

Dismissed symptoms, misdiagnoses, and exclusion from clinical trials put female patients at risk. Here, the disturbing truth about gender bias in medicine—and how to get the first-rate care you deserve.

How Health Care Fails Women

BY KENNETH MILLER
PHOTOGRAPHS BY CHRISTINA HOLMES

Katie Ernst was 19 when she first began having rashes, joint pain, hair loss, and bouts of fatigue, along with occasional heart palpitations and fainting spells. Lab tests for autoimmune and cardiac diseases

came back negative. Over the next 13 years, doctor after doctor told her she was depressed or suffering from panic attacks, though she felt emotionally healthy. “I’m a go-getter,” says Ernst, now 35, a lawyer



Meghan Cleary searched for decades before getting proper treatment for endometriosis.



Katie Ernst has become a patient advocate, and she hopes her daughters never have to suffer as she did.

in Norristown, PA. “Being told that I was malnourishing was incredibly frustrating.”

After she got married, she began taking her husband to appointments for support. Finally, the couple found a physician who agreed to run more tests, which showed that Ernst had lupus (an inflammatory disease in which the body’s immune system attacks its own tissues and organs). “It was a good idea to bring your husband along,” the doctor said. “I have another patient with similar symptoms, and I’ve always assumed hers were psychosomatic.”

Just how hard is it for women to

get past doctors’ biases and get effective treatments? Women having a stroke are 33% more likely than men to be misdiagnosed in the ER, with potentially devastating consequences, researchers at Johns Hopkins recently reported. Studies show that women experiencing a heart attack are also likelier to be misdiagnosed. Women have an even harder time getting a correct diagnosis for ailments that solely or mostly affect women. For instance, about 75% of patients with autoimmune disorders are female; on average, they see five physicians over 4 years before their illness is identified, according to a survey by the American Autoimmune Related Diseases Association. In addition, more than 45% have been labeled chronic complainers. As documented in the new book, *Ask Me About*

My Uterus: A Quest to Make Doctors Believe in Women’s Pain, by Abby Norman, women with disorders of the female reproductive system, such as endometriosis and polycystic ovary syndrome, face similar obstacles to getting a correct diagnosis and treatment.

Women Deal With More Pain

The gender divide is especially glaring when it comes to pain. According to a study published in the journal *Academic Emergency Medicine*, female ER patients wait longer than males to receive painkillers—a median time of 65 minutes, versus 49 for men—and are less likely to receive those drugs at all. In her new book, *Doing Harm: The Truth About How Bad Medicine and Lazy Science Leave Women Dismissed, Misdiagnosed and Sick*, journalist Maya Dusenbery describes a “trust gap”: the fact that women’s accounts of their symptoms are too often not believed. A 2014 online survey by the National Pain Report found that 65% of women felt doctors took their pain less seriously because of their sex. “There seems to be an ‘Oh, she’s so neurotic’ attitude toward female chronic pain patients,” one respondent wrote.

Ally Niemiec, 27, a digital marketing manager in Atlanta, grew familiar with that experience in her early 20s, when she began suffering from frequent kidney stones. Every few weeks, she would limp into her local hospital emergency room with stabbing pain in her abdomen or lower back. Doctors there, she says, grew wary of her visits; though she’d been diagnosed with a hereditary condition known as medullary sponge kidney, which commonly causes such symptoms, they accused her of exaggerating her agony to get

WHAT EVERY WOMAN NEEDS TO KNOW

- If you feel your doctor isn’t listening to you, get a second opinion—or a new doctor. “There’s an increasing number of women’s health centers nationwide,” says Noel Bairey Merz, director of the Barbara Streisand Women’s Heart Center at Cedars-Sinai Medical Center in Los Angeles.
- When your physician prescribes a drug, ask if there are dosage considerations or side effects specific to women. “As doctors, we should be tailoring the treatment plan to the individual,” says Janine Austin Clayton, director of the NIH’s Office of Research on Women’s Health. “We need to incorporate sex-specific factors.”
- If you need surgery, research whether certain approaches are more beneficial—or riskier—for women. “Because women are more likely than men to awaken during surgery, make sure your anesthesiologist knows any factors that could heighten that risk, including the medications you take and your alcohol consumption,” says Daniel J. Cole, a professor of clinical anesthesiology at UCLA.

attention or score painkillers. Finally, they told her not to return.

Niemiec then sought help at other ERs around Atlanta but was turned away again and again. Once, she drove for hours before finding a hospital where doctors identified the source of her pain: an obstructed kidney stone that they were able to remove surgically. “Otherwise,” she says, “I would have lost the kidney.”

Eventually a cocktail of medications reduced the frequency of Niemiec’s attacks and her need for painkillers. She also joined a support group for men and women suffering from the same condition, where she learned she was not alone in being denied desperately needed care. Her fellow ER outcasts had one thing in common: their gender. “Many of the other women in the group had been accused of drug seeking when they went to the hospital,” says Niemiec. “But the men were quickly given pain meds and admitted. It’s infuriating.”

The Knowledge Gap

Dusenbery blames the gender inequities in the health care system on two interlocking problems. In addition to the trust gap—in which women’s accounts of their symptoms

are doubted or taken less seriously than men’s—there’s a knowledge gap that may be even more dangerous: Far less is known medically about women’s bodies and the ailments that afflict them than about men’s. “It’s really a vicious circle,” says Dusenbery, who interviewed dozens of patients, doctors, and researchers and dove deep into medical history for her book. “Because medicine has traditionally been a male-dominated field, it has invested relatively little in research to explain women’s symptoms scientifically. Then when women have symptoms that health care providers can’t explain, those symptoms are dismissed as made up, exaggerated, or psychogenic—all in the patient’s head.”

Research on women’s health issues is chronically underfunded. For example, over the past decade, the National Institutes of Health (NIH) has spent about \$883 million annually on studying autoimmune diseases like lupus, which affect an estimated 23 million Americans—one-sixth the expenditure for cancer, which affects about 14 million. While cancer is obviously more deadly, the spending discrepancy is still striking considering how many more people are affected by lupus and how much of an impact it has on their quality of life. Similarly, chronic pain affects 100 million Americans, and women are at greater risk of developing conditions that cause it. Though that’s more than the patient population for diabetes, heart disease, and cancer combined, pain research gets only 5% of the funding devoted to those diseases. What’s more, women were largely left out of clinical studies for decades,



Many women spend years searching for a diagnosis.

in part because researchers worried that women’s fluctuating hormones might skew results. For similar reasons, scientists relied mostly on male lab animals. These practices have proved to be misguided. “We now know that sex is an essential biological variable,” says Janine Austin Clayton, director of the NIH’s Office of Research on Women’s Health.

One example is cardiovascular disease, while men typically suffer from obstructive coronary disease, in which clumps of plaque block major arteries in the heart, women often have more evenly spread plaques, which prevent small arteries from dilating properly. Women are also likelier than men to develop multiple sclerosis and Alzheimer’s disease, to get lung cancer as nonsmokers, and to suffer from still-enigmatic disorders like fibromyalgia and chronic fatigue syndrome. To better understand such tendencies, Clayton says, it’s “crucially important” to include both sexes in

studies involving conditions that aren’t gender-specific.

In 1993, after prolonged pressure from activists, Congress mandated that women be included in NIH-funded clinical research; today, about half of participants in such studies are female. Yet many currently used therapies were developed using data compiled before that shift occurred. It wasn’t until 2016, moreover, that the NIH implemented rules requiring grant applicants to describe their plans to study both males and females in animal studies—and still the vast majority of lab rats studied today are male.

The longtime lack of women in clinical trials continues to do damage. Over the past 2 decades, for instance, numerous drugs and medical devices have been pulled from the market because they turned out to have greater adverse effects on women than on men. One study found that 8 of the 10 treatments withdrawn between 1997 and 2000 fit that description. Examples include fen-phen, a weight loss drug that was prescribed primarily for women and caused heart problems in many patients, and troglitazone, a diabetes drug also prescribed more frequently for women that could cause liver failure. In 2013, the Food and Drug Administration lowered women’s recommended dosages of

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the sleep medication zolpidem, marketed as Ambien, after a spate of auto “mishaps” among drivers who’d taken it the night before; women were more likely to have these accidents because the drug is cleared more slowly from their bodies. Yet the FDA still doesn’t require most medications to be tested in ways that take gender into account. When flibanserin, the “female Viagra,” was approved in 2015, its interactions with alcohol had been tested on 23 men and only 2 women.

Medical Education Is Still Biased

Gender disparities in health care also reflect stubborn inequalities in medical education. Although nearly

half of all US medical students are women, they make up only 38% of full-time medical school faculty—and just 21% of full professors. A recent survey of medical schools in the US and Canada showed that only 30% integrated sex and gender topics into their general curriculum. “There’s still a lot of research to be done on the differences between men and women and how that affects disease. And therefore, there’s not a lot of education,” says Rebecca Nebel, director of scientific programs at the Society for Women’s Health Research (SWHR). All these factors help explain why patients suffering from “women’s diseases” often have trouble finding doctors who can properly diagnose and treat them.

Meghan Cleary, a 45-year-old writer in Los Angeles, had suffered from crippling menstrual cramps and pelvic pain since her teens. “The first

doctor I went to told me I needed to get in touch with my body,” she recalls.

Other health professionals prescribed exercise or laxatives, or suggested she just accept her suffering. She was finally diagnosed with endometriosis (a disorder in which tissue similar to the lining of the uterus grows outside of the organ) in 2016, when a surgeon told her he’d burned away some endometriosis lesions while removing a uterine fibroid. But that treatment

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only made her symptoms worse. After learning, through online research, about wide surgical excision—considered the gold standard therapy for endometriosis—she decided to have a top specialist in Northern California do the procedure, even though he didn’t accept her insurance plan. (She petitioned her insurer, which did eventually pay for the surgery—an unusual outcome, she says.)

The operation was a success—“I’m not in chronic pain with my period anymore”—and Cleary says it was worth seeking out a specialist trained in performing that procedure. She later launched an informational website, *bad-periods.com*, for women with menstrual disorders. “This whole experience has transformed my life,” she says. But it angers her that the procedure isn’t more widely available. “You’ve got millions of women who’ve had multiple instances of these burning surgeries with no relief. Yet ob-gyns don’t learn about the latest techniques for treating this disease in medical school. It’s really heartbreaking.”

Maya Dusenbery agrees. “You shouldn’t have to be a superinformed patient in order to get proper medical care,” she says. Organizations like SWHR, the American Medical Women’s Association, the National Women’s Health Network, and the Sex and Gender Women’s Health Collaborative are working to make that unnecessary by promoting gender equity in medical research, education, and practice. But as long as the trust and knowledge gaps persist, Dusenbery advises, women need to navigate carefully when they step into a doctor’s office. “The important thing is to trust yourself. Don’t let anyone dismiss you, because you’re the expert on your body. Instead of second-guessing yourself, get a second opinion.”

Katie Ernst, now in remission from lupus, offers similar counsel on her blog, *Miss Treated (misstreated.org)*, where women who’ve encountered gender bias in health care can share their stories and find resources. “I have two daughters, and one of them may end up having the same problems I do,” Ernst says. “I’m a realist. I don’t expect that medicine will ever have all the answers. What’s crucial is that doctors learn to listen to women and respect their lived experience. More than anything else, I pray that my daughters will be believed.”

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LEARN MORE

- The Society for Women’s Health Research (swhr.org) promotes research, education, and advocacy on a wide range of issues.
- The National Sex and Gender Coalition
- Physician Registry (sgwhc.org) lists medical practitioners who have completed an accredited program of gender-specific medical education.
- The National Women with Heart Disease (womenheart.org) offers listings of physicians who specialize in women’s cardiovascular issues as well as support groups nationwide.
- The American Autoimmune Related Disease Association (arda.org) is an essential resource for patients and their loved ones suffering from these diseases, which primarily affect women.