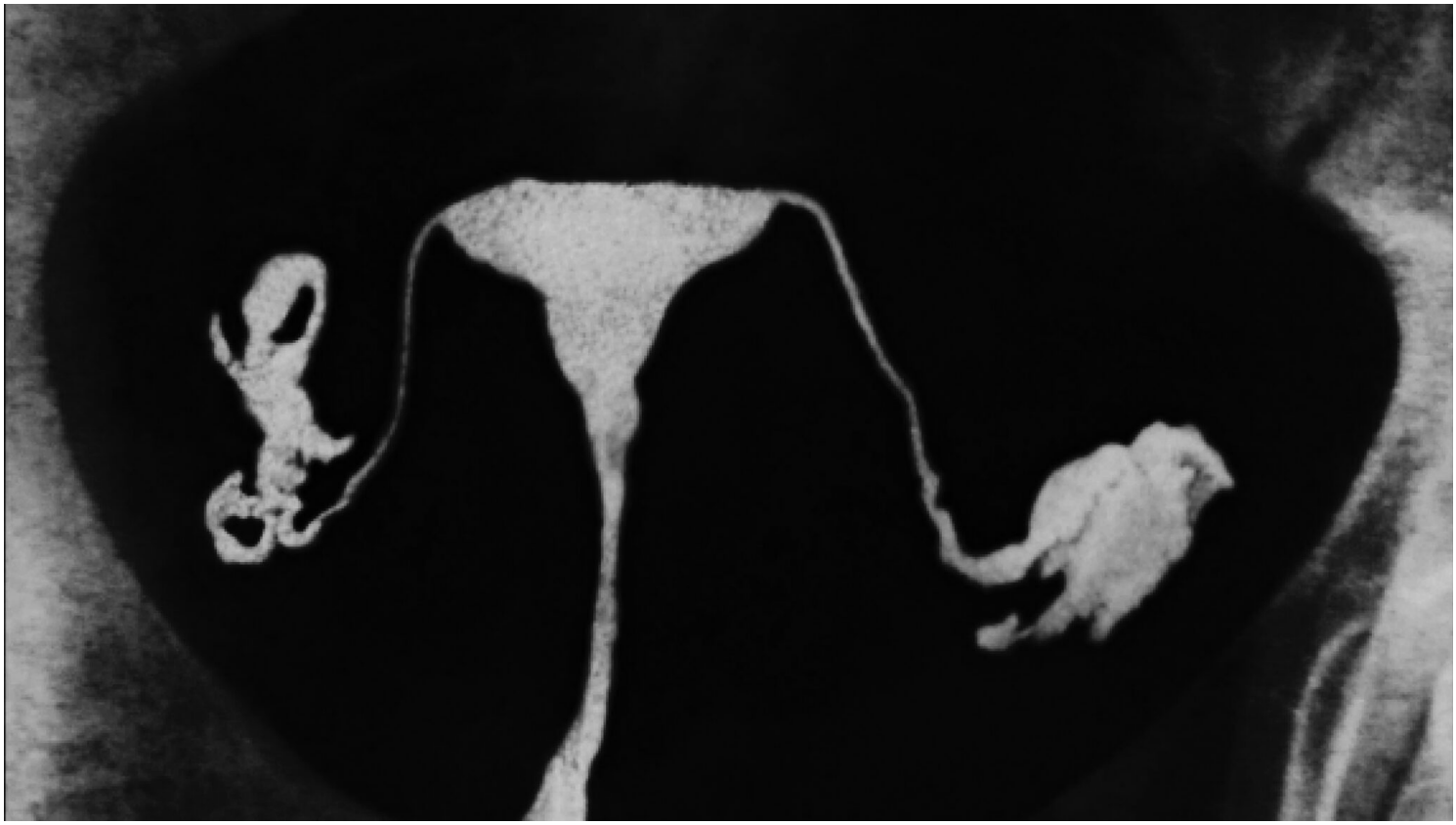
HEALTH

To prevent ovarian cancers, fallopian tube removal is on the rise

There's long been confusion between 'tube-tying' and salpingectomy. Now, oncologists are trying to dispel it



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By Eric Boodman

General Assignment Reporter

To Rebecca Stone, the single most important fact about ovarian cancer is that it's usually a misnomer. The most common kind — responsible for 70% of cases and 90% of deaths — often has its silent beginnings not in the ovary, but in the fallopian tube. This isn't just an

interesting factoid; as a gynecologic oncologist at Johns Hopkins, Stone sees it as a reason to evangelize. There's no way to screen for so-called ovarian cancer, no colonoscopy, mammogram, or Pap smear equivalent. It's typically found late, once it's already spread. The treatments are middling at best. Among the best tools is surgical prevention: If someone doesn't want more kids, and is considering another abdominal surgery, a surgeon can offer to take the tubes out.

Opportunistic salpingectomy, it's called. "Somebody says, 'Can I get my tubes tied?' And I will say, 'Well, actually, we don't tie tubes anymore, we remove them,'" said Greg Marchand, an OB-GYN in Mesa, Ariz. There are exceptions, but generally, since the American College of Obstetricians and Gynecologists recommended offering it in 2015, he's gone with salpingectomy.

Yet if Stone feels the need to proselytize about it, it's because she often meets doctors who don't know about it. She remembers her surprise when she clicked into a virtual meeting in 2023 with medical bureaucrats whose jobs involve tracking diagnoses and interventions. "There were hundreds of people on this call, lots of them medical coders — people who are familiar with the development of new coding for new discoveries — and they had never heard of this. No one," Stone said.

Confusion abounded. Salpingectomies were documented as tubal ligations; patients didn't know whether their tubes had been blocked off or completely removed. Beneath those ambiguities was a wonkier one. In the lexicon doctors use to chronicle and bill for their work, there were no medical codes specific to opportunistic salpingectomy.

Now, after two years of advocating, Stone has convinced the committee behind the American diagnostic bible to create those codes. When they come into use in October, she hopes it will help clarify what patients are signing up for. That's part of her mission: To give true consent, people need to understand the difference between these procedures — and the cancer risk that had set this whole change in motion to begin with.

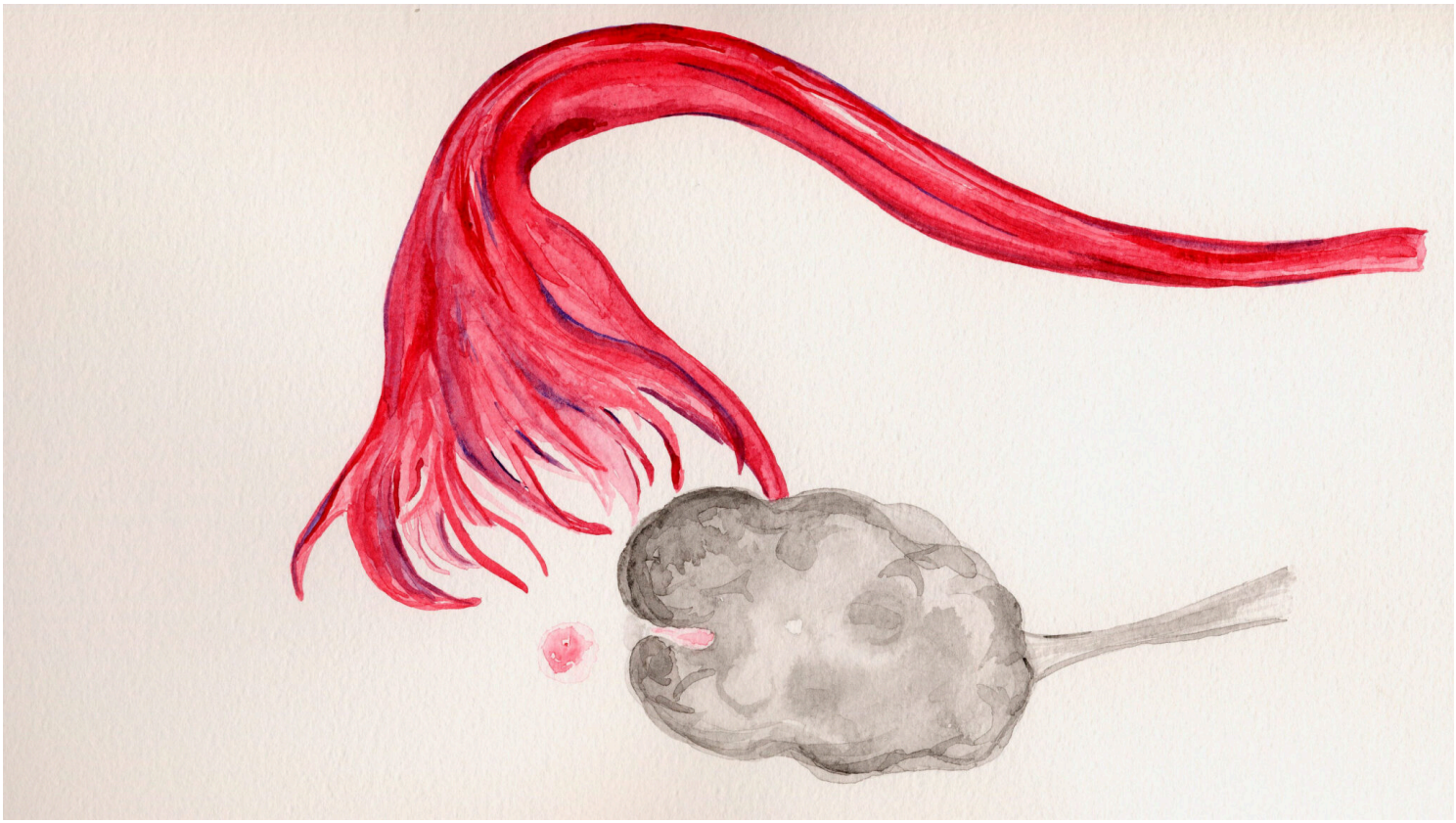
It started in the 1990s, with a different kind of risk-reducing surgery. Geneticists had discovered that mutations in BRCA genes drastically increased the rates of certain tumors, mothers and aunts and sisters all born without a molecular tool for repairing damaged DNA, all dying of breast and ovarian cancer. For their surviving relatives, surgeons began offering to remove those tissues. It was invasive and awful, and in the case

of ovaries, caused sudden menopause, which carried a host of complications. But it might just save their lives.

Pathologists, meanwhile, began examining the tissues that had been excised. If they could figure out where the tumors began, they might see how better to detect and treat them. The trouble was, they never found consistent precursors in the ovary. The cancers clung to its surface, but the seeds seemed to be coming from elsewhere. There was some hypothesizing that they emerged in the fallopian tube, but it seemed far-fetched. The tube was just a backdrop for the drama of fertilization, a mere conduit connecting uterus and ovary.

“I came to a meeting probably around 2003, and I got up and said I didn’t think it happened,” said Christopher Crum, a pathologist at Brigham and Women’s Hospital. He’d examined plenty of tubes in his time, and seen little to suggest that’s where cancers arose.

But then he started having second thoughts. Like others, he’d been examining a smidgen of the tube, cut from the middle. What if that were the wrong place? Each tube was 4 or 5 inches long, and wasn’t uniform. It was a widening flume with tentacle-like fringes at the end: a Dr. Seussian cross between a medieval trumpet and a sea anemone. Crum wondered what he would find if he sectioned and inspected the whole thing.



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"I wasn't expecting to get knocked over," he said — but within six weeks, he'd found five early cancers, mostly in the fringes he normally would have thrown away. In the previous decade, he hadn't found any. Pathologists hadn't seen anything in the tubes because they hadn't truly been looking.

This wasn't unique to people with BRCA mutations. The tubes of women with average cancer risk, it turned out, sometimes had potential precursors: cells that looked largely healthy but had telltale signs of DNA damage. Most wouldn't go on to become cancers, but carried that sliver of a threat. When researchers in Vancouver examined the tubes of 12 consecutive ovarian cancer patients, they saw that threat borne out: Every single one had either those DNA-damaged cells, oncologist Dianne Miller recalled, "or the fallopian tube had been totally blown apart."

Why so many cancers begin in the tube still isn't entirely clear, but one hypothesis has to do with ovulation. The less often someone ovulates — because of pregnancy, say, or birth control pills — the lower their risk of ovarian cancer. It makes a certain kind of sense, given the DNA damage involved: "In order for that egg to kind of ooze or burst out of the ovary, it has to essentially erode some of the layers of the ovary itself," explained Ronny Drapkin, a pathologist at the University of Pennsylvania.

The tasseled end of the fallopian tube hovers right there, draped over the ovary, ready to catch the egg and swish it toward potential fertilization, and, eventually, the uterus. It gets a repeated dose of the tissue-eroding chemical cocktail that allows for ovulation, and its cells may be less well equipped to deal with molecular injury than others.

Whatever the cause, there was a growing consensus that most so-called ovarian cancers had a similar backstory. It started with quiet DNA damage going unrepaired in one fallopian tube, pushing cells into proliferating wildly, breaking free of the membrane they usually clung to for survival. Some migrated out to colonize the ovarian surface, and from there, spread further into the pelvic cavity. People with BRCA mutations were more susceptible, with the double whammy of normal wear and tear plus a faulty internal fix-it crew. But it happened in others, too. By the time the symptoms were noticeable, it was often too late.

By 2010, the idea of removing tubes was cemented in Miller's mind. She was a gynecologic oncologist at the University of British Columbia, and knew that vast numbers of women got pelvic surgeries. For some, it was a hysterectomy to treat fibroids or heavy menstrual bleeding: removing the uterus, which connects to the tubes' narrow ends. For others, it was a tubal ligation — colloquially, "tube-tying" — a sterilization procedure that involved severing, blocking, or clamping a tiny bit of the tube. To Miller, those surgeries were opportunities: a chance to remove cancer precursors before they arose.

When her team looked at the medical records of British Columbians who'd had ovarian cancer, some 40% of them had previously had one of those operations. That represented thousands of potentially preventable cancers. "That was part of the impetus," said Gillian Hanley, an epidemiologist at the University of British Columbia. "This was worth trying, because people were so tired of watching women die from ovarian cancer. They were willing to try anything."

So began a province-wide campaign, with Miller asking surgeons to suggest salpingectomy to anyone considering either hysterectomy or tubal ligation. Ovarian cancer is rare enough — and often occurs late enough in life — that it would take years to see any statistically meaningful decrease in cases. In the meantime, opportunistic salpingectomy started taking root. The Canadian society representing gynecologic oncologists recommended offering it in 2011. The American equivalent did the same in 2013. The American College of Obstetricians and Gynecologists got on board two years later.

Already, there were hopeful data. In Sweden, researchers dug through decades of records of tubes excised for other reasons: an abscess, an ectopic pregnancy. Those who'd had both tubes removed had half the ovarian cancer risk of those who'd had only one tube out, as if the surgery were a preventive drug, more effective in its full dose.

Miller and Hanley's results, when they came in 2022, suggested the same thing. If the nearly 26,000 British Columbians who'd opted for opportunistic salpingectomy had gotten the most common and deadliest form of ovarian cancer at the same rate as the control group — who'd kept their tubes — there should have been at least five cases. Instead, there were zero.

This wasn't just an artifact of salpingectomy-choosers smoking less, exercising more, and being less cancer-prone overall. Their rates of breast and colorectal tumors were the same

as the control group's. Rather, though it sounded drastic to some, opportunistic salpingectomy seemed like a potential boon for public health.

Look at the uptake statistics, and you might be surprised at Stone's quest to publicize salpingectomy. There's already been a massive increase. From 2010 to 2017, among Americans with private insurance, salpingectomy rates jumped 18-fold during sterilizations and 8-fold during non-cancer-related hysterectomies. When STAT asked medical records giant Epic's research arm for more recent data on tubal removals replacing tube-tying, the company reported that there were 115 salpingectomies for every 100 tubal ligations in 2015, and 332 salpingectomies for every 100 tubal ligations in 2024.

But Stone was worried about what lurked behind those crisp-seeming numbers. Epic Research reported running into the same issues. In some cases, it was impossible to know whether a patient had gotten a tubal ligation or a salpingectomy.

Partially, it was a question of translation. To get reimbursed, American doctors report what happened in a clinical encounter using two different codes, one describing the diagnosis, the why of the visit, and another describing the services rendered, what they did about it. But certain "what" codes didn't distinguish between ligating a small bit of the tube and removing the organ entirely, and there were no "why" codes that captured some patients' cancer-prevention rationale when going in for another surgery.

This being the United States, the problem is exacerbated by insurance hurdles. Some state Medicaid programs explicitly won't pay for salpingectomy for sterilization purposes; some private insurers deny those claims, too. The National Women's Law Center estimates that its contraception coverage hotline gets about 20 to 25 intakes a week, and three quarters of them are about issues with salpingectomy.

The very thing that makes it alluring to doctors and patients alike — permanent contraception and cancer prevention in one fell swoop — doesn't compute in insurer-speak. "The insurer will be like, 'We can't cover it, because this is not a preventive code. We'll cover it if your doctor changes it to a preventive code.' And so they go to their doctor, and their doctor is like, 'I can't change it, I coded it correctly,'" explained Lauren Wallace, a lawyer at the center. "It's an absolute mess."

There's also evidence of deliberate fudging, patients counseling each other on Reddit to ask their doctors to perform salpingectomies but code them as tubal ligations, to get around insurance denials.

On the flip side, some patients don't know exactly what surgery they've gotten until after the fact. Tonya Gegenheimer, a bail bond agent and mother of three in Monrovia, La., only discovered she no longer had any tubes when she contacted a surgeon about getting her tubal ligation reversed, an operation that involves suturing the severed ends of the tube back together. "I was asked to get my operative and pathology report, and when I brought that to my appointment, he said, 'Unfortunately, you're not a candidate for reversal. They removed everything,'" Gegenheimer said. "That was not what I wanted. That was not the terminology that I agreed upon. I was very distraught."

She is part of an online community of patients who've experienced a constellation of debilitating symptoms — abdominal pain, heavy menstrual bleeding, mood swings, brain fog — after a tubal ligation or salpingectomy, and can't shake the feeling that this mysterious syndrome was caused by the sterilization. Though it doesn't always work to restore fertility, which is the primary reason doctors offer it, to these patients, reversal is a way to potentially ease their symptoms. You can't reverse a tubal removal, though, and some worry about the trend toward salpingectomy.

They know that the syndrome they describe is controversial, and often dismissed by doctors: There's robust safety data on both sterilization procedures, and the complication rates are low. But what this community wants, besides recognition and relief, is more in-depth consent, such that patients know in greater detail — and in advance — what each surgery involves.

Stone wants that, too. She's often appalled at how poorly doctors explain procedures to patients, how often women know they've had a hysterectomy but aren't sure whether they still have ovaries or tubes, how often they know they've had a "sterilization" but aren't sure what exactly that means. So, in 2023, she proposed new "why" codes for opportunistic salpingectomy. She hoped it might boost insurance coverage, but also knowledge about the procedure beyond OB-GYNs. "The most real things in medicine are the things you can bill for," she said. "It doesn't matter how great the discovery is. If people can't access this cancer prevention, you're dead in the water."

Now, after two years of work, those codes will be published in the coming weeks, and come into use in October. Doctors will have the bureaucratic terminology to convey the distinction between these operations to insurers — and Stone is gearing up for more campaigning, so that that distinction gets transmitted not just in code but in plain English (and other languages), too. She wants patients to know that salpingectomy can significantly reduce the risk of certain ovarian cancers, but doesn't eliminate it entirely. There are subtypes that begin elsewhere. There could be rare instances in which a tube is removed after a mutated cell has already floated out of the tasseled opening and seeded itself on the outside of the ovary.

There are other places this procedure could go. Research is underway to understand if it might protect BRCA-mutation carriers against so-called ovarian cancers, allowing some to avoid the sudden menopause that comes with ovary removal. For now, though, Stone mostly wants patients to know what's in the most basic names their doctors bandy about. That "ovarian cancer" isn't always as ovarian as it sounds. That "sterilization" can mean different things. Only then, can patients actually choose.