**"What I am seeking is pain relief, I am not seeking drugs”: lived experiences with pelvic pain and endometriosis.**

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**Introduction/Background**

Persistent pelvic pain (PPP), effects up to 1 in 4 women with significant biopsychosocial and economic impact irrespective of diagnosis. Overlapping conditions, including endometriosis, often involve overlooked muscular contributors to PPP (pelvic floor myalgia), treatable with physiotherapy and Botox. Qualitative research on PPP, endometriosis and pelvic floor myalgia remain limited.

**Materials and Methods**

The primary objective was to explore the lived experiences of adult women (≥18 years) with PPP ( ≥6 months) with self-reported endometriosis and/or pelvic floor myalgia, or those without a diagnosis yet. The secondary objective was to examine their diagnostic journey, healthcare access, utilization, barriers, supports, assessment and management. Participants were recruited via snowball sampling from clinics, social media, completing one-on-one, semistructured virtual interviews. Reflexive thematic analysis was used to identify key themes and insights.

**Results**

Thirty participants were interviewed with a median age of 32.5 years (21-47) and mean duration of PPP of 11.4 years (2-29). Diverse diagnostic groups were represented, including participants with both pelvic floor myalgia and endometriosis (33.3%), pelvic floor myalgia alone (26.7%), endometriosis alone (23.3%) and those who did not have a diagnosis (16.7%). Majority (70%) had an undergraduate degree, living in areas (63.3%) of least disadvantage according to the Index of Relative Socio-economic Disadvantaged (IRSD). Three overarching themes were identified, ‘psychosocial and psychological impacts of the condition’, “psychosocial and psychological impacts of the healthcare journey’ and ‘economic impact of the condition’. Participants described impacts from the invisible costs, non-monetary toll, uncovered healthcare expenses and challenges in diagnostic journey at multiple levels of the healthcare system.

**Conclusion**

Our data reveal that women experience wide-ranging psychosocial impacts related to their condition itself (PPP) and its associated healthcare, often without tailored and streamlined support. Our findings, highlight the need for person-centered care models that prioritize improved diagnostic experience, access, ongoing psychosocial support, enhancing the lived experience and healthcare journey.

**Key words**

persistent pelvic pain, endometriosis, pelvic floor myalgia