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COMMUNITY
INFORMATION
2024

Persistent pelvic pain – a common but often overlooked problem

What is persistent pelvic pain?

Persistent pelvic pain is pain in the pelvic area (the lower part of the belly) which happens for longer than a few months. It is often linked to menstrual periods.

It affects millions of women and girls¥, causing them to miss school or work and have trouble with daily activities. About half of adult women report having problems with pelvic pain in the past year, and up to one in five report having pain with sex. One in four girls will miss school because of period pain. We don't have more accurate statistics as persistent pelvic pain isn't well studied.

In the past, pelvic pain was often dismissed as something normal for women, or wrongly thought to be "all in their heads". Many health professionals advised women that their persistent pelvic pain would simply "go away" as they got older or went through a pregnancy. As a result, many had poor treatment and feelings of hopelessness. Today many women still don't get effective treatment, which means they keep suffering. In addition to the personal costs to women, it also costs a lot in healthcare and lost work. There is still stigma and misunderstanding, affecting how women seek and receive help.

- Persistent pelvic pain is like many other persistent pain conditions but has its own characteristics:
- It often starts in adolescence.
- Many body systems can be involved.
- Menstrual cycles can cause inflammation that can result in pain.
- People might not get help early because period pain is seen as normal.
- Psychological factors often play a role in how it starts and how it's kept going.

Society, government, and healthcare are starting to recognise the problem more. However, most funding goes toward diagnosing specific issues like endometriosis. Traditional treatments usually involve medicines or surgery, but these don't always work well. Newer evidence suggests that a combined approach, addressing physical, emotional, and social aspects, is more effective for women with persistent pelvic pain.

The link between endometriosis and persistent pelvic pain

Focusing on endometriosis (a condition where tissue similar to the lining of the uterus is found outside the uterus) isn't always helpful.

It used to be thought that endometriosis directly caused pain, but we now know that's not the case. Endometriosis is only found in about half of women with persistent pelvic pain and the amount of endometriosis found doesn't match how much pain women experience. Endometriosis is also found in up to 45 per cent of women who do not have pain. This means that we don't know if endometriosis is actually causing pain or not.

Surgery to remove endometriosis doesn't always help pain, and sometimes can make things worse. Even for women who do report some improvement from surgery, this doesn't usually last for long. Surgery carries risks and costs more than other types of treatment.

Challenges with current diagnosis and treatment

Being diagnosed with endometriosis doesn't always lead to women feeling better. A health system which concentrates on surgery (or getting a diagnosis of endometriosis) can delay other care early on when it could help most, spends money on treatments that don't work well, and doesn't treat all causes of persistent pelvic pain. This can also lead to unhelpful experiences for women and waste healthcare resources.

Healthcare should focus more on whole-person care based on what works best for other types of persistent pain. Research is needed to understand why women suffer persistent pelvic pain and to find better and safer treatments.

A more inclusive approach

Understanding persistent pelvic pain involves more than just blaming endometriosis. We need to move away from just focusing on physical evidence of endometriosis alone. Instead, we should use a whole-person approach to manage persistent pelvic pain whether endometriosis is present or not. This approach includes medical, psychological, and social care, leading to better results and less need for healthcare.

¥ The term 'women' is used to indicate women, girls and those assigned female at birth.

About the Faculty of Pain Medicine

The Faculty of Pain Medicine trains doctors to become pain specialists. We promote safe care aimed at reducing pain for people in Australia and New Zealand. As experts in this area we set standards in pain management. We are making our standards available to all.