Title:
Endometriosis

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Endometriosis

Endometriosis is a life challenging disorder that affects over 1.5 million women in the UK – around one in 10 women (Rogers et al, 2009). It is a complex illness and evidence suggests that care can be delayed due to a lack of awareness and understanding of the disease amongst health care workers, which leads to a lengthy diagnosis; it can take on average up to seven years for some women to receive a full diagnosis and access the best treatment for their condition (Endometriosis UK, 2011). Nurses working within primary care services need to have an understanding of this condition and an awareness of the range of presenting symptoms to facilitate a timely referral to more specialist services.

This article provides an overview of endometriosis and identifies the role of the nurse in supporting women with this diagnosis through their patient journey.

**Key words:** endometriosis, nursing, primary care, investigations, treatment options

**What is endometriosis?**

Endometriosis is an oestrogen-dependent chronic condition where endometrial tissue forms lesions outside the uterus, which induce a chronic, inflammatory reaction (Rogers et al 2009). Most ectopic endometrial deposits are found on the ovaries, peritoneum, uterosacral ligaments, pouch of Douglas, and retrovaginal septum (Jackson & Telner, 2006). However, endometrial deposits have also been seen outside the pelvic cavity such as the brain and lungs (Kennedy et al 2005). The ectopic tissue responds and reacts to ovarian stimulation and proliferates and sheds in a similar way to the eutopic endometrium. This results in internal bleeding, inflammation, fibrosis, and adhesion formation.

**Prevalence**

The exact prevalence of endometriosis is unknown, due to the differences in presentation and the difficulty women having in getting diagnosed, but estimates range from between 2-10% within the general female population but up to 50% in infertile women (Holoch & Lessey, 2010). It is estimated that around 1.5 million women in the UK are currently living with the condition; this is comparable
to the number of women affected by diabetes (Diabetes UK, 2012). Endometriosis costs the UK economy £8.2bn a year in treatment, loss of work and health care costs (Simoens, et al. 2011).

**Aetiology**

The cause of endometriosis is uncertain and contested and there is no definite cure (World Endometriosis Society and the World Endometriosis Research Foundation, 2012). Several theories have been suggested, See table 1:

<table>
<thead>
<tr>
<th>Table 1: Possible Causes of Endometriosis</th>
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<tbody>
<tr>
<td>• Retrograde menstruation</td>
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<tr>
<td>• Genetics</td>
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<tr>
<td>o affects women of every ethnicity but is less common in women of African-Caribbean origin and more common in Asian women than in white women</td>
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<td>o family history of endometriosis.</td>
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<td>• Immune dysfunction</td>
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<td>• Environmental causes</td>
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<td>o caused by certain toxins such as dioxins which affect the immune system and reproductive system – evidence of a link in animals but not known if this is the case in humans</td>
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<tr>
<td>• Unknown or a combination of the above</td>
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(World Endometriosis Society and the World Endometriosis Research Foundation, 2012)

**Signs and Symptoms**

The symptoms of endometriosis vary in their presentation and severity. Whilst some women can experience painful symptoms and / or infertility, for other women they have no symptoms and their endometriosis is found incidentally, therefore severe disease may remain undiagnosed. See table 2 for range of symptoms:
Table 2: Range of Symptoms

- dysmenorrhea
- chronic pelvic pain
- painful bowel movements, painful urination and blood in urine
- dyspareunia
- cyclical or premenstrual symptoms with or without abnormal bleeding and pain
- chronic fatigue
- depression
- infertility
- painful caesarean section scar or cyclical lump
- back, legs and chest pain

(Royal College of Nursing, 2015)

The process of obtaining a diagnosis from symptom onset can take several years, with the average ranging from 5 years (Sepulcri and do Amaral, 2009) to 8.9 years (Fourquet et al., 2010), due to both delays in women seeking help, who perceive that painful periods are normal and delays by healthcare professionals. This can be compounded by the nature of the symptoms which may lead to referrals to other specialties before gynaecology such as colorectal and general surgeons. This delay to diagnosis can lead to significant amounts of distress amongst women (Denny, 2004; Lemaire, 2004). Early diagnosis and provision of information and support may help women and their partners better understand the condition and enable them to make informed decisions about their treatment options and how they can best manage this condition and its impact on their day to day lives.

**Impact on women’s lives (physical, psychological, social, relationships etc.)**

Given the uncertain and enigmatic nature of the condition and the reported delays to diagnosis, endometriosis has a significant impact on women’s lives across a wide range of domains, including family life, work and social life (Culley et al, 2013) and quality of life more generally (Gao et al., 2006;
Jia et al., 2012). Endometriosis not only has physical implications but can lead to significant amounts of distress amongst women (Denny, 2004; Lemaire, 2004).

On a basic level living with a condition that can give rise to chronic pelvic pain may lead to distress and depression. Facchin et al (2015) found that women with pelvic pain and endometriosis had poorer quality of life and more depression than other women. Women often feel isolated and can lack support socially from friends and family who may just perceive that they have ‘period pain’. This social isolation may result in feelings of emotional distress, hopelessness, worthlessness, depression and feeling suicidal (Whelan, 2007).

This condition can also affect fertility, sexual relationships and body image. Due to the pain that some women can have with sexual intercourse this can lead to avoidance of sex and then problems within relationships. Around 40% of women with endometriosis and chronic pelvic pain are reported to have sexual dysfunction and decreased frequency of sexual intercourse (Tripoli et al, 2011). Even women who have received treatment for this condition can still fear pain with sex and can have ongoing psychosexual dysfunction.

Endometriosis is also associated with infertility, with a strong association between severity of disease and impact on fertility, probably due to impaired tubo-ovarian function, the presence of ovarian endometrioma, subclinical pelvic inflammation, possibly reduced oocyte quality and reduced endometrial receptivity to implantation (Lessey, 2011). It is suggested that up to 50% of women with endometriosis are infertile and for some women the diagnosis is only made as part of infertility investigations (Luk & Taylor, 2011). Agreement about treatment options has been difficult to establish (Holoch & Lessey, 2010).

In addition to this if women are not able to have intercourse due to pain this may cause additional stress or tension within the relationship especially if they are trying to conceive. Infertility and depression, are also associated with the impairment of sexual function (Ter Kuile et al, 2010) so further compounding this vicious cycle where women must decide whether to tolerate pain to allow for sexual intercourse, or reduce their level of intimacy which in turn may impact on their relationships and chances of pregnancy.
Investigations and Diagnosis

Diagnosis is based on the women’s history, signs and symptoms, corroborated by a physical examination and imagining techniques, and finally proven by histological examination of specimens collected during laparoscopy, which is considered the gold standard for diagnosis of this disease (European Society of Human Reproduction and Embryology, 2013).

In addition to general history questions asked, these more specifically ones are aimed at women with endometriosis:

a) History-taking: questions relating to:
   - Gynaecological and obstetric history
   - Menstrual history including:
     - recurrent painful periods
     - severe dysmenorrhea - elicit cyclical nature of pain, severity and/or association with other symptoms like pelvic pain
   - Painful intercourse such as deep dyspareunia
   - Chronic lower abdominal, pelvic and lower back pain. Constant aching dragging pain may be exacerbated by menses due to stretching of tissues, and local production of prostaglandins within the ectopic endometrial implants
   - Infertility
   - Painful micturition manifesting as cystitis or cyclical haematuria
     - Infrequent presentation is obstructive uropathy
   - Dyschezia due to gastrointestinal tract endometriosis.
     - Cyclical rectal bleeding may occur due to endometriotic bowel disease
   - Family history of endometriosis
   - Other cyclical symptoms related to endometriosis outside the pelvis, i.e. hiccups or chest problems caused by deposits on the diaphragm or in the thoracic cavity

b) Examination
   - Abdominal examination generally does not show any pathology but should be undertaken to exclude any masses and or tenderness
Pelvic bimanual examination – the detection is improved by examination during menses. A fixed retroverted uterus with adnexal tenderness and cervical excitation is suggestive of endometriosis. The uterosacral ligaments may be tender, but nodular posterior pelvic endometriosis is not easily palpable at vaginal examination, unless by an experienced clinician.

Rarely disease may be visible in the vagina or cervix – blueberry lesions

c) Investigations

- Ultrasound - Imaging techniques like Ultrasound lack resolution to visualise superficial peritoneal and ovarian implants and adhesions. However, a transvaginal ultrasound scan (TVS) can detect ovarian endometriomas, solid nodules within the posterior vaginal wall and/or bladder nodules. TVS is less expensive than Magnetic Resonance Imaging (MRI) and should a first line. In some specialist centers, clinicians are using ultrasound in place of MRI to detect endometriosis.

- MRI - In posterior pelvis endometriosis MRI can be combined with TVS to determine the extent of disease and MRI can pick up endometriomata >1 cm size. MRI can be useful when planning surgery in specialist centres.

- Laparoscopy - On laparoscopy it can sometimes be difficult to delineate the endometriotic lesions from fibromuscular tissue. The use of laparoscopy for diagnosis of endometriosis is important but it is an invasive procedure. Biopsy of at least one lesion is advisable at laparoscopy. Laparoscopy can be either diagnostic but can also be operative to treat any endometriosis found.

Laparoscopic features of ovarian endometriota are: i) adherent to pelvic side wall and posterior side of the broad ligament and/or uterus, ii) there is usually a tarry thick chocolate fluid content, iii) retraction of ovarian cortex, iv) powder-burns and pink, red, blue or black spots on the ovaries.

- Serum markers Ca125 and Ca19-9 are elevated though sensitivity and specificity are low. Measuring CA125 has no value as a diagnostic tool

- Intravenous pyelogram to exclude obstructive uropathy

- Barium enema studies as appropriate

- Rectal sonography can be used to evaluate the thickness of the uterosacral ligaments and presence of rectal involvement

Treatment Options

As there is no cure for endometriosis, patients’ treatment pathways are aimed at managing the disease and focus on symptom management. These treatment options can be hormonal, non-hormonal, or surgical, and they have with varying rates of success (European Society of Human Reproduction and Embryology, 2013). If women are trying to conceive then non-hormonal treatment is the only option open to them, other than surgery. Symptom recurrence is common following any medical and surgical treatment of endometriosis as this suspends the endometriosis but does not cure it. Treatment options may also have potential side-effects which may impact negatively on women’s quality of life.

Medical Treatment of Endometriosis

Medical treatments can be in combination with surgical interventions and can be hormonal or for pain relief.

1. Non-hormonal
   a) Analgesics: Non-steroidal anti-inflammatory drugs work by blocking the production of prostaglandins in the body. Prostaglandins are naturally occurring in response to injury or disease, and cause pain and inflammation. In women, they also make the uterus contract during a period, and it may be that women with endometriosis have more prostaglandins and therefore more pain. As with most analgesia they are more effective if taken before the onset of pain, such as when the period is due to start. Women can also be advised to use other analgesia at the same time such as Paracetamol or codeine-based analgesia.

   b) Pain modifiers: Some women may not want to, or be able to, take hormones and may be referred to pain clinics where they can have more specialized medications such as pain modifiers. These drugs are not normally first line treatments but can be used by pain specialists if needed. They work by altering the body’s perception of pain. This group of drugs include Amitriptyline, which can be prescribed for depression but can also help with nerve pain.
2. Hormonal

a) Combined oral contraceptive pill (COCP): The COCP contains a combination of oestrogen and progesterone. It works by suppressing ovulation and therefore menstruation. Due to the effects of the hormones the endometrium and the endometriosis deposits are thinner. The COCP is usually suggested to be used continuously for women with endometriosis so there are no breaks and no bleeding, although this is an off-licensed usage.

b) Mirena (levonorgestrel-releasing hormone Intrauterine System; LNG IUS): The Mirena is a small plastic T-shaped intrauterine device. It contains a progestogen that is released into the uterus over a period of 5 years. The IUS may also be used for contraception. The progestogen release suppresses the growth of the endometrium and endometrial deposits so they become thin and inactive. The Mirena does not always prevent ovulation and some women find the Mirena fitting painful. As the progestogen can also act locally, it reduces endometriosis linked pain (dysmenorrhoea, dyspareunia) associated with extensive pelvic and rectovaginal endometriosis.

C) Oral Progestogens: Progesterones (e.g Provera) are thought to relieve the symptoms of endometriosis by suppressing the growth of endometriosis deposits and may also reduce endometriosis-induced inflammation. During treatment a woman will stop ovulating and menstruating, although they are not licensed for contraception, and some women experience Pre-menstrual Syndrome like side effects.

D) Gonadotropin-releasing hormone (GnRH) analogues: GnRH analogues are modified versions of the naturally occurring GnRH. GnRH controls the menstrual cycle and by switching off these hormones the women is put into a temporary menopausal state. This means menstruation will cease and the endometriosis becomes inactive and reduced. It is often recommended that a woman is prescribed hormonal ‘add-back’ therapy or Hormone Replacement Therapy (HRT) to reduce or even prevent the side effects of these drugs. Examples of these drugs are: Leuprorelin (Prostap); Goserelin (Zoladex)
These drugs are generally restricted to six months use due to bone demineralisation in some women after this period of time. The “adding back” of oestrogen and progestogen can protect against bone mineral loss during and for up to six months after treatment.

E) Other medical therapy: Evidence is emerging about the efficacy of newer drugs used for the treatment of endometriosis (Muñoz-Hernando et al, 2015)

i) preliminary data show aromatase inhibitors like Letrazole may be effective in reducing endometriosis-related pain but are associated with significant bone loss. These drugs inhibit oestrogen production in endometriotic lesions without affecting ovarian function. ii) Emysa. There may be a role for the selective progesterone receptor modulator (SPRM) drug ulipristal but there is limited research and it does not have a license for the treatment of endometriosis.


Surgical Management of Endometriosis Associated Pain

a) Laparoscopic ablation / excision of endometriosis lesions: This is undertaken by laser or diathermy and is effective for a large number of women. There is however, limited data which is part of the work now being undertaken by the British Society for Gynaecology Endoscopy (BSGE) to assess whether which surgical method is superior. Although this is minimally invasive surgery as defined by laparoscopy, this surgery can be complex and women should be given realistic expectations about post operation recovery.

Radical surgery: Total abdominal hysterectomy (TAH) and bilateral salpingo-oophorectomy (BSO) removes the entire lesions in severe and deeply infiltrating endometriosis resulting in improved pain relief. In a ‘frozen pelvis’ a subtotal hysterectomy may be safer, as there is less risk of damage to the bladder. However even with a hysterectomy there may still be pain as there can be deposits which can be reactivated with hormones and 15% of women still complaint of chronic pelvic pain after a TAH (Vercellini et al., 2009). For endometriosis that is in the bladder and bowel or close to the bowel, there should be management by multidisciplinary teams in BSGE specialist endometriosis centres.

Complementary Therapy / other interventions

a) High frequency tens; acupuncture
b) Vitamin b1 and Magnesium may help to relieve dysmenorrhoea

c) Dietary adjustments

d) Support groups: There is an enormous role for patient support groups

e) Physiotherapy: Physiotherapists can develop a programme of exercise and relaxation techniques designed to help strengthen pelvic floor muscles, reduce pain, and manage stress and anxiety. After surgery, rehabilitation in the form of gentle exercises, yoga, or Pilates can help the body get back into shape by strengthening compromised abdominal and back muscles.

Role of the Nurse

Nurses come into contact with women with endometriosis in a variety of clinical environments (Denny, 2004), such as primary care settings, schools, urgent care and emergency departments, and sexual health services. An awareness of endometriosis, and an understanding of the current evidence and best practice guidance, is important in supporting nurses to provide appropriate individualised care to women.

Nurses working within these clinical areas can be instrumental in recognising the symptoms, and understanding the impact of, this diagnosis on women’s activities of daily living and their relationships. Endometriosis can affect women on a physical, psychological and social level, so a holistic and sensitive approach to care is imperative in supporting women to cope with this condition. Nurses can play a pivotal role in facilitating diagnosis, providing patient education and psychological support, to empower women to feel able to negotiate their own needs and treatment preferences.

To address this, the Royal College of Nursing (RCN, 2015) has developed a factsheet for nurses to use to help recognise the symptoms of endometriosis and aid earlier referral (available at: https://www.rcn.org.uk/professional-development/publications/pub-004777)

What can the practice nurse do?

Nursing interventions:

• taking a detailed history
• using the RCN endometriosis checklist to help recognise and focus upon specific signs and symptoms of endometriosis
• listening to the woman’s account of how her activities of daily living are affected
• allowing time for the woman to disclose sensitive information such as the impact on her sexual relationship, fertility concerns
• empowering women by educating them about this condition
• exploring the range of treatment options and their consequences
• discussing health promotion interventions
• signposting to other support services
• recognising the need to refer to other members of the multidisciplinary team

Conclusion

Endometriosis is a condition which can have a significant impact on a woman’s fertility and quality of life. This condition is often misunderstood and misdiagnosed leading to reported lengthy delays in achieving a diagnosis. All nurses who have contact with female patients should be aware of the range of endometriosis symptoms, in order to accelerate earlier diagnosis and referral. This article highlights the important educational role of nurses in raising awareness of this condition and providing a holistic individualised approach for women with endometriosis to support their overall quality of life.

Useful links

• Endometriosis UK
• British Society for Gynaecological Endoscopy
• Endometriosis.org
• Royal College of Obstetricians and Gynaecologists
• European Society of Human Reproduction and Embryology
• The World Endometriosis Society

Key Points

• One in ten women of reproductive age in the UK suffer from endometriosis
• The prevalence of endometriosis in women with infertility is as high as up to 50%
• On average it takes 7.5 years from the onset of symptoms to get a diagnosis
• Endometriosis has a profound impact on women’s lives
• The cause of endometriosis is unknown but there are many different treatment options

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