

## Short title: Statement on pelvic pain and endometriosis

### Introduction

The World Health Organisation has described persistent pelvic pain (PPP) as “a neglected reproductive health morbidity”. PPP is recognised to have wide-reaching impacts on the quality of life, education and work potential of millions of women, girls and those assigned female at birth (henceforth referred to as “women”) in Australasia. Estimates of the prevalence of dysmenorrhea (period pain) range between 2-97%, cyclic pain 45-97% and dyspareunia (pain with sex) 8-22%. These wide ranges reflect the lack of consensus in these definitions and heterogeneity of included studies.

The ongoing burden of suffering, which persists despite billions of dollars of healthcare costs per year around the world, suggests that current management approaches are inadequate.

Historically many women have had their suffering dismissed. The approach to managing PPP was informed by misconceived notions that pelvic pain was an ‘expected’ component of womanhood and would spontaneously improve with pregnancy or with age. This has created a sense of helplessness in many sufferers and continues to result in the ongoing lack of a commensurate systemic and institutional response to PPP.

The burden of suffering caused by PPP is increasingly being recognised by the community, government and healthcare professionals. At present, attention and funding are usually directed towards diagnosable end-organ pathology, such as endometriosis. Current best practice pain management principles emphasise an individualised whole person approach.

### The relationship between endometriosis and PPP

The long-held paradigm that endometriosis lesions are a direct cause of PPP is no longer tenable.

Lesions are found at laparoscopy in 40-60% of those with PPP, and also in up to 45% of pain-free women. This is likely to be an underestimate of the pain-free incidence as women without pain are less likely to undergo laparoscopy for any reason. Pain intensity has not been shown to reliably correlate with lesion volume, distribution, histological type or even presence of endometriosis lesions. Surgical treatment of lesions has not been shown to reliably improve pain and disability outcomes. Some evidence suggests that ill-advised surgery may in fact worsen outcomes for some women.

PPP shares many important similarities with other types of persistent pain states.

There are however notable differences including:

- onset of symptoms in adolescence
- multisystem contributors including visceral, neurological and musculoskeletal
- the repeated inflammatory processes associated with the menstrual cycle
- a lack of early intervention due to sociocultural normalisation of period pain and painful sex
- the assumption of psychological contributors as causal

In common with other persistent pain states, PPP results in loss of functioning across many roles in life, and both share a documented beneficial response to comprehensive, whole-person,

sociopsychobiomedical management. The propensity of PPP to affect younger women and girls, more so than other persistent pain states, has far reaching social and economic impacts. The introduction by International Association for the Study of Pain (IASP) of nociplastic pain as the third mechanistic descriptor may be particularly relevant for this cohort of patients, in reconceptualising the relationship between endometriosis and PPP.

**The Faculty of Pain Medicine (faculty) asserts that PPP should be considered as a type of persistent pain state with some unique characteristics. The overarching approach should adopt principles in line with best practice management of other persistent pain states, that of multidimensional whole person care.**

#### **The importance of moving away from an end organ pathology focused care**

Consistent with experience in other types of persistent pain states, pathoanatomical models do not adequately explain the clinical phenotype in most cases. Receiving a diagnosis of endometriosis has not been demonstrated to improve outcomes in women with PPP. Research is needed to clarify the degree of contribution of endometriosis lesions to the overall burden of PPP, as well as to develop specific treatments that are effective and safe for these lesions. Research also needs to be directed towards identifying patients who will be helped by invasive treatments. Waiting for this research to be conducted should not preclude healthcare systems embracing a more comprehensive whole-person approach to PPP informed by established evidence.

Harms and limitations of the current paradigm of diagnosis and management include:

- delay in provision of symptom directed care at the time most likely to have a transformative impact on health, functioning and wellbeing,
- exposure to low-value procedures which are often repeated (medical procedures which yield little benefit in relation to the risks/costs involved),
- inequitable funding, remuneration and perceived value of surgical and percutaneous interventions compared to multimodal whole-person care, leading to wastage of healthcare spending
- misattribution of PPP to endometriosis without consideration and management of other contributors,
- invalidation of the lived experiences of those with PPP (those with and without endometriosis)

**The faculty advocates that timely and equitable access to sociopsychobiomedical assessment and treatments should be prioritised above a narrowly-targeted end-organ focused approach to pelvic pain care. This should be underpinned by early socio-culturally appropriate menstrual and pain education.**

Widespread adoption of the faculty's position of early access to education and timely best-practice management which encapsulates the whole-person and their context would improve function of the individual and reduce long-term disability. This would also improve the safety and cost-effectiveness of the care of women with PPP by reducing the number of unnecessary interventions.

The faculty's position would also ensure timely validation of the lived experience of women, over the current emphasis on finding and treating endometriosis lesions.

#### **Conclusion**

Current evidence-based understanding of the relationship between endometriosis lesions and PPP has moved beyond a simple assumption of causality. It is time to recognise that a sociopsychobiomedical approach to pelvic pain is most appropriate, whether endometriosis lesions are present or not.

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**GUIDELINE** – A document that offers advice on a particular subject, ideally based on best practice recommendations and information, available evidence and/or expert consensus. A guideline is not prescriptive.

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