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Title

Endometriosis and pelvic pain- time to treat the symptoms not the assumptions?

Short running title

Endometriosis: treat the symptoms not assumptions

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Title

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Abstract:

The high incidence and burden of pelvic pain is increasingly recognised in both the healthcare sector and by general public. Current approaches to management make the assumption that the diagnosis and remediation of identified lesions will ease this burden. The evidence base and successes in other areas of medicine would suggest that this assumption requires reconsideration.
As gynaecologists we are only too aware of the epidemic of pelvic pain and the substantial impact it has on the lives of so many of our patients, their families, and the resources of our health services[1]. Despite high healthcare expenditure, the number of women continuing to suffer indicates that outcomes of current care are suboptimal.

The Australian National Action Plan for Endometriosis[2] has the goals of improving quality of life and reducing burden of disease of endometriosis and pelvic pain, for individuals and for the nation. As we strive to meet these goals it is time for us to heed the evidence before us, as well as learn from our colleagues in other specialties.

The development of the RANZCOG Australian Endometriosis Guideline - while a pivotal component of the Action Plan - faces significant challenges. The guideline committee members have the herculean task of delivering recommendations to mitigate the huge burden of suffering, whilst navigating and acknowledging the very limited and low quality evidence base to guide them. An evidence informed review however, would conclude that a complete change in current practice is required.

The solution to this complex problem is not simply to 'do more'. The temptation to increase high-cost interventions, without robust evidence to support them, risks not only unintentional harms but also uncontrolled increases in healthcare expenditure without corresponding benefits.

Treatment guidelines should review the supporting evidence for each modality and the risks associated; clinical and financial. When there is equipoise in recommendations then the Hippocratic principle of 'first do no harm' would support lower risk (clinical and financial) interventions. The Choosing Wisely approach of reducing unproven therapies and low-value care is respectful not only of patients but also of society.

The last two decades have seen substantial progress in the scientific knowledge and evidence base in the pathophysiology and management of chronic pain; translating into a paradigm shift in the

management of chronic musculoskeletal pain syndromes[3]. Guidelines have changed the focus from radiological tests searching for facet joint narrowing, arthritic changes and bulging discs (recognising that these findings are also common in the asymptomatic population), to a symptom based management of 'non red flag low back pain'. Gone are the days of prolonged bed rest, high dose opioids and back braces - replaced with a neuroscience informed sociopsychobiomedical multidisciplinary (MDT) approach, and advice to keep moving and return to usual activities[3]- with improvements in disability and reductions in costs[4].

Despite increasing recognition of the similarities between the mechanisms and comorbidities in persisting pelvic pain and other chronic pain conditions[5,6], this wealth of knowledge and experience has not been translated to the care of women with pelvic pain.

In common with other cohorts of people living with chronic pain syndromes, women with persisting pelvic pain report a wide range of extra-pelvic pain syndromes, such as migraine, irritable bowel syndrome and widespread musculoskeletal or myofascial pain syndromes.

The lack of correlation between surgical findings and symptoms experienced by women with pelvic pain also mirrors that seen with many musculoskeletal pain presentations; where radiological findings commonly fail to correlate with pain in chronic back, hip and knee pain. Numerous authors have demonstrated that central sensitisation (an increased responsiveness of the central nervous system) is the likely explanation for this[6]. Menstruation is an inflammatory process releasing substances that are promoters of central sensitisation[7].

Thirty years ago multimodal MDT care for women with pelvic pain was shown to demonstrate superiority over solely biomedical treatments in quality-of-life outcomes, cost-effectiveness, iatrogenic risk, and reducing future surgeries and emergency department visits[8,9]. However subsequent enthusiasm - backed by a fledgling research base- for surgical intervention has seen surgery become the mainstay of management for many women with pelvic pain. In the intervening years the evidence base has not seen significant new contributions. A recent Cochrane review[10] found the level of evidence for pain and quality of life outcomes of laparoscopic surgery for endometriosis as low or very low, stating, "it is uncertain whether laparoscopic surgery reduces overall pain associated with minimal to severe endometriosis".

Isn't it time for a rethink? To acknowledge that this 'lesion focused care' is not only lacking scientific support but also ignoring and minimising the importance of the person who is attached to the painful pelvis? That despite high and increasing health expenditure this unidisciplinary biomedical model has failed to deliver improved quality of life for many? That countless women have been exposed to the risks of multiple and futile surgical interventions at the expense of a lack of investment into other lower-risk, higher-efficacy treatments?

If Orthopaedic surgeons, who are commonly the butt of jokes such as "what is a holistic orthopod? One who treats the whole bone!"- can respond to the challenge of chronic pain by modifying their practice, surely gynaecologists can too?

Whilst our colleagues in orthopaedics have followed the evidence base, drastically reducing their rate of arthroscopy[11] and finding that MDT input can reduce the need for knee replacements[3], they have not hung up their scrubs. By 'Choosing Wisely' only those patients who will benefit from a surgical approach, they not only avoid the risks of unnecessary surgery but also reduce the numbers of 'high-cost low-value' procedures. This redirects scarce health dollars and waiting list spaces to those who will most benefit.

Thus we too have the opportunity to 'Choose Wisely' with regard to what care we offer our patients with pelvic pain to optimise their outcomes, minimise harms, and prioritise valuable health dollars towards the most benefits.

A shift in focus from the visible lesions, tissues and organs to the lived experience of the person-in-pain, using a symptom focussed approach, is the best opportunity to deliver this. While this approach does not exclude the judicious use of surgical interventions it recognises them as just one 'tool in the tool box'- rather than a hammer to which everything looks like a nail.

We need acknowledge that presently there are no symptoms, symptom cluster nor algorithm that enables us to identify if superficial peritoneal endometriosis is present[12,13] ; and to question the pursuit of such an algorithm when it has been shown that those with pelvic pain and no demonstrable lesions share the same characteristics[13-15] and central changes as those with them[6]. This approach risks delaying the commencement of effective management strategies for pain, whilst we expend valuable health dollars, often at substantial out of pocket costs for our patients. It also fails to validate and belittles those women who have disabling pain, but do not have endometriosis;

implying that normal investigations suggest pain is not real. The ICD-11 recognises chronic pain as a disease in its own right and it is time that the distress and disability suffered as a result of the disease of chronic pelvic pain is recognised.

We are failing to listen to the symptoms and suffering of our patients. It is time we selected treatments for symptoms, not what our tests can identify - valuing the persons' lived experience, over what we can see.

By focussing on the presence of visible lesions, not the person, we also miss the opportunity to identify the other factors contributing to their pain-experience, disability and suffering; from their past sexual or childhood abuse or their current life stressors including domestic violence. We also fail to recognise and initiate treatment or referral for commonly co-existing pain problems such as migraines, pelvic floor muscle pain, IBS and vulvodynia[5,6,14] ; and other comorbid difficulties, such as anxiety and depression, chronic fatigue, neurocognitive changes[5], with the associated impacts on social relationships, work and productivity[1].

We acknowledge that the literature tells us that women with endometriosis have an eight-year delay before they are diagnosed[2]. Is the problem really a delay in making a diagnosis? Or is it the eight years of 'treatment delay' in having their symptoms acknowledged, their pain validated and appropriate management commenced, which can be done without the need for invasive procedures?

It is vital that we address the dysmenorrhoea that is impacting 20% of adolescents who are missing education, social and sporting activities. Early and effective management of these symptoms, which for the majority requires only low-cost low-risk menstrual suppression[16], mitigates this loss of schooling and provides the best hope of minimising progression to chronic pain[17].

All gynaecologists need to develop broad skills to recognise and manage pelvic pain and associated symptoms, rather than acting solely as 'surgical technicians', aiming to locate and remove an assumed end-organ lesion, only to abandon their patients when this fails to bring relief. We also need to be powerful advocates for further research; both via large controlled trials, but also pragmatically by maximising data collection using standardised outcomes[18] to quantify and publicise the outcomes of current management.

We recognise that significant investment and systemic change will be required to achieve the goals of the National Action Plan, but believe that women living with and suffering with pelvic pain deserve this effort.

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