Let's not normalise period pain

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March is endometriosis awareness month, setting the scene for a timely review of this common and debilitating condition

ENDOMETRIOSIS is more common than diabetes or breast cancer, but has no known cause or cure.

About 176 million women worldwide, including adolescents, suffer from endometriosis, yet it is rare before menarche or after menopause.

Up to 47% of female adolescents with pelvic pain have endometriosis. Yet alarmingly, the average delay in diagnosis of endometriosis is 7-10 years. This is due to girls and women, as well as doctors, normalising symptoms such as dysmenorrhoea.

A delayed diagnosis can be associated with infertility, debilitating pain and reduced quality of life.

Endometriosis can affect many aspects of a woman's life. Beyond the physical effects, there can be heavy financial, relationship, emotional and mental health impacts. In Australia, the annual cost of medical and surgical treatments for women with endometriosis is $6 billion.[1]

Early diagnosis and treatment can reduce the long-term impact of endometriosis on individuals and the economy; lost productivity is estimated to be twice the cost of the healthcare expenses associated with endometriosis.

In December 2017, federal Health Minister Greg Hunt formally apologised to women with endometriosis as he announced a national plan to address the condition, including an education and awareness campaign and a $160,000 research grant for the NHMRC.

BACKGROUND

Endometriosis is defined as the presence of endometrial-like tissue outside the uterus, which causes a chronic, inflammatory reaction. It is primarily found on the pelvic peritoneum, uterosacral ligaments and Pouch of Douglas.

More severe disease can involve the bladder and bowel and in rare cases it can be found on abdominal surgery scars and in organs outside the pelvic cavity.

It is not fully understood how endometriosis begins. However, associated risk factors include a genetic link (if a first-degree relative has the condition, endometriosis is 10 times more likely in a patient), early menarche and lower body weight.

Women are sometimes told that pregnancy will cure endometriosis, but this is not the case and should not be suggested.

SIGNS AND SYMPTOMS

Symptoms are diverse and non-specific, and do not correlate with disease severity. Endometriosis can be asymptomatic or present, but not the cause of pelvic pain.

Possible symptoms include:

- Dysmenorrhoea and pelvic pain (present in 79% of patients). This often starts 1-2 days prior to menses, can last throughout menses and for days afterwards. Pain may not develop for years after menarche, but can be superimposed on primary dysmenorrhoea.
- Dyspareunia (present in 51% of patients). This is typically deep discomfort and may persist for hours or days after intercourse.
- Bowel upset or pain. Symptoms include diarrhoea/constipation, bloating, cramping and dyschezia (pain when opening bowels). These can occur even when endometriosis is not infiltrating the bowel. PR bleeding is rare.
- Subfertility (present in 30% of patients).

Practice points

- Dysmenorrhoea that impairs quality of life is not normal — first referral should be to a gynaecologist
- Early diagnosis and treatment reduce the long-term impacts of endometriosis and frequency of invasive treatment and fertility treatments
- A possible diagnosis of endometriosis should be considered in patients presenting with:
  - persistent pelvic pain (cyclic and/or non-cyclic)
  - severe dysmenorrhoea
  - dysmenorrhoea resistant to NSAIDS and the oral contraceptive pill
  - pain interfering with daily activity
- The combination of laparoscopy and histological verification is considered the gold standard for endometriosis diagnosis
- Seek out health professionals with endometriosis experience including: gynaecologists with advanced laparoscopic skills, psychologist/pain specialist, fertility specialist, community health nurse, pelvic floor physiotherapist, dietitian, accredited exercise physiologist, sex therapist and naturopath.

- Ovarian mass/cyst (present in 29% of patients).
- Urinary symptoms. These include urinary frequency/urgency during menses; suprapubic pain with micturition; urinary retention/haematuria/flank pain from ureteric obstruction is not common; urinary tract endometriosis may be asymptomatic.
- Non-specific symptoms including low back pain, pre-menstrual spotting, and fatigue.[2]

CONSULTATION

Obtain a menstrual history from the patient including details about menarche, cycle, timing and/or progression of dysmenorrhoea. Also enquire about bowel and bladder symptoms and dyspareunia and assess the severity of symptoms and impact on quality of life.

Explore past and current treatments including surgery and outcomes. Assess mental and emotional health — patients with persistent or severe pelvic pain have an increased risk of depression or anxiety.

Undertake an abdominal examination for tenderness, masses or scars and perform a pelvic examination if appropriate. This is often normal — the most frequent abnormal finding is tenderness in the posterior fornix.

INVESTIGATIONS

There are no diagnostic blood tests for endometriosis. CA125 can be elevated, but is not sensitive or specific for the condition. Pelvic ultrasound scan (USS) may aid the diagnosis and this should preferably be performed transvaginally by a well-trained provider. Standard ultrasound will not detect superficial endometriosis or adhesions. Specialist endometriosis USS can identify size, location and depth of infiltrating lesions, adhesions and features of superficial disease.

MANAGEMENT

Pelvic pain and possible endometriosis may be managed initially with empiric medical therapy. About 80-90% of women with endometriosis will experience some improvement with medical therapy. NSAIDs and/or hormonal treatments are both appropriate to reduce pain and inflammation. Appropriate hormonal therapy includes progestogen-only or combined oestrogen/progestogen contraceptives.

Medical therapy will not decrease endometriomas or adhesions, or improve fertility.,Pregnancy does not cure endometriosis. Consider referral to a gynaecologist in the following circumstances:

- Failure to respond adequately to 3-6 months of medical management;
- Previously diagnosed endometriosis with return of symptoms that have not responded to appropriate medical management;
- Symptoms/signs suggestive of deep infiltrative endometriosis (dyschezia, deep dyspareunia, endometrioma on pelvic USS)
- Infertility.

Laparoscopy is required for a definitive endometriosis diagnosis, while surgical treatment is associated with a reduction in pain. Symptom recurrence requiring re-operation is common and increases with time (occurring in 21.5% of patients two years after surgery and 40-50% five years post-operatively).

Hormonal treatment post-operation (for >1 year) increases the duration of pain relief and delays disease recurrence.[3] In minimal and mild endometriosis, removal of endometriosis is associated with an increased spontaneous conception rate and can lead to an improvement in IVF success. If pelvic anatomy is distorted by more severe endometriosis, surgery to remove these adhesions can remove mechanical barriers to conception such as tubal adhesions.

However, treating severe endometriosis does not clearly improve the spontaneous conception rate, although it may improve IVF outcomes with better access to the ovaries for egg retrieval. If a woman has severe endometriosis and her only symptom is infertility, the first line would be ART (assisted reproductive techniques) rather than surgery for the endometriosis.

References available on request

Patient resources:
Jean Hailes for Women's Health www.jeanhailes.org.au
Endometriosis Australia www.endometriosisaustralia.org

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