Endometriosis: Living With a Silent Disease

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Abstract

Endometriosis is a common female health disorder that occurs when cells of the lining of the uterus grow in other areas of the body. This may lead to pelvic pain, irregular bleeding, migraines and infertility. Due to the complexity of this condition, many women suffer delayed diagnosis if even diagnosed at all. While cause and cure are not fully understood, there are many ways to help improve the quality of life for women with Endometriosis.
Endometriosis: Living With a Silent Disease

An estimated 176 million women worldwide are affected by endometriosis. This is one in ten during their reproductive years, which is typically when their period starts until menopause. Many women remain undiagnosed and are therefore not treated. Endometriosis is a chronic condition where tissue similar to the lining of the uterus (the endometrial stroma and glands, which should only be located inside the uterus) is found elsewhere in the body (See Fig.1) (Endometriosis website, About Endometriosis link, 2011). Each month, this misplaced tissue responds to the hormonal changes of the menstrual cycle by building up and breaking down just as the endometrium does, resulting in internal bleeding. Unlike the menstrual fluid from the uterus which is excreted by the body, the blood from the misplaced tissue has no place to go, resulting in the tissues surrounding the endometriosis to become inflamed and swollen. This then can produce scar tissue which may develop into lesions or growths (Ohio State University, Endometriosis link, 2011).

Endometriosis lesions can be found on the ovaries, the fallopian tubes, the peritoneum, the uterosacral ligament, the cul-de-sac, the Pouch of Douglas and the rectal-vaginal septum (See Fig. 2). Other less common

Fig. 1 Endometriosis

Fig. 2 Possible locations for endometriosis.
locations include caesarian-section scars, laproscopy/laparotomy scars, the bladder, the bowel, the intestines, the colon, the appendix and the rectum. In even rarer cases, endometriosis has been found inside the vagina, inside the bladder, on the skin, on the lung, on the spine and in the brain (Endometriosis website, About Endometriosis link, 2011)

**Cause**

Hypothesis-driven research has taken place over the past 50 years and still there is no definitive cause of Endometriosis. According to information on the DynaMed Website, the most common theory is retrograde menstruation. This is when menstrual tissue flows backwards through the fallopian tubes and deposits on the pelvic organs where it seeds and grows. Other theories include metaplasia, lymphatic dissemination, vascular dissemination, immunologic defect, genetic predisposition, and environmental influences.

Metaplasia is to change from one normal type of tissue into another normal type of tissue. “It has been proposed by some that endometrial tissue has the ability in some cases to replace other types of tissues outside of the uterus” (Endometriosis website, Causes link, 2011, overview section, last sentence). Lymphatic/vascular dissemination is the thought that endometrial fragments may travel through blood vessels or the lymphatic system to other parts of the body. “This may explain how endometriosis ends up in distant sites such as the lung, brain, skin, or eye” (Endometriosis website, Causes link, 2011, Lymphatic or vascular distribution section). When it comes to immunologic defects, we are yet to know “whether this is a cause or effect of the disease” (Endometriosis website, Causes link, 2011, Immune system dysfunction section). Genetic disposition has been demonstrated in women with Endometriosis. Chances are if you have a first-degree relative with endometriosis, you are more likely to develop Endometriosis. Also, when there is a hereditary link, Endometriosis tends to be worse in the next generation.
Environmental factors have been pointed out as contributors to the development of Endometriosis, specifically relating toxins in the environment with reproductive hormones and immune system response. This is a very controversial theory that is not yet proven. According to the Endometriosis website, endometriosis may be an attributed to a combination of these theories.

**Stages of Endometriosis**

There are four stages of endometriosis (See Fig. 3). Stage I consists of minimal disease with superficial and filmy adhesions. Stage II consists of mild disease with superficial and deep endometriosis. Stage III consists of moderate disease with deep endometriosis and adhesions and Stage IV consists of severe disease with deep endometriosis and dense adhesions. Moderate and severe endometriosis are characterized by chocolate cysts and severe adhesions (Endometriosis A Guide for Patients, 2007). The stage of endometriosis does not necessarily reflect the level of pain, risk of infertility or symptoms present. For example, it is possible for a woman in Stage I to be in an abundant amount pain, while a woman in Stage IV may be

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**Fig. 3 Stages of Endometriosis**

asymptomatic. “In addition, women who receive treatment during the first two stages of the disease have the greatest chance of regaining their ability to become pregnant following treatment” (Ohio State University, Endometriosis link, 2011, What are the different stages section, last ¶)

**Common Symptoms**

The most common symptoms of endometriosis is pelvic pain. The pain often correlates to the menstrual cycle, before and during menstruation and during ovulation. Women may also experience pelvic pain that doesn’t correlate to their cycle or ovulation such as when passing urine, during sexual intercourse and in the lower back region. This is one of the reasons this condition is so unpredictable and frustrating. For many women, the pain of endometriosis is so severe and debilitating that it impacts their lives in significant ways. Other symptoms that correlate with menstration are pain in the bowel, diarrhea or constipation, abdominal bloating and migraines. Women may also experience heavy or irregular bleeding, fatigue, irritable bowel syndrome, interstitial cystitis, fibromyalgia and infertility (Endometriosis website, Symptoms link, 2011). Endometriosis can cause scar tissue and adhesions to develop that can distort a woman’s internal anatomy. In advanced stages, internal organs may fuse together, causing a condition known as *frozen pelvis*. This condition is not common, but is possible (Endometriosis website, About Endometriosis link, 2011). Endometriosis has also been known to lead to endometrial cancer. Fortunately, this too is a rare occurrence, pertaining to less than one percent of women with Endometriosis (Ohio State University, Endometriosis link, 2011).

**Diagnosing**

Diagnosis of endometriosis may affect the management of pain or infertility, and thus should be considered in patients with these symptoms. Prior to attributing many of these
individual symptoms to endometriosis, bowel, bladder, psychiatric and musculoskeletal etiologies should be ruled out. “Given that endometriosis may be a diagnosis of exclusion, the diagnosing of endometriosis is unfortunately often delayed and stretches over several years” (Kennedy et al., 2005 as stated in Hsu, Khachikyan and Stratton, 2010, ¶ 2). When attempting to diagnose endometriosis, a complete history and physical exam should be performed. According to the Uptodate Website, (2011):

Physical findings in women with endometriosis are dependend upon the location and size of the implants [Vercellini et al., 1996]. There are often no abnormal findings on physical examination. When findings are present, the most common is tenderness when palpating the posterior fornix. Other frequent findings include: localized tenderness in the posterior cul-de-sac (pouch of Douglas) or uterosacral ligaments; palpable tender nodules in the posterior cul-de-sac, uterine ligaments, or rectovaginal septum; thickening and induration of uterosacral ligaments; pain with uterine movement; tender, enlarged adnexal masses and fixation of adnexa or uterus in a retroverted position (Physical findings section).

**How imaging can help**

“Although the physical exam has poor sensitivity, specificity or predictive value in diagnosing endometriosis, findings on examination can suggest the benefit of imaging prior to surgery” (Hsu et al., 2010, Clinical diagnosis section, ¶ 3).

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**Fig. 4 Endometriosis of the posterior cul-de-sac: transvaginal ultrasound.**

Hypoechoic solid mass (asterisks) merging with the outer echolucent layer (white arrowheads) of ventral rectal wall with preservation of hyperechoic submucosa. Arrows point to ventral aspect of sacrum; black arrowheads indicate normal dorsal rectal wall. R= rectum.

Tests that may be done in order to assist in the diagnosis of endometriosis include ultrasound (See Fig. 4), magnetic resonance imaging (MRI), and pelvic laproscopy. Further research is being explored to detect if serum markers and endometrial nerve fibers will assist in diagnosis. “Ultrasound is a readily available and inexpensive tool for the diagnosis in large endometriosis lesions. Transvaginal ultrasound can help diagnose endometriomas, bladder lesions, and deep nodules such as those in the rectovaginal septum.” (Hsu et al., 2010, Imaging section, ¶ 2). The issue many have with ultrasound is it is user-dependent. Hsu et al. states “With an experienced sonographer, transvaginal ultrasound has high specificity and sensitivity in the diagnosis of ovarian endometriosis” (Imaging section, ¶ 2). Transrectal ultrasound (See Fig. 5) may also be used to demonstrate rectal involvement in endometriosis, the depth of the infiltration by endometriosis and to detect lesions on the posterior bladder wall but it has not been proven to be superior to transvaginal ultrasound.

MRI (See Fig. 6) may be of assistance to guide surgical approaches for patients with suspected endometriosis, especially for deep infiltrating endometriosis and other unusual sites of presentation. MRI is superior to ultrasound in...
diagnosing endometriosis when it comes to pelvic masses, rectosigmoid lesions and endometriosis of the bladder (Hsu et al., 2010). Unfortunately due to the relatively high cost of MRI it is not as commonly used when compared to ultrasound.

Serum markers have been eagerly sought out for their use in diagnosis, to measure activity and to monitor improvement. To this day, no individual serum marker has been found to be both sensitive and specific for the diagnosis or monitoring of endometriosis. As previously stated, investigations are underway to seek whether panels of markers would be more successful. Endometrial biopsy is also being explored for the diagnosis in endometriosis. Recent studies have shown an increasing number of nerve fibers in the endometriosis compared to women without endometriosis (Hsu et al., 2010).

With the exception of laproscopy, none of these methods can fully confirm endometriosis, although they may suggest it. (Endometriosis website, Diagnosis link, 2011) Laproscopy followed by a biopsy of the tissue is the most “reliable way to definitively diagnose endometriosis”. This is known as the “gold standard” when diagnosing endometriosis. (Endometriosis website, Diagnosis link, 2011, ). It also provides an opportunity for conservative surgical treatment (Uptodate website, Overview of the Treatment, 2011). Unfortunately for the patient, laproscopy is an expensive, invasive procedure. Furthermore, if the surgeon is not a specialist in endometriosis they may not recognise the disease, which can result in a ‘negative’ result meaning the patient may be told they do not have endometriosis when in reality they do because the surgeon was unable to recognise the disease and therefore was unable to take a specimen for biopsy. “The fact that there is no non-invasive, definitive diagnostic method for endometriosis is as frustrating for clinicians as it is for women with the disease.” (Endometriosis website, Diagnosis link, 2011, Tests for endometriosis section)
A closer look at laproscopy

“The introduction of laproscopy in the sixties [1960’s] provided a golden tool for the visual diagnosis and surgical therapy” (Brosens & Benagiano, 2011 p.582). Laproscopy is a surgical operation that uses an instrument known as a laparoscope to diagnose and temporarily treat endometriosis by removing adhesions caused by the disease. A laparoscope (See Fig. 7) is a thin instrument, similar to a telescope, that is about 30 centimeters in length with a light source and lens on the end. This makes it possible for the surgeon to see inside the pelvic area without having to fully cut the patient open, this would be considered a laparotomy, which is rarely used when compared to laproscopy. The laprascope is inserted into the pelvic cavity along with another surgical instrument, used to retrieve tissue, cauterize and or laser the site. (Endometriosis website, Surgery link, 2011)

Treatment

There is no high quality evidence proving that one medical therapy is superior to another for managing pelvic pain due to endometriosis or that any type of medical treatment will affect future fertility with the exception of removing the reproductive organs. Therefore, “treatment decisions are individualized, taking into account the severity of symptoms, the extent and
location of disease, whether there is a desire for pregnancy, the age of the patient, medication side effects, surgical complication rates and cost” (Uptodate website, 2011, Overview of the Treatment, General Approach section). Treatment options include expectant management, analgesia, hormonal medical therapy, estrogen-progesterin oral contraceptice pills, gonadotropin-releasing hormone (GnRH) agonists, progestins, danazol, aromatase inhibitors, surgical intervention: which may entail retaining the uterus and ovarian tissue (conservative) or removing the uterus and possibly the ovaries (definitive), and combination therapy which entails medical therapy given before and/or after surgery.

Conclusion

"Endometriosis should be viewed as a chronic disease that required a life-long management plan with the goal of maximizing the use of medical treatment and avoiding surgical procedures” (Uptodate website, 2011, Overview of the Treatment, Introduction section). Endometriosis is what some would call a mystery disease; we do not know the origin, what causes such extreme pain in some women while others suffer none and treatment options can be hit and miss based on the woman. The best thing for a disease that is not well known, understood or accepted is to raise awareness about Endometriosis. With continuous research and a growing understanding of Endometriosis, hopefully a cure will exist in the near future.
References


Up to Date Web site; 2011, Pathogenesis, clinical features, and diagnosis of endometriosis.