Health Matters

In treating ovarian cancer, a little-known specialist can make a big difference

By LAURIE MCGINLEY
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In January 2006, Peg Danowski didn't feel right. She had gained seven pounds over the holidays, was exhausted and was having odd sensations -- "like little electric volts running up and down the tops of my legs," she says.

Puzzled, the Washington , D.C. , mother of three went to Damian Alagia, her longtime obstetrician and gynecologist. Tests showed a growth on her ovary, perhaps a benign cyst, and he scheduled laparoscopic surgery. But when Dr. Alagia inserted the scope, he found her pelvic area covered with what looked like blisters. He carefully withdrew some fluid and the scope. When Ms. Danowski awoke, he told her to go see a gynecologic oncologist.

It was the right call. Ms. Danowski had advanced ovarian cancer and needed extensive surgery and chemotherapy. Today, she's in remission and recently went on a trans-Atlantic cruise with her husband of 21 years. "It was like being on the Titanic with a better outcome," she says.

This year, more than 16,000 women in the U.S. will die of ovarian disease, and more than 25,000 will be diagnosed. More than half of the cancers will be found in women older than 63 -- the risk increases with age. Most women will be diagnosed at an advanced stage, when the disease is especially lethal. But unlike Ms. Danowski, many won't get the aggressive treatment that's their best shot for beating the disease.

Limited Awareness

One problem, experts say, is that many women with ovarian cancer are treated by general gynecologists or surgeons, rather than by gynecologic oncologists, who are trained in advanced surgical techniques and other aspects of treatment. While general gynecologists often provide excellent care for benign conditions, studies show that women with ovarian cancer get more comprehensive care and live longer when treated by gyn oncs, as they're called. Conversely, women do worse when treated by doctors who handle a low volume of ovarian-cancer cases, often true of general gynecologists. Even with a busy practice, Dr. Alagia, director of minimally invasive gynecologic surgery at George Washington University Hospital , sees only a few ovarian-cancer cases a year.

But if it sounds simple enough -- women with ovarian cancer should see a gynecologic oncologist -- it's not that simple in real life. For one thing, many women, and their husbands, don't know such a specialty exists. "The importance of getting to a specialist isn't well known," says Patricia Goldman, who helped found the Ovarian Cancer National Alliance, an advocacy group.

In addition, ovarian cancer can be tricky to diagnose. There's no reliable screening test. The symptoms -- including bloating, weight gain and abdominal pain -- can all be mistaken for digestive disorders. When women do have a growth, doctors don't do biopsies, because puncturing a malignant tumor "could seed the abdominal cavity," says Andrew Berchuck, director of gynecologic oncology at Duke University Medical Center . So while most ovarian masses aren't cancer, sometimes there's no definitive way for doctors to know before surgery. That makes it hard to send women with benign masses to gynecologists and those with malignant growths to gyn oncs.

To address that, two groups -- the American College of Obstetricians and Gynecologists and the Society of Gynecologic Oncologists -- developed joint guidelines on when a patient should be referred to a gyn onc. For postmenopausal women, the guidelines recommend such a referral when a pelvic mass is "suspicious," as indicated by at least one sign: an elevated level on a blood test called CA-125; fluid in the abdomen; evidence of abdominal or other cancer; or a family history of ovarian or breast cancer. Mitchell Edelson, an official with the college of ob-gyns who is a gynecologic oncologist in Abington , Pa. , says the group is trying to impress on gynecologists that all women with suspicious growths should be referred to gyn oncs.

Risk Factors

The risk of ovarian cancer peaks for women in their late 70s. Other risk factors include a later menopause -- defined as after age 50 -- and being a carrier of the BRCA1 or BRCA2 genetic mutations, which are also linked to high rates of breast cancer. Overall, the incidence of ovarian cancer has risen in recent years to one in 57 women, according to Johns Hopkins University . When the disease is found before it spreads beyond the ovaries, 90% of patients survive at least five years. If it's caught after the disease has spread, only 25% survive five years. The cancer is diagnosed at the early stage only 25% of the time.

Gynecologic oncologists, who get three additional years of training in treating gynecological cancers, are experts in cytoreduction, the removal of cancerous masses -- which is directly linked to patients' chance of survival. Stephen Rubin, chief of the division of gynecologic oncology at the Hospital of the University of Pennsylvania , says he has seen patients where a general gynecologist has removed the ovarian mass but missed "the abdominal spread."

Gyn oncs also do "staging" -- the sampling of lymph nodes and tissue around other internal organs -- during surgery. The results show the progression of the disease, which is critical for deciding postsurgery chemotherapy or other treatment. Not having such staging is especially dangerous for women who are thought to have early-stage cancer but might have a more advanced case because the cancer is lurking out of view.

On Standby

At some hospitals, gynecologists and gyn oncs work closely together. At Winthrop-University Hospital in Mineola , N.Y. , gynecologists who think patients might have cancer schedule surgeries when gyn oncs are on standby. That way, says Eva Chalas, the hospital's chief of gynecologic oncology, "if we're needed, we are there" to perform the more-extensive surgery.

When Ms. Danowski got sick, she was only 44, younger than many women with ovarian cancer. She had a family history of breast cancer, but didn't realize she might be at higher risk for ovarian cancer. It wasn't until after her ovarian-cancer operation that she underwent genetic testing and discovered she had the BRCA1 mutation.

When Dr. Alagia, while doing the laparoscopic surgery, saw that Ms. Danowski had cancer, he didn't hesitate to refer her to someone with greater expertise. "If it were my wife," he says, "I would want her to be treated by an expert."

She chose Jeffrey Lin, a gynecologic oncologist who practiced with Dr. Alagia at George Washington but has since moved to Sibley Memorial Hospital in Washington . In June 2006, Dr. Lin removed Ms. Danowski's ovaries, uterus and fallopian tubes, and did "staging" that, according to the pathologist, showed she had Stage IIIc ovarian cancer, an advanced form. Dr. Lin says he removed every bit of cancer he could see.

Ms. Danowski later underwent an aggressive regimen of chemotherapy. Today, she's hopeful that she will beat the odds.

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