Endometriosis: Who gets it and how we treat it

Editor's note: Shazah Khawaja, MD, FACOG, director, NCMA Women's OB/GYN Center, was a featured speaker at this month's 2019 Physician Regional Spring Symposium in Santa Rosa. She spoke about endometriosis and the pain and impact it has on women's lives to an audience of primary care physicians and other specialists. Following is an article authored by Dr. Khawaja that details how endometriosis is diagnosed, treated and what patients can expect.

What is endometriosis?

Endometriosis is a chronic gynecologic disorder in which tissue that normally lines the inside of your uterus — the endometrium — grows outside your uterus in other parts of the abdomen. As a condition that occurs in 6–10 percent of women of reproductive age, endometriosis represents a significant health problem for millions (maybe as high as 6.5M) of U.S. women.

If you're still reading, you're probably one of them, or you may know someone who has had to deal with these common endometriosis symptoms:

- Painful periods (dysmenorrhea).
- Pain during intercourse.
- Pain with bowel movements or urination.
- Excessive bleeding.
- infertility.
- Other symptoms, which may include fatigue, diarrhea, constipation, bloating or nausea, especially during menstrual periods.

Clearly, this is not a fun list. The symptoms or clinical manifestations of endometriosis are variable and unpredictable in both presentation and course. It can vary greatly from woman to woman.

One thing to keep in mind is that the pain associated with endometriosis may not correlate with the stage of the disease. In other words, a woman experiencing significant endometrial pain may not necessarily be in a deep stage of the disease, and the opposite may also be true for someone else. There may be some association with the depth of infiltration of endometrial lesions. Painful defecation during menses and painful sexual intercourse are the most predictable symptoms of deeply infiltrating endometriosis.

According to U.S. Department of Health & Human Services' Office on Women's Health, other health problems women experience with endometriosis can include, allergies, asthma, chemical sensitivities, autoimmune diseases (these can include multiple sclerosis, lupus, and some types of hypothyroidism), chronic fatigue syndrome and fibromyalgia.

There is some good news: Endometriosis isn't a fatal disease. In some cases, endometrial cells create cysts that can rupture and bleed. While this is serious and may sound a bit like cancer, endometriosis isn't cancer. However, ovarian cancer does occur at higher than expected rates in women with endometriosis. Some studies suggest that endometriosis increases this risk, but it's still relatively low, according to Mayo Clinic. Although rare, another type of cancer — endometriosis-associated adenocarcinoma — can develop later in life in women who have had endometriosis.

Who is likely to get endometriosis?

Endometriosis usually develops several years after the onset of menstruation (menarche). Signs and symptoms of endometriosis often end temporarily with pregnancy and end permanently with menopause, unless you're taking estrogen.

Endometriosis is especially common among women in their 30s and 40s, but I've also treated patients in their 20s that had the disorder. Statistically, it is racially neutral, meaning there appears to be no racial predisposition to endometriosis. Research suggests a familial association of endometriosis. Patients with an affected first-degree relationship have a seven- to ten-fold increased risk of developing the disorder.

How do we diagnose endometriosis?

A definitive endometriosis diagnosis can only be made by a diagnostic laparoscopy procedure. Your doctor will then order a histology (a study of the microscopic structure of tissues) of the lesions removed during the surgery.

Before recommending a diagnostic laparoscopic procedure, your doctor will talk to you about your symptoms and do or prescribe one or more of the following to find out if you have endometriosis:

- Pelvic exam.
- Imaging test (ultrasound or MRI).
- Prescription medicine. If your doctor does not find signs of an ovarian cyst during an ultrasound, he or she may prescribe:
  - Hormonal birth control (which may help lessen pelvic pain during your period).
  - Gonadotropin-releasing hormone (GnRH) agonists, which block the menstrual cycle and lower the amount of estrogen your body makes. GnRH agonists also may help pelvic pain.

If your pain gets better with hormonal medicine, you probably have endometriosis. But, these medicines work only as long as you take them. Once you stop taking them, your pain may come back.

How do you treat endometriosis?

There is currently no cure for endometriosis, but several different treatment options can help manage symptoms and improve your chances of getting pregnant. Talk to your doctor about your treatment options.

It is important to note that the best course of action for you will be greatly informed by whether you are or wish to remain fertile. Other important factors include your age, how severe your symptoms are and how severe the disease is.

Endometriosis treatments will vary depending on whether the focus of your care is for pain or more for fertility concerns. For pain, there are three possible approaches:

- Pain medications (NSAIDS, opioids).
- Hormone therapy (birth control pills, progesterone, progestin, GnRH agonists).
- Surgical treatment (laparoscopy, others).

Endometriosis is different for every woman. My colleagues and I at our practice, NCMA Women's OB/GYN Center, first seek to treat the whole person, rather than address presenting symptoms only. In many cases, we will recommend laparoscopy to remove growths as a way to also improve fertility in women who have mild or minimal endometriosis.

Although studies show improved pregnancy rates following this type of surgery, the success rate is not clear. For some, we recommend in vitro fertilization (IVF) as the best option to improve fertility.

Even though the use of hormones in IVF is successful in treating infertility related to endometriosis, other forms of hormone therapy are not as successful. The American College of Obstetricians and Gynecologists does not recommend using oral contraceptive pills or GnRH agonists to treat endometriosis-related infertility. The use of these hormonal agents prevents ovulation and delays pregnancy, so this risk means you and your doctor must be on the same page about your risks and health goals.

The hormones used during IVF do not cure endometriosis lesions, which means that pain may recur after pregnancy and that not all women with endometriosis are able to become pregnant with IVF. The relationship between the extent of disease and the degree of symptoms, the effects on fertility, and choosing the best treatment, remains a challenge for many patients.

For more information, the NIH's Eunice Kennedy Shriver National Institute of Child Health and Human Development offers excellent information on endometriosis treatment options.

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By NCMA Communications | April 8th, 2019 | Patient Education