Endometriosis a mysterious malady

Many women suffer due to misdiagnosis

By LAURIE SMITH ANDERSON
Advocate staff writer

When Mattie Cox suffered from severe bouts of vomiting and diarrhea in the 1980s, it never occurred to her—or her doctors—that she had endometriosis. Medical tests and exams revealed no abnormalities in her stomach, intestines or reproductive tract, so she was diagnosed as having irritable bowel syndrome.

Following a miscarriage a few years later, her symptoms worsened to the point that one physician diagnosed her with "pseudo appendicitis." In other words, it was "all in her head."

By this time, Cox was suffering from chronic pelvic pain, painful and irregular menstrual cycles, fatigue, allergies and infertility. In her own research, she came across a reference to endometriosis causing cases of pseudo appendicitis. Because she had once been treated for cervical endometriosis in her 20s, she pursued the question with her obstetrician, Julius Mullins Jr., who agreed to do a laparoscopy.

Local gynecologist Joanne Pine, who treats patients with endometriosis, also suffered from the condition.

The procedure revealed the presence of large tissue adhesions in her abdomen, and on her ovaries and the lining of her stomach, bowel and bladder, which resulted in internal bleeding, formation of scar tissue and inflammation—endometriosis.

Endometriosis is an abnormal condition that affects women in their reproductive years, in which endometrial tissue is found outside the uterus, in other areas of the body. The growths are generally not malignant; however, they can cause pain, infertility and other medical problems as the tissue accumulates in the body.

Endometriosis affects an estimated 10 percent of the population of women in their reproductive years, although actual case numbers are lower because of difficulties women have in getting an accurate diagnosis. No one knows what causes the condition, although hereditary and environmental factors are suspected.

Surveys of patients with endometriosis show that 50 percent of the women suffer from symptoms for more than 10 years before they are properly diagnosed; 50 percent see more than five doctors before diagnosed; and 70 percent are told at some point that their problem “is all in your head,” Cox said. Many are misdiagnosed with pelvic inflammatory disease and other disorders such as irritable bowel syndrome and pseudo appendicitis.

Even Joanne Pine, a local gynecologist who treats a number of patients for endometriosis, went years with painful symptoms of the...
Endometriosis

CONTINUED FROM 1C

disease before she sought treatment for herself.

“When I finally broke down and had a hysterectomy four years ago, they found endometriosis. In a patient, I would have done a laparoscopy long ago,” she admitted.

“All too often, women are told that painful menstrual cramps are their cross to bear. So, they put up with it for years; many endometriosis patients do not get treatment for their condition until they finally come in as infertility patients,” Pine said.

“When I speak on the subject, I tell women that it’s important to stress the severity of their pain. If it’s disabling and prevents them from work or school or normal daily activities, then it needs attention. And it may be necessary to seek a second opinion.”

Aggressive treatment early in the disease, even in adolescence, is called for in order to relieve symptoms and provide the best possible chances for restored fertility, she said.

The laparoscopy is required for a definitive diagnosis, Pine said. Laparoscopy is a minor surgical procedure in which a lighted tube is inserted into a tiny incision in the abdomen to view the endometrial implants. Surgery can be performed through the scope at the same time, using lasers or small instruments, to remove the growths.

Most patients who undergo conservative surgery alone will have recurrent problems with endometriosis and may have to undergo additional operations and/or medication.

Treatment with hormones aims to stop ovulation and can sometimes force endometriosis into remission.

Pregnancy and breast feeding can also cause a temporary remission. As a last resort, radical surgery, involving a hysterectomy and removal of all growths and the ovaries, may be necessary in cases of long-standing, troublesome endometriosis. Menopause generally relieves the symptoms.

The Louisiana Capital Area Endometriosis Support Group meets quarterly to provide education and help for patients. The next meeting is scheduled for 7 p.m. May 5 at the Bluebonnet Library.

For more information about the disease, the Endometriosis Association can be reached at 1-800-992-3636.