Juliette (PP) described sexual pain impacting on her “self-confidence”, particularly in relation to forming new relationships, sharing with us, “like dating relationship[s], that’s a constant, when do I bring this up, how do you mention that sex is off the cards?”

The impact of infertility on quality of life, mental health and identity was a struggle that was consistently brought up among women with endometriosis, reflecting previous findings in the literature (Hudson et al., 2016; Jones et al., 2004). However, we found that concerns about fertility were also highly relevant for some women with non-endometriosis pelvic pain. For example, Elise (PP) reflected how the “flow on effect” from her vulvodynia pain has impacted on her capacity to become a mother. She said:

The flow on effect from that lack of sex life which is my husband and I would really love to start a family but, you know, we can’t, and I’ve got friends all around me having babies and that side of it is really very tough to deal with. The pelvic pain as a whole really invades a vast majority of my life.

This finding highlights the impact of CPP beyond the effect of pelvic pain on penetrative sex and intimate relationships, which has been the focus of literature examining conditions such as vulvodynia (Ponte et al., 2009; Shallcross et al., 2018). One study, for
example, has highlighted that vulvodynia pain can impact on women’s experiences across the reproductive continuum, including experiences of assisted reproductive technology, conception, pregnancy and childbirth (Johnson et al., 2015). Parenthood is an expected cultural norm in most societies, particularly for women. Women who experience a disruption to childbearing opportunities, due to chronic sexual or reproductive health conditions, report loss and grief, with negative implications for their identity as women (Hudson et al., 2016).

While previous research has explored women’s experiences of parenting with chronic diseases, such as multiple sclerosis (Parton, Katz, et al., 2017; Parton, Ussher, et al., 2017), less attention has been paid to experiences of parenting among women with endometriosis or CPP. In particular, much of the endometriosis literature focuses on women’s experiences at the beginning of their reproductive journeys, including planning for children and conception (Culley et al., 2013; Young et al., 2015). However, our findings suggest that chronic pelvic pain has significant implications for women’s experiences of parenting and motherhood far beyond conception. The impact of pain on women’s capacity to parent was discussed on numerous occasions across both groups. Alison (PP) told us, “my two boys … when they were young … I couldn’t even pick them up, and they would see their mother lying on the couch in pain … every single day for six years”. Similarly, Tara (EP) described:

I have three boys and we’d wrestle, but I always have a sore tummy and I feel like such a horrible mum because I’ll suddenly go, “No, you don’t. You can’t touch my tummy.” We’ve just been having the best time [and] I’m suddenly in all of this agony, and it ruins the moment … it stops all of that connection.

The ability to parent was particularly compromised when women who had endometriosis needed to take strong pain medication. Nicole (EP) adopted the position of a “terrible” and “disgraceful” mother after forgetting to put the rail up on her child’s cot because she was in so much pain and taking strong pain medication. She said:

I know that makes me sound like a really terrible mother that I did that … I just think you’re a disgrace as a mother … and all because of pain that I don’t know how to manage it any other way, I don’t know what to do. So that’s my biggest thing that I can’t be the mother that I thought I would be and that I wanted to be.

In a similar account Natasha (EP) described sacrificing taking pain medication so that she could drive to pick her daughter up from school, saying, “When I’ve had an attack at work and she [co-worker] was like, ‘Oh, have you got pain?’ I’m like, ‘Yeah, I do but I can’t drive home if I take that’, and I’ve got a two-year-old daughter so I have to pick her up and then I have to function with her.” The inability to be the mother that women wanted to be resulted in distress, with women feeling “sad” and “horrible”, and as though “they were letting their children down” (Tara, EP). Adopting this position reflects normative cultural constructions of motherhood, where “good” mothers are expected to
be self-sacrificing and always physically or emotionally available to meet their children’s needs (Bassin & Honey, 1994). Where women do not meet these idealised cultural discourses due to chronic ill health, they may report feelings of failure and psychological distress (Parton, Katz, et al., 2017), as was reported by women in our study.

Across both groups of women, participants frequently described that pain significantly impacted on their work life, resulting in lost opportunity. While this has been reported in past research among women with endometriosis (Ponte et al., 2009), our findings demonstrate that this is also a significant issue for women who suffer CPP, an area less explored. Elise (PP) told us, “if I’m having a really bad flare up day, my vulval pain, it just distracts me, it’s horrible constantly sitting there at the back of your head, like you’ve got this burning”. For some participants with PP, the chronic pain they endured meant they could not go for a promotion or had to leave their chosen career pathway. For instance, Alison (PP) described:

I have not been able to work full-time, I have not been able to pursue my career … I had often been asked to take on the role of becoming an assistant principal. I have not been able to and I have not been able to tell anybody why either.

Furthermore, as alluded to in Alison’s comment, what made matters worse for both groups of women with pelvic pain, was their inability to communicate to their colleagues why they could not work. Emma (PP), for example, said she struggled to tell colleagues why she needed to miss a meeting, telling us, “I’m not going to sit here and go, ‘actually, guys, I can’t come into this meeting because I’ve got chronic urethral pain … I feel like I’m wee ing razor blades’”, and Juliette (PP) said, “you can’t just say to your boss ‘Hey, look, I need to go home because my vagina is burning,’ I can’t say that.” In many instances, this led to women silencing their pain in the workplace. While the taboo of openly discussing menstruation is well known and often causes women to self-silence (Johnston-Robledo & Chrisler, 2013), women with chronic pelvic pain conditions such as vulvodynia may have even more difficulty, as it would require them to speak specifically about genital pain or discomfort. Women with genital pain report struggling to discuss their pain with romantic partners, friends, and family, often attributing this difficulty to social codes, embarrassment and the taboo which associates the vagina with sex (Hintz, 2019; Shallcross et al., 2018).

The unheard woman

Women with both pelvic pain and endometriosis described a long journey to diagnosis, with some women from the CPP group still experiencing undiagnosed pelvic pain. For instance, women said, “it was a long story to being diagnosed” (Alison, PP) and “I don’t really have a diagnosis … It’s been a long road” (Kate, PP). Difficulties in diagnosis for non-endometriosis conditions, as with endometriosis, are a reflection of the limited knowledge of gynaecological disease aetiology and poor consensus on pathologic definitions of diseases, such as adenomyosis (Loring et al., 2021). Feminist scholars argue that
the limited understanding of gendered health conditions is a reflection of the patriarchal perspectives of women and their bodies, reflecting the dominant mode in which medical research has historically taken place (Martin, 2001). Furthermore, for many women, not being listened to and having their pain being dismissed resulted in a delayed diagnosis, as has consistently been reported in the endometriosis literature (Cole et al., 2020; Young et al., 2015). Despite women across groups describing knowing that “something is not right” (Elise, EP), healthcare professionals, friends and family “assume that women or females exaggerate the pain” (Elise, PP). Feeling dismissed by medical professionals and family is not uncommon among women with endometriosis (Young et al., 2015, 2019), and reflects the feminisation of pain – a persistent attitude that results in women’s pain being taken less seriously or conceptualised as emotional or hysterical.

Where no explanation for women’s pain was seemingly apparent to healthcare professionals, the materiality of their pain was often completely dismissed as being psychological. As Kate (PP) said, “my local gynaecologist just thought it was all in my head I think, which is really painful”. Internalising this diagnosis left women second-guessing their own subjective experiences and feeling as though they were “absolutely crazy because no one believes that you’re in pain” (Tara, EP). This has significant negative implications for women, as described by Jones (2016, p. 557): “rewriting pain as psychological suggests that those with endo are hysterical, denies them necessary medical intervention, and reduces social support”. Even when participants did receive a diagnosis, for some women across groups it “took ages to come to terms” with the diagnosis (Elise, PP), positioning it as “really confronting” (Emma, PP). For women with endometriosis, it was more likely to be positioned, paradoxically, both a “relief” because it legitimised their pain, giving them “permission to feel sick” (Michelle, EP) but also “devastating”, as women realised they had a chronic disease with “no set thing [treatment]” (Susan, EP) for cure, a finding that reflects previous literature (Cole et al., 2020)

Across both participant groups, women also described a lack of “deep” listening from healthcare professionals when they were describing their symptoms. For example, Alison (PP) said, “my GP continuously for four or more years kept telling me it’s simply referred back pain … I’m telling them that I have got deep, deep abdominal pain … for them to simply say, ‘Oh yeah, it’s just referred back pain’”. Not having symptoms listened to meant that many women experienced multiple incorrect diagnoses. As women told us, “a doctor tells me I had Chlamydia” (Susan, EP) and “It’s because you are overweight” (Tara, EP). In many instances, these misdiagnoses led to unnecessary drugs or invasive procedures and distress. As Kate (PP) told us, “the amount of different treatments I had … pudendal nerve block, I had Botox, I had some pulsed radiofrequency”. For some participants, particularly women with endometriosis, this led to significant mistrust in healthcare professionals, with Tara (EP) telling us, “I just had more surgery that just made things worse. I’ve got adhesions, I’ve pleural endometriosis now which is everywhere, and I don’t trust anyone. I don’t want to go see doctors.” These accounts demonstrate that medical practitioners who often lack understanding of the extent of women’s pelvic pain (Fauconnier et al., 2013; Grundström et al., 2016) may struggle to provide comprehensive biopsychosocial care (Young et al., 2017) and experience frustration in accurately managing complex diseases such as endometriosis (Rowe et al., 2019).
Contrary to women’s experiences above, some participants did describe positive experiences with healthcare professionals. The key commonalities across women’s accounts was the importance of empathetic care, underpinned by being listened to and feeling “heard”. As Elise (PP) told us, “thankfully I found a GP and she’s been really good all along, as in she listens and she’s quite empathetic … they don’t minimise pain and that they really listen”, and Kate (PP) described:

My specialist now … they’re kind of the opposite … you go there and you feel like you’re being heard … they’re trying their best to understand and piece all the pieces of the puzzle together, rather than just clutching at straws.

These accounts highlight the importance of a supportive and empathic physician who balances both pelvic pain knowledge and sensitivity to address women’s concerns. This aligns with previous research among women with endometriosis who ask “to be heard and believed” in encounters with health professionals (Young et al., 2019, p. 34).

The self-silenced woman

The theory of self-silencing describes the way in which women silence thoughts, feelings and actions as a relational strategy to avoid conflict or maintain relationships (Jack, 1991). Self-silencing in accounts by women in this study was largely manifested through the normalisation of sexual pain and menstrual pain by doctors and other women in their lives. This meant that when women did experience pain, they silenced their concerns and were less likely to seek help. The normalisation of sexual pain was brought up across both groups of women but was particularly apparent among women with pelvic pain. For instance, Kate (PP) said, “when I started to try to have sex and it was quite painful … I realise[d] that things weren’t quite right … advice from my friends and even mum [was] to maybe just keep trying to make it better”. In a similar account Elise (PP) described trying to have sex on her honeymoon, telling us:

It was very agonising and not pleasant, the worst holiday I’ve ever had in my entire life. But shortly after that, we battled through for a little while, maybe a month or so trying to work out what was going on. Again, I had mum in my life and ladies saying, ‘Oh, it’s normal to have pain.’

Menstrual pain was similarly normalised among women with endometriosis, with Amy (EP) saying, “pain for me was normalised, I didn’t really pursue having it looked after or checked”. A commonality across both groups of women was the normalisation of sexual and menstrual pain by mothers and female friends, when they too had experienced difficult menstrual cycles. As Nicole (EP) described:
Because my mother experienced a lot of pain, a lot of bleeding, it was normal for her … there was like, ‘Yeah, stay home’, but there wasn’t like, ‘Let’s investigate this further,’ because in her mind it was normal.

The normalisation of menstrual and sexual pain reported by our respondents is common (Armour, Hyman, et al., 2020; Moradi et al., 2014) and is likely a reflection of women experiencing difficulties in knowing what a “normal” period is, mothers’ own discomfort in discussing sensitive topics, and “menstrual etiquette” – rules of silencing and concealment that women must adhere to as a means of avoiding menstrual stigmatisation from others (Laws, 1990; Seear, 2009).

The sociocultural silencing of women’s bodies, particularly with regard to reproductive health, also contributed to women having limited health literacy, including not knowing about their anatomy or what was “normal” menstrual pain or bleeding. Elise (PP) described, “I’m ashamed to say it, before I started going down the journey of getting help for this pain, I didn’t know about how my body works and I didn’t know anything”. This reflects previous research where women have described their reproductive bodies, including vaginas, as “inherently unknown” (Fahs, 2014, p. 214), demonstrating how silencing leads to women’s bodies being rendered invisible. For participants who experienced pelvic pain, fear of judgement and embarrassment was a further mechanism to silence women’s experiences. This, for some women, led to feelings of isolation or not being able to reach out for support, as has been reported amongst women with endometriosis (Cole et al., 2020). Alison (PP) said, “I don’t talk about it at all … it is secret women’s business … It’s shocking … So it’s secret and it shouldn’t be”, and Juliette (PP) said:

I was too embarrassed or too confronted by my condition to even tell anyone … I didn’t tell friends or family or anyone else because – I don’t know if it’s because it was sex related or vagina related, but for some reason I just didn’t know how to open my mouth and either ask for help or express what was going on.

In conjunction with dismissive attitudes from healthcare professionals, women’s self-silencing may be why so few young women seek medical help for their menstrual symptoms (Armour, Parry, Al-Dabbas, et al., 2019) and may explain why there is a two and a half year delay on average in Australian women between the onset of their pelvic pain symptoms and visiting a doctor to speak with them about these symptoms (Armour, Sinclair, et al., 2020).

In contrast to the accounts of silencing above, some women, especially participants with endometriosis, described talking about their condition and reaching out to seek support. Many women with endometriosis described seeking support from online forums, Facebook, or reaching out to leading advocates; “there’s Facebook groups as well as Endometriosis and Me, and Endometriosis Australia” (Lucy, EP); “Facebook groups completely rescued me … Jill from Endo Warriors, oh my God, she runs this group that’s international on Facebook and if you message her, she will respond to
you personally about any questions” (Susan, EP). These accounts demonstrate that there are a number of prominent avenues for endometriosis support, education and advocacy groups in Australia (Endometriosis Australia, 2020; QENDO, 2020), which contribute to women feeling supported and able to access the information they need.

In contrast, while women with endometriosis described that they “feel like there’s like an endo movement really starting … everybody is talking about” (Nicole, EP), it was apparent that fewer avenues for support were available for women with pelvic pain. Participants with pelvic pain did seek support from online Facebook pages and found this helpful but, for some, the sharing of “negative stories … I find that it fuels my symptoms and fuels my anxiety, which then fuels my urethral burning” (Emma, PP). Women with pelvic pain also described more commonly that when reaching out they “found it really, really hard to find credible information online … it’s so hard to find something that’s decent and credible” (Kate, PP) and that resources were “very general and very broad” (Juliette, PP). A lack of tailored information and support for pelvic pain could lead to isolation, poor support networks and lack of coping skills. Limited reliable information is especially concerning given that over half of young Australian women report non-cyclical pelvic pain at least once per month (Armour, Ferfolja, et al., 2020) but often report they think it is not necessary to speak to a doctor about this or other pelvic pain symptoms such as pain during urination (Armour, Hyman, et al., 2020). Awareness of endometriosis in young Australian women is still relatively low, with only 52% of adolescents having heard of endometriosis, while other forms of chronic pelvic pain are almost unknown, with a vanishingly small percentage of adolescents (less than 10%) having heard of vulvodynia (Armour, Hyman, et al., 2020). Additionally, while there is a National Action Plan for Endometriosis in Australia (Australian Government Department of Health, 2018) and over $9 million of funding has been committed to endometriosis in 2020 and beyond, there are not similar initiatives in Australia for those without endometriosis whose pelvic pain symptoms have a similar impact on their lives, as illustrated in women’s accounts above.

**Conclusion**

Our findings mirror recent quantitative research which highlights that chronic pelvic pain and endometriosis impact women across many similar life domains, with overlaps particularly in relation to intimate relationships, difficulties with fertility and work. In addition, both groups of women reported that negative experiences with healthcare professionals as well as the normalisation of sexual and menstrual pain leading to diagnosis delays. However, this study also contributes several new findings to the literature. Despite the similar, significant impact on work, women with CPP experience greater difficulties communicating about their pain in the workplace, as pain can commonly be associated with genitalia – a highly sexualised and taboo topic. Furthermore, a novel finding across both groups of women is the impact of chronic pain on women’s identity as mothers due to the impact of pain on their capacity to parent, a finding that warrants a study in its own right. Lastly, it was evident that while women with chronic pelvic pain reported similar impact on their lives to those with a diagnosis of endometriosis,
they had less social and information resources to mobilise for support and coping. The consistency of women’s accounts of being ignored, downplayed and discounted speaks to a broader feminist issue. We must challenge gendered norms that silence and dismiss women’s pain and approach all chronic pelvic pain, regardless of its cause, as legitimate and worthy of quality psychosocial support and appropriate medical intervention.

**Strengths, limitations and future research**

A strength of this study is its qualitative approach, allowing for the complexity and depth of women’s narratives to be explored and the inclusion of women with lived experiences of both endometriosis and, uniquely, pelvic pain. The limitations include small sample size, particularly women with non-endometriosis related pelvic pain. Future research is needed to examine experiences of women from different cultural backgrounds, where meanings associated with menstruation, sexuality, fertility, motherhood and work may differ, and where discussion surrounding such topics may be even less acceptable (Hawkey et al., 2017, 2018). Furthermore, demographic data including sexuality and gender diversity were not captured. This would be an important factor to consider in future research as women’s negotiation with difficulties, such as sexual pain, may be different across heterosexual and non-heterosexual relationships. Future research could also consider the experiences of non-binary or transgender people who experience pelvic pain, but don’t identify as women. Transgender and non-binary people are often excluded from sexual and reproductive health research, which leads to the perpetuation of inadequate healthcare, as knowledge of specific needs of such populations is poorly understood.

**Implications**

The findings from this study have translational implications for the way that healthcare professionals and services support women with CPP and endometriosis. Satisfaction with medical interactions is dependent on information and support provided across the spectrum, including pain management, fertility and mental health (Lukas et al., 2018). Given women from both groups experienced difficulties across a number of life domains, referring women with pelvic pain, regardless of diagnosis, for holistic care with multidisciplinary professionals (Rush & Misajon, 2018), such as fertility specialists, sex and occupational therapists, is critical to improving their lived experiences with pelvic pain. Similarly, healthcare professionals can support women with pelvic pain to address concerns about their capacity to parent by addressing feelings of “failure” as a mother, and ensuring women have access to networks for social and practical support (Parton, Ussher, et al., 2017). Increasing physician and medical student understanding of how to provide patient-centred care (Apers et al., 2018) for women living with pelvic pain, viewing women as experts of their own bodies, continuity of care, and shared decision-making in treatment plans can all contribute to more positive health outcomes and lived experiences of women with pelvic pain. In addition, the findings of this study have implications specific for women with non-endometriosis related chronic
pelvic pain. While there is an increasing debate on the potential benefits and harms of menstrual leave in the workplace (Levitt & Barnack-Tavlaris, 2020), it is unclear if women with non-menstrual pelvic pain would be covered by such leave or if they would feel they were entitled to it. It may therefore be important to have policies for flexibility in work for all women with chronic pain or health conditions, rather than policies that focus exclusively on menstrual related leave. Women with undiagnosed pelvic pain or non-endometriosis related pain participants experience more difficulties due to a lack of diagnosis and collective organisation and resources to address their concerns. Ensuring that the development and tailoring of informational resources (e.g., around fertility, workplace concerns, etc.) and support services (e.g., support groups, webpages, online forums) are equally available to women with chronic pelvic pain is a social justice issue vital to ensuring equity.

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