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What the physiotherapist needs to know about endometriosis

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Abstract

Endometriosis is a gynaecological condition that affects millions of women around the world. In some cases, it does not pose significant problems, but in many others, it can cause severe pain, which significantly affects these individuals' ability to carry out day-to-day tasks and reduces their quality of life. Endometriosis can go undiagnosed for years, but treatment is often straightforward and effective. For a proportion of women, the chronic pelvic pain associated with this condition can be a trigger for the development of further musculoskeletal symptoms, and therefore, the women's health physiotherapist is ideally placed to address these problems.

Keywords: endometriosis, gynaecology, infertility, pelvic pain.

Introduction

Endometriosis is one of the most common gynaecological problems, but many women can have its symptoms for years before a diagnosis is made. Although it was first described in 1869, the cause and natural history of the condition are still poorly understood.

What is endometriosis?

In this disorder, endometrial tissue, which forms the lining of the uterus, is found in other locations. Commonly affected areas include the ovaries, the ligaments supporting the uterus, and the bowel, bladder and vagina. In rare cases, deposits of endometrial tissue can even be found in surgical scars, the lungs and the umbilicus. The appearance of the condition ranges from blister-like spots or dark patches, which are called implants, to large cysts, which are known as endometriomata, in the ovaries. Deposits can cause an inflammatory reaction in the surrounding tissue, leading to the formation of areas of scar tissue called adhesions. In severe cases, this condition can alter normal anatomy, and cause the pelvic organs to become buried or distorted by scarring (Kennedy *et al.* 2005).

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Who gets endometriosis?

Because endometriosis can only be diagnosed with an operation, it is difficult to know how many individuals have the disease. It has been estimated that between 5% and 10% of women of reproductive age are affected. However, because some of them never experience any symptoms, such figures are open to question, and some authorities believe that up to one in three women may have the condition (Eskenazi & Warner 1997).

Symptoms can occur at any age between the onset of menstrual bleeding and its cessation, i.e. the menarche and menopause. While it is uncommon to diagnose endometriosis in teenagers, the symptoms often begin at menarche. This condition is usually detected when women are between 25 and 35 years of age. A large survey of 7025 individuals with endometriosis revealed that 27 was the average age at which the diagnosis was made (EST 2005). It had taken an average of 9 years for the problem to be identified in these women, and 68% had initially been misdiagnosed with another condition (EST 2005).

There appears to be no difference in the incidence of endometriosis in different ethnic and social groups (Viganò *et al.* 2004). It used to be thought that delaying starting a family to a later age was associated with an increased risk

of endometriosis, leading it to be called “the career woman’s disease”, but this has not been supported by research studies (Moen 1991). There is an approximately six-fold increase in the incidence of this condition in women with a first-degree relative who has suffered from it (Simpson *et al.* 1980), and identical twins are both likely to be affected (Hadfield *et al.* 1997). Current research is focused on investigating the genetic basis of the disease in the hope of identifying new treatments (Burney 2013).

What does endometriosis look like?

Endometriosis can be seen with the naked eye during surgery. The deposits of abnormal tissue are called implants, and in the early stages of the condition, these resemble small raised spots, blisters or areas of dark pigmentation. On inspection alone, it is difficult to tell how deeply these implants infiltrate into the pelvic tissues, but more severe forms of the disease are associated with larger collections of endometrium that have a nodular feel and appearance, and extend further into normal tissue. As time passes, endometriotic implants may disappear. However, in many cases, these areas can persist, grow larger or become scar tissue. Changes usually happen over several months or years since endometriosis typically grows slowly, and most women have a stable manifestation of the disease that does not progress.

Endometriomata are benign, i.e. non-cancerous, cysts that may form in the ovaries. These growths vary greatly in size and can be seen on ultrasound scans. The ovarian tissue often looks normal on the outside, but when an incision is made, the cysts are found to contain a thick brown liquid composed of altered blood, giving rise to the commonly used description “a chocolate cyst”. If an endometrioma bursts or has bleeding within it, the woman may experience sudden and severe pain. Once released, the contents of the cyst can cause irritation, which further adds to the development of scar tissue.

In severe cases of scar tissue or adhesion formation, the pelvic organs may literally become stuck together. Endometriosis can be found in the bowel, or extending into the tissues between the rectum and the vagina (the rectovaginal septum). These manifestations of the disease are difficult to manage, and require expert assessment and treatment.

What is normal?

The delay in diagnosis occurs partly because the symptoms of endometriosis overlap with what is normal. Many women will take simple household pain-killers during their periods, but manage to continue with work and activities of daily living. Occasional discomfort during sexual intercourse is common and probably normal (Overton & Park 2010).

What are the symptoms?

The symptoms of endometriosis vary greatly between individuals, and in some cases, there may be none at all. There is no correlation between the acuteness of the disease and the severity of the symptoms, and therefore, women with very mild symptoms may have a very serious form of the disease.

The most commonly reported symptoms of endometriosis are painful periods, i.e. dysmenorrhoea, and pelvic pain between menstruations. These problems can be very severe and may have a negative impact on daily life. Pelvic pain typically starts in the 2 weeks before a period is due, building in intensity as the start of menstruation approaches and then easing as the bleeding stops. Although this pattern is commonly seen with endometriosis, very painful periods can occur without the condition. Other symptoms include prolonged heavy or irregular periods, a deep pain during intercourse (i.e. dyspareunia), and pain on opening the bowels (i.e. dyschezia) or on passing urine. These pain symptoms can be severe, and have been reported to lead to absences from work by 82% of women with endometriosis, with an estimated cost in Europe of €30 billion per year (EST 2005). Symptoms such as fatigue and low mood are often described, and these reflect the impact the disease can have on day-to-day life. On rare occasions, women may notice blood in their stools or urine during a period, which can indicate severe endometriosis deeply infiltrating the bowel or bladder (RCOG 2006).

The condition is painful and its symptoms are typically cyclical. The clinical signs of endometriosis improve when the combined oral contraceptive pill is taken, and during pregnancy and breastfeeding. Therefore, women commonly present when they experience a relapse after having stopped taking the oral contraceptive pill or when their periods return after childbirth.

If a woman who was missing work or having difficulty carrying out her day-to-day tasks

because of cyclical painful symptoms was assumed to have endometriosis, then the time taken to make a diagnosis would be considerably shorter (Overton & Park 2010).

When should a physiotherapist refer to a gynaecologist?

It would be reasonable to treat a woman who did not want to conceive with the combined oral contraceptive or progestogen-only pill in the first instance, but if the symptoms do not improve, referral should be considered for any patient who is missing work or having difficulty carrying out her day-to-day tasks because of pain. Women should be referred without delay if either the clinical examination or the ultrasound scan is abnormal (e.g. revealing an ovarian cyst or endometrioma). Urgent referral is required for any woman with rectal or vaginal bleeding between periods who is over 40 years of age.

How does endometriosis affect fertility?

Although endometriosis can be linked with infertility, most women who suffer from this condition will conceive without difficulty. However, the diagnosis can lead to a great deal of anxiety among women who have yet to complete their family.

Marcoux *et al.* (1997) investigated the number of pregnancies in women following treatment for mild endometriosis at the time of a laparoscopy in comparison to those who had only had a diagnostic laparoscopy without any treatment. This study demonstrated an improvement in fertility that reached statistical significance in those individuals who had received treatment (50 pregnancies in a group of 341 women) compared with those who had not (29 pregnancies in a group of 169 women) (Marcoux *et al.* 1997).

There is debate about whether fertility can be affected or not in cases of mild endometriosis. Eighty per cent of couples in which the woman has no endometriosis will achieve a pregnancy by the end of their first year of trying to conceive compared to 75% of couples in which the woman is affected by mild endometriosis. However, if lesions caused by mild endometriosis are destroyed surgically (e.g. by surgical removal or vaporization with heat), then the successful pregnancy rates are higher (RCOG 2006).

In cases of more severe endometriosis, there is more scar tissue, which distorts the pelvic anatomy and pulls the fallopian tubes away from the ovaries, meaning that the egg can no longer

reach the tube. In couples in which the woman has moderate endometriosis, 50% will achieve a pregnancy by the end of their first year of trying to conceive. This figure is 25% in couples in which the woman has severe endometriosis, but in these cases, it may be possible to surgically release the adhesions and restore normal anatomy. Fertility treatments such as *in vitro* fertilization can be considered if surgery is unsuccessful.

Once a woman has conceived, this condition does not affect her ability to carry the pregnancy to term or influence the way in which she gives birth. Some individuals may experience an increase in the intensity of their symptoms of endometriosis in the first 3 months of pregnancy because of the changing levels of hormones, but after this, most are free from pain.

How is endometriosis diagnosed?

The symptoms that a woman suffers from may suggest endometriosis, but the diagnosis cannot be made on the basis of this history alone. There are other conditions that may present with similar problems, and not all women who have endometriosis will exhibit its symptoms. At present, there is no blood test that can confirm the diagnosis, and although endometriomata (i.e. endometriotic cysts on the ovaries) can be seen on ultrasound scans, the more commonly seen implants cannot. Therefore, a normal scan does not exclude the diagnosis.

Examination

Vaginal and pelvic examination can be very useful in cases of endometriosis. A woman may have tenderness over areas that contain endometriotic nodules, or her ovaries may be tender and enlarged by endometriomata. Speculum examination of the vagina and the neck of the womb, i.e. the cervix, may reveal dark brown or bluish lumps that feel firm.

Laparoscopy

For a definitive diagnosis of endometriosis, a surgical procedure called a laparoscopy is required. Under a general anaesthetic, a slender endoscope (i.e. the laparoscope) is introduced through an umbilical incision. This instrument allows direct inspection of the pelvic organs and the peritoneum, the membrane lining the abdomen and pelvis. Because endometriotic implants have such a characteristic appearance, the diag-

nosis is often made by visual inspection alone. It is possible to confirm this histologically by taking a biopsy, i.e. removing a small piece of tissue for inspection under a microscope (RCOG 2006).

Women undergoing laparoscopy for suspected endometriosis will be counselled about the options available for treatment during the surgical procedure. Consent will be sought to remove endometriotic implants by heat destruction, i.e. cauterization, or to divide areas of scar tissue with laparoscopic surgical scissors, i.e. adhesiolysis. If fertility is a concern, the patency of the fallopian tubes can be investigated by flushing these with blue dye. If the tubes are open, then the dye will fill up the tubes, and be seen flowing out of the ends and into the pelvis (RCOG 2006).

Ultrasound and imaging

Ultrasound scans cannot be used to diagnose endometriosis, but these may well give clinicians valuable information about the presence of cysts in the ovary. Blood-filled cysts could be functional (i.e. part of the ovulation cycle) or might represent endometriomata. An ultrasound scan may also reveal other problems that could explain a woman's symptoms (e.g. hydrosalpinges or fibroids). When severe endometriosis is suspected and complicated surgery is planned, computerized tomography or magnetic resonance imaging may be used to investigate the extent of the disease. These investigations can also be useful when endometriosis is suspected in unusual locations, such as the lungs or diaphragm.

How is endometriosis treated?

Treatment for endometriosis is tailored to the individual. The approach adopted takes into account the woman's personal preferences, and her symptoms and their impact on her daily life. If a patient wishes to conceive, then careful decisions need to be made about the most appropriate form of management because most medical options for symptom control are also contraceptive in nature. The overall aim is to relieve pain and improve the ability to conceive, although symptoms may relapse when treatment is stopped.

Hormonal treatment

The symptoms of endometriosis resolve with pregnancy or the onset of the menopause. These situations are respectively characterized by high and low levels of oestrogens and progestogens.

Medical treatment works by mimicking these physiological states, but symptoms often relapse after it stops. Available hormonal drugs include the combined oral contraceptive pill, progestogens, danazol, gestrinone and gonadotrophin-releasing hormone agonists (GnRH-As). These are all equally effective, but differ with regard to the methods of administration and potential side effects.

The combined oral contraceptive pill is simple to take, good at controlling symptoms, and both acceptable to and well liked by many women. Packets can be run sequentially so that three or four are taken one after the other without a break (tricycling). There may be a degree irregular bleeding, which some patients will find unacceptable. Progestogen hormones can be given as tablets or injections, but these are less well tolerated because of the potential side effects, which include irregular bleeding, water retention, low mood and poor skin. The progestogen injection (Depo-Provera) is also a long-term contraceptive, and fertility can take up to a year to return following the discontinuation of treatment.

Danazol and gestrinone are used less frequently now, but were very popular in the 1970s. These drugs are taken as tablets and can improve symptoms in up to 90% of cases. During treatment, the levels of oestrogen produced naturally by the ovaries dramatically decreases, inducing a menopause-like hormonal state. Endometriosis improves, but women may suffer side effects similar to the menopause, including hot flashes, low mood and weight gain. The growth of facial hair or a deepening of the voice can occur on rare occasions, and in these instances, treatment should be stopped immediately.

Gonadotrophin-releasing hormone agonists also induce a reversible menopause-like state. This treatment is delivered as a daily nasal spray or a monthly injection, and is effective in reducing symptoms for 90% of women. Treatment usually lasts for 6 months. Because of the low-oestrogen hormonal state, there is a reduction in bone density during this period. This issue can be minimized with "add back" hormone replacement therapy, which can also help other menopausal-type side effects, such as vaginal dryness, hot flashes and mood changes (Kennedy *et al.* 2005).

Surgical treatment

Medical forms of treatment are less suitable for those women who wish to conceive because,

although these are effective, the majority are contraceptive and such approaches do not improve subsequent pregnancy rates. Surgery can be used both to confirm the diagnosis and to treat endometriosis, and it improves the chance of getting pregnant. If medical treatment has failed, or in cases in which symptoms are severe, the surgical removal of endometriosis can offer relief from pain and restore some quality of life.

Laparoscopic (keyhole) surgery is often used in the treatment of endometriosis because women generally favour this approach and recovery is quicker. The laparoscope gives good views of the pelvis, and it is possible to introduce surgical instruments through further “keyhole cuts” in order to operate laparoscopically so as to destroy or excise endometriotic implants. Pictures or videos can also be taken during the operation, and these form a useful part of a woman’s health record.

Surgery can range from very simple procedures to extremely involved operations that take hours to perform and involve a team of expert surgeons from different fields (e.g. gynaecologists, colorectal surgeons and urologists). Where complicated surgery is anticipated, a larger incision may be required.

Regional endometriosis centres encourage research in the field, and provide expertise in planning treatment for women with severe and complex forms of the disease. These hubs also offer additional support through services such as pain control clinics and specialist nurse practitioners.

Hysterectomy and oophorectomy, i.e. the removal of the womb and ovaries, can be performed in cases in which the woman has no wish to become pregnant and whose symptoms are resistant to other forms of treatment. A trial of treatment with GnRH-As can assist in deciding whether to proceed with such major surgery because the relief of symptoms during this period suggests that the operation will be helpful. At the time of surgery, any visible endometriotic implants are also removed. There is a significant chance of recurrence of endometriosis if the ovaries are not removed. This part of the procedure produces a permanent menopause, which can be associated with severe symptoms. To prevent these problems, and to preserve bone density, hormone replacement therapy is prescribed until 50 years of age, which is when the average woman reaches the menopause (Kennedy *et al.* 2005).

What if no treatment is chosen?

Endometriosis is a hormone-dependent condition and its symptoms normally improve with the onset of the natural menopause. It is benign in nature and some women choose to manage their symptoms conservatively. There is no disadvantage to this approach, and many sufferers will benefit from finding alternative ways of coping with this disease since there is no cure. Severe forms of the disease may be characterized by the blockage of structures such as the ureter or bowel by endometriosis, and lesions may occasionally be seen in distant sites such as the lungs. This is not a malignant process, and no deaths have occurred from endometriosis alone.

What is the recurrence rate?

Medical treatments for endometriosis (e.g. oral contraceptives, danazol, gestrinone and GnRH-As) are all equally effective, but these do not affect any of the underlying mechanisms that are responsible for the disease process. A return of the symptoms is common, and this can happen as soon as 6 months after treatment (Miller *et al.* 1998).

After surgical removal of endometriosis, the recurrence rate of symptoms and endometriotic lesions can vary from 10% to 55% within 12 months (Vercellini *et al.* 2009), with relapses affecting approximately 10% of the remaining women in each subsequent year (Guo 2009). The chance of requiring another operation is greater in women younger than 30 years of age at the time of their first surgical procedure (Shakiba *et al.* 2008), but repeat operations are less effective. According to Abbott *et al.* (2004), pain improved in 83% of women 6 months after their first surgery compared with only 53% following a second procedure.

What is the role of physiotherapy?

Women’s health physiotherapists have an important role to play in supporting women who suffer from endometriosis because the condition affects the pelvic floor musculature in different ways. Chronic pelvic pain can be associated with posture and movement disorders, and the correction of these problems often leads to an improvement in some symptoms. Physiotherapy can help in the management of the symptoms of endometriosis by treating connective tissue dysfunction, myofascial trigger points and hypertonus within the pelvic floor (Herzig & Stein 2006).

In addition, many patients presenting to women's health physiotherapists for assistance with pelvic floor deficiencies may have symptoms that are suggestive of endometriosis. During examination, tender nodules or focal points within the vagina should prompt consideration of a diagnosis of endometriosis, and such women should be directed to their general practitioners in the first instance.

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