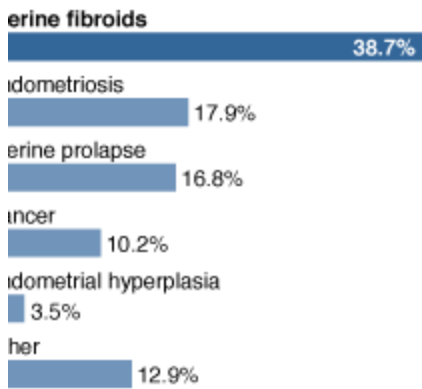


Major reasons U.S. women received hysterectomies, 1994-1999



Source: National Center for Health Statistics

Silent Treatment

Hysterectomy Alternative Goes Unmentioned to Many Women

Gynecologists Often Don't Cite Less-Invasive Procedure To Treat Fibroid Tumors Bailiwick of Other Specialists

By KEVIN HELLIKER and LAUREN ETTER
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Hundreds of thousands of women go to gynecologists each year with a common condition known as uterine fibroid tumors. When it's severe, a majority of them get the same recommendation: a hysterectomy, or removal of the uterus.

In recent years, a less invasive procedure, known as uterine artery embolization or UAE, has been growing in popularity. Yet some patients, and even some gynecologists, say many gynecologists aren't telling their patients about the alternative.

A study presented at a medical conference in 2002 found that of 100 UAE patients at Chicago's Northwestern Memorial Hospital, 79 had learned about the procedure from a source other than a gynecologist. A survey by Yale University School of Medicine in 2003 found that 13 of 21 UAE patients had learned about the procedure from the Internet.

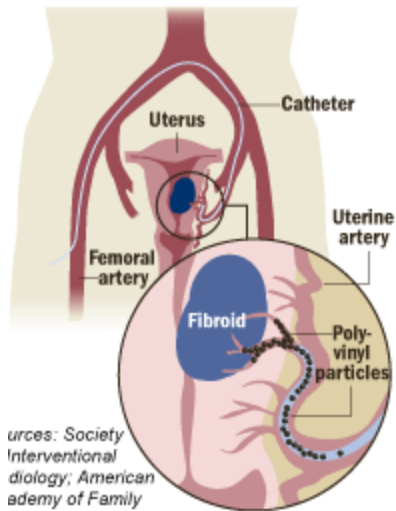
"It's sad," says Juergen Eisermann, a gynecologist who is medical director of the South Florida Institute for Reproductive Medicine. "We do a disservice not to mention all the options."

In the large majority of cases, UAE brings relief from uterine fibroid tumors, and it has a much shorter recovery time than hysterectomies. These tumors aren't cancerous, but their growth can be debilitating. UAE involves cutting off the blood supply to the tumors, causing them to shrink.

Some gynecologists blame the failure to inform patients about UAE on the fact that gynecologists generally don't perform the procedure. Instead, members of a specialty known as interventional radiology do UAE. When gynecologists lose the chance to perform a hysterectomy, they also lose the roughly \$2,000 fee the gynecologist might have earned.

"When you are sitting in a gynecologist's office, and they know that their livelihood is depending on the services that they provide, they are less likely to refer you" to another specialist, says Ruth Shaber, a gynecologist who heads

uterine artery embolization uses small polyvinyl particles to cut off the blood supply to fibroid tumors in the uterus.



Sources: Society of Interventional Radiology; American Academy of Family Physicians

women's health at Kaiser Permanente, Northern California, a large health-maintenance organization.

Gynecologists in the U.S. perform about 200,000 hysterectomies a year for fibroids, meaning that \$400 million in annual fees is at stake. Women who may have uterine problems almost always go to, or are referred to, gynecologists, the medical profession's experts on the uterus.

UAE isn't a perfect solution. It isn't recommended for women who want to have children. Studies have shown that as many as 20% of patients who undergo it experience further fibroid symptoms after three years, and the procedure is too new for doctors to know whether that percentage will rise with time.

"It's difficult to strongly recommend a procedure without long-term data," says Howard Sharp, a University of Utah

gynecologist who is vice chairman of the American College of Obstetrics and Gynecology's gynecologic practice committee.

About 15,000 women with fibroids have UAE performed annually in the U.S. But many don't hear about UAE from gynecologists. "My gynecologist didn't say a word about UAE," says Collette Styles, whose heavy bleeding from fibroids last year prompted her to visit Thermutus McKenzie, an Atlanta gynecologist. After Dr. McKenzie recommended hysterectomy, says Ms. Styles, who is 36 years old, she got on the Internet and learned about UAE. "I didn't want anybody cutting on me. I didn't want anybody removing my uterus," she says.

After undergoing UAE in January, she left the hospital the same day, sporting a Band Aid. She returned to work as a flight attendant one week later, free of fibroid troubles, she says. A hysterectomy could have grounded her for as long as eight weeks. Dr. McKenzie didn't return phone calls or written requests for comment.

Some gynecologists are telling their patients about UAE, and some patients choose hysterectomy even after they are told about the other procedure. But interventional radiologists and some gynecologists say that the majority of women with fibroids are candidates for UAE and ought to know about it.

"If gynecologists did UAE, the procedure would be done 100,000 times a year," rather than 15,000, asserts Robert Vogelzang, chief of interventional radiology at Northwestern Memorial Hospital in Chicago.

Fibroids grow in the uteruses of about half of all women, striking African-American women with greater frequency. Half of the time, they produce no symptoms and require no treatment. But ignoring fibroids becomes impossible for

about 25% of all women. In these cases, fibroids cause bleeding that can lead to anemia and other problems. Pain can be debilitating.

Typically, symptoms strike women between the ages of 35 and 50. Gynecologists commonly recommend that as a first step, these women try nonsurgical treatments, such as taking birth-control pills to reduce menstrual blood flow. But these measures usually fail to work over the long term, and gynecologists then typically recommend major surgery.

For women who want to retain their ability to give birth, gynecologists tend to recommend yet another procedure, myomectomy, the surgical removal of individual fibroids, not the whole uterus. Myomectomy, performed by gynecologists, can be a more elaborate surgery than hysterectomy, with more blood loss and a longer and more difficult recovery.

Hysterectomy is the gynecologist's standard treatment for women with fibroids who aren't planning to have children. Typically done by cutting through the patient's abdomen, it puts a permanent end to uterine fibroids. Another virtue of hysterectomy is that it reduces the risk of other uterine conditions, including relatively rare cases of cancer. But hysterectomy is a major operation, requiring general anesthesia and the risks that accompany it, including potentially fatal allergic reactions.

Quick Recovery

UAE, done under much-less-risky local anesthesia, involves a small incision in the right groin. A catheter is inserted into the femoral artery and guided into the uterine artery. An embolizing agent that functions like a tiny cork is injected to cut off blood flow to the fibroids. The catheter is then removed, typically leaving only a nick in the skin that is plugged with gel foam and covered with a Band Aid. Patients usually leave the hospital or clinic the same day. Most insurers and health-maintenance organizations now cover UAE.

While sparing women major surgery and the loss of an organ, UAE isn't free of risk. Out of the more than 40,000 women who have undergone the procedure in the U.S. since 1996, four are known to have died of infections or other complications, according to the Society for Interventional Radiology.

But when compared with hysterectomy -- which itself is a very low-risk procedure -- UAE may have a lower rate of complications, including death. A Georgetown University study of 102 UAE patients and 50 hysterectomy patients, presented at a medical conference in 2003, found that the UAE patients had half as many complications as those undergoing hysterectomy.

That is information Angela Augustine-Daye says she wishes her gynecologist had given her. But when Ms. Augustine-Daye, a 40-year-old police detective in

New Haven, Conn., visited a gynecologist last year with pain and bleeding caused by fibroids, she says, he didn't mention UAE but recommended hysterectomy. Normally skeptical because of her work as a detective, Ms. Augustine-Daye says she simply trusted the doctor, Carl M. Cassin.

After he did a hysterectomy, Ms. Augustine-Daye became infected, nearly died and missed an entire year of work. Only after the hysterectomy did she learn about UAE. "I feel sort of guilty because I am old enough to know better, and I just trusted him," she says of Dr. Cassin. The doctor didn't return calls or written requests for comment.

Most states have passed so-called informed-consent laws, requiring physicians to tell patients about all "reasonable alternatives" to surgery. In addition, medical societies such as the American Medical Association and American College of Obstetrics & Gynecology have made informed consent a cornerstone of their ethical codes.

Medical ethicists and legal experts say the term "reasonable alternative" is meant to free physicians from having to mention home therapies and herbal treatments. A just-invented procedure also wouldn't constitute a reasonable alternative, if little research on it exists yet.

The association for gynecologists, known as ACOG, declined to comment on whether UAE constitutes a reasonable alternative to hysterectomy. ACOG published a report in February noting that UAE effectively provides fibroid relief with a low rate of complications. But a fibroid pamphlet the organization sends to patients makes no mention of UAE.

The society says each physician must decide whether UAE constitutes a reasonable alternative. "To tell them what kind of information to give their patients -- that wouldn't be right," says ACOG's Dr. Sharp.

The ACOG spokesman on informed consent is Jeffrey L. Ecker, a Harvard Medical School gynecologist. "Whether or not this specific procedure has reached the point where it is a recognized alternative is up to the physician," says Dr. Ecker. "My sense is that UAE has not reached that point." He says that he hasn't studied the research on it and doesn't specialize in treating fibroids.

A fellow Harvard gynecologist takes the opposite position: Patients must be told about UAE. "You absolutely should mention it," says Elizabeth A. Stewart, clinical director of the Center for Uterine Fibroids at Brigham and Women's Hospital in Boston, who has studied UAE and specializes in treating fibroids. "For many women it is a reasonable option."

Arthur Caplan, chairman of medical ethics at the University of Pennsylvania School of Medicine, says it's "a no-brainer" that gynecologists should disclose the

availability of UAE to fibroid patients. A gynecologist can recommend a hysterectomy instead, but the patient should make an informed choice, Dr. Caplan says. "When a legitimate medical specialty is offering an alternative that's been around for eight years, you need to tell your patients about it," he says.

The discovery of UAE occurred by accident in the mid-1990s from the collaboration of gynecologists and interventional radiologists in France. Basic radiologists traditionally have taken and studied scans before and after surgery. Interventional radiologists are those who have gained additional skills in using the latest scanning technology to do minimally invasive repairs and procedures, usually by threading delicate catheters through blood vessels. Along the way, they have become experts on controlling bleeding by inserting stopper-like embolizing agents in those vessels.

The French gynecologists enlisted interventional radiologists to embolize the uterine artery weeks before a myomectomy, to control bleeding during the procedure. It turned out the embolization itself dramatically shrank the fibroids, eliminating symptoms. Word of this development spread quickly through the ranks of interventional radiologists. In 1996, members of the specialty began providing the procedure in the U.S.

Many gynecologists soon were teaming up with interventional radiologists at hospitals such as the Cleveland Clinic. The procedure worked well, and news about it spread on the Internet. Scores of women, facing a hysterectomy recommendation from their gynecologist, learned about UAE online and sought out interventional radiologists.

Second Thoughts

More American women were having second thoughts about hysterectomy for other reasons. Physicians perform the surgery for fibroids and other conditions about 650,000 times a year in the U.S., for a per-capita rate that is three to four times as high as in European countries. Although studies show that the complication rate for hysterectomy is very low, research has linked the surgery to other problems, such as depression, sexual dysfunction, weight gain, high blood pressure and premature menopause.

Carla Dionne, 48, says she visited 16 gynecologists from 1985 through 1998, hoping to hear about an alternative to hysterectomy as a treatment for her uterine fibroids. The 17th suggested UAE. After undergoing the procedure, she started the National Uterine Fibroids Foundation, a nonprofit that offers information on hysterectomy and its alternatives.

The Internet-fueled rush of patients helped interventional radiologists conduct studies on UAE. A study of 200 UAE patients at Georgetown University, published in the July 2001 issue of *Obstetrics & Gynecology*, found improvement

in more than 90% of patients at 12 months. There was only one case with a major complication -- a pulmonary embolism, or blockage, and that was resolved with medication.

Evan Myers, chief of clinical and epidemiological research in the department of obstetrics and gynecology at Duke University Medical Center, says that interventional radiologists have done diligent research on UAE. "I was impressed that interventional radiologists went to the effort to gather data in this way," Dr. Myers says. After years of studying and compiling research on UAE, he calls it a viable alternative to hysterectomy.

Interventional radiologists and some gynecologists agree that many women can benefit from the two specialties collaborating on UAE. Gynecologists ordinarily examine the patient both before and after the procedure. "We don't know the reproductive system as well as gynecologists do," says John Lipman, an interventional radiologist in Atlanta who has performed more than a 1,000 UAE's. "We welcome their involvement." A small number of gynecologists are undertaking the lengthy and highly specialized training required to do UAE themselves.

But many gynecologists remain silent about UAE. In recommending that Cindy Harding, then 48, undergo hysterectomy last year, Don Kratz of Springfield, Mo., didn't mention UAE. Dr. Kratz says in an interview that he didn't know whether insurance covered the procedure and that he had heard it cost about \$30,000.

Insurance does usually cover UAE. And a cost comparison published this year in the journal *Radiology* found that UAE costs about \$6,800, including hospital and doctor fees, or nearly \$1,000 less than hysterectomy.

After learning about UAE on the Internet, Ms. Harding, a bank executive, had the procedure performed by another doctor in March of last year and has been free of symptoms ever since.

In 2003, Merrill Albert, plagued by bleeding and anemia, visited a gynecologist named Ruth Clemens in suburban Atlanta. After Dr. Clemens diagnosed uterine fibroids, the gynecologist wrote a letter to the patient's primary-care physician describing as options myomectomy and hysterectomy. Disturbed at the thought of having either surgery, Ms. Albert, a 38-year-old computer consultant, went online and learned about UAE. "I figured Dr. Clemens hadn't mentioned it because she was opposed to it," says Ms. Albert.

But during her next visit with Dr. Clemens, she says she asked Dr. Clemens to repeat the options facing her. The doctor said myomectomy and hysterectomy, says Ms. Albert.

"So then I asked her about UAE," says Ms. Merrill. "And she said, 'You would be a candidate for that.' "

"I walked out of there too stunned to ask her why she hadn't said anything about it earlier," says Ms. Albert. Last October, Ms. Albert underwent UAE, performed by an interventional radiologist, and is now free of fibroid symptoms.

Dr. Clemens didn't return phone calls or a written request for comment.

Linda Bradley, a gynecologist at the Cleveland Clinic, has referred more than 300 women to interventional radiologists for UAE and says that 70% of women with fibroid symptoms are candidates for the procedure. "I'm quite passionate about this procedure," she says.

Dr. Bradley recognizes, however, that many in her specialty don't share her view. "When I give a talk about this procedure to gynecologists," she says, "my standing joke is that I need to wear a bulletproof jacket."