

## **Medicine's Biggest Blind Spot - Women's Bodies**

By Helene M. Epstein

What do these stories have in common? A “funny” pain in a neck is ignored until it’s almost too late. A physician treats a patient for anxiety but misses the signs of a failing heart valve. An issue with blood flow to the brain is misdiagnosed as major depression disorder.

All of these patients have been trapped by medicine’s biggest blind spot: our lack of knowledge about how women’s bodies work.

The truth is we don’t fully understand how female bodies differ from males for many common diseases and medicines. That means that over half of the population in the U.S. is experiencing a lower standard of healthcare than the rest. [Diagnosis is a complex process](#) involving many steps and people. Missing valuable information makes it that much harder. Mark Gruber, MD FACP — and the founder and Chief Medical Officer of the [Society to Improve Diagnosis in Medicine](#) (SIDM) — likes to remind us there are only a few hundred symptoms but over 10 thousand diseases.

If you’re a woman, chances are you’re nodding your head. You may have your own story about feeling let down at your last doctor’s visit. If you’re a man, you might be rolling your eyes but the weight of evidence bears it out.

### **The Knowledge Gap**

Maya Dusenberry, author of [DOING HARM: The Truth About How Bad Medicine and Lazy Science Leave Women Dismissed, Misdiagnosed, and Sick](#), calls it the *Knowledge Gap*. She says women patients have been left out of all kinds of research until very recently. She notes that the National Institutes of Health [NIH] only began to officially tackle overwhelming male bias in medical research in 2014, a scant five years ago.

Gruber agrees. “The *Knowledge Gap* is very real,” he says. “It’s definitely true that the vast majority of studies in medicine were done on men and usually pretty healthy men...So, there are built-in biases to the knowledge that we’ve been given.”

When he was in medical school and during his residency, Gruber says that his training consisted of “facts” that applied primarily to men. “We were taught that the classic symptoms of heart attack are X Y & Z but those are all studies done in men. You weren’t taught that there are different presentations for women.”

Substandard care of women with heart disease and diabetes, two common conditions, are both so well documented that study after study, including one as recently as [2018](#), begin by stating it as accepted fact.

Lyn Behnke is a Michigan-based cardiovascular nurse practitioner who knows all about the differences between the way women and men experience heart disease symptoms. "As a clinician, I see women misdiagnosed all the time," she says. Yet, when it happened to her, she felt "an incredible sense of denial." She knew she had some risk factors — she was a smoker, a bit overweight, over fifty and in a high-stress job — but she ignored them. Her heart disease symptoms began with a funny pain in her neck that wouldn't go away no matter what she tried. She didn't think it was a cardiac problem. "I wasn't thinking like a clinician," she says. "I dismissed it right away." By the time she finally went to see her doctor, she was shocked when she failed her stress test. Because she had a 99 percent blockage of her coronary arteries Behnke had triple bypass surgery. Behnke is now on the governing board for [WomenHeart](#), the national coalition for women with heart disease. She is also a Patient Partner for SIDM's [Patients Improving Diagnosis in Research \(PAIRED\) initiative](#). You can read the rest of her story [here](#).

### **Women and Drugs**

Another big gap is participation in drug trials. Many pharmaceutical companies still exclude women in their first round of human testing. For example, over 9 million women take birth control pills but Dusenberry says only 12 percent of recently approved drugs were studied for interactions.

This is really important because women still take most of the same medicines as men, yet no one really knows how medicines that weren't tested on women may affect them. In a [recent study](#), we learned that "women are 50 to 75 percent more likely than men to experience an adverse drug reaction." As a result, new "symptoms" could be a side-effect of a medication or something related to a new condition. How can doctors or nurses know? A female patient's drug side effects may be dismissed as unlikely or something completely different. This can lead to misdiagnosis, or other complications, high expenses, and overtreatment.

Why are women left out of drug studies? The official reason is to protect women and their future children from the dangers of testing, especially women young enough to get pregnant.

The unstated reasons, though, may be closer to the truth. Women's bodies are different than men's so that can affect the clarity of research results. To have a study large enough to separate the results by sex costs more money, a lot more.

Although women, especially pregnant women, were left out of research to "protect" us from harm, over 90 percent use at least one medicine while pregnant and about 70 percent take at least one prescription. Unfortunately [few medicines \(~ 2%\) approved for use](#) since 2000 have

enough data for doctors and nurses to know whether they may cause birth defects. Even fewer studies ask the question, “How will this medication affect the pregnant mom-to-be?” We need to learn the impact of the medicines they take, especially considering the hormonal and other changes they’re going through.

### **We Don't Know What We Don't Know**

Many doctors still expect women to display the same symptoms as men for all conditions. That can cause delays in diagnosis in places where time is of the essence, like emergency rooms (ERs). [Women with abdominal pain](#) waited 16-minutes (65 vs 49 minutes) longer in the ER to receive pain medications than men did. A [2013 study](#) of women in the midst of heart attacks also noted a 16-minute delay in both diagnosis and treatment (88 vs. 72 minutes).

The little research we do have confirms that women experience many diseases differently. Stroke is the third leading cause of death for women while for men it's number five. Perhaps that's because women's strokes don't always present like men's. According to the [National Stroke Association](#), very common things can actually be signs of a stroke in women including fainting, general weakness, shortness of breath, nausea and agitation. Neurologists say that if a stroke isn't recognized within the first three hours of the first symptoms, treatments may be less effective. Delays due to gender may lead to a higher death rate from stroke.

Heart conditions are another classic example; 48 million American women are living with or at risk for heart disease. However, women's heart attacks rarely arrive in the same dramatic way men's do: clutching chest pain, pain shooting down the left arm, gasping for air. Ours are more subtle. ([Learn more here](#)).

### **Not Really Anxious**

New York advertising executive Lucy Reasoner [not her real name] says “I was in the best shape of my life” when she woke one morning with a heaviness in her chest, shortness of breath, a racing heart rate, and cough. She had a good relationship with her primary care doctor and he agreed to see her despite not having office hours that day. She had a history of very mild mitral valve prolapse (MVP), which is a relatively common and usually harmless issue with the flaps of one of the heart’s four valves. The flaps don’t close smoothly or evenly, but instead bulge (prolapse).

The doctor listened to her heart and told her, “You’ve got quite the murmur.” That surprised Reasoner. She had never heard that before, but the doctor didn’t think it was serious. To be on the safe side, he did an EKG test and an x-ray of her chest. However, after talking about the other issues weighing on her mind, he diagnosed her with anxiety, prescribed Valium and sent her home.

Reasoner took the Valium for a week but felt worse every day. "I have 50 steps up to my front door and I'd been zipping up and down these steps for twenty years," she says. "It was a measurable change. Suddenly, I had to rest, halfway up." She called the doctor to say the Valium hadn't helped and he prescribed a nasal spray and inhaler. "I have no idea why he did that," she says. "Maybe it was for the cough."

After two weeks, Reasoner decided to trust her gut. Her racing heart beat wasn't improving. She knew she wasn't anxious and that the cough wasn't due to asthma. She called the same group medical practice and asked to see whichever cardiologist had an opening that day. She got an appointment, he reviewed her test results, listened to her heart, ordered an echocardiogram immediately, and told her she needed open heart surgery. Her mild mitral valve prolapse had deteriorated; the valve had failed, and required immediate surgery to correct the problem.

Lucy Reasoner's story is an excellent example of how the *Knowledge Gap* affects women patients. Her doctor was Harvard-trained, fond of his patient, and wanted to heal her. Perhaps he hadn't been trained to understand the differences between how men and women experience heart conditions. Or was it something else?

### **The Trust Gap**

Reasoner's story also demonstrates the other way we are blind-sided in medicine, what Dusenberry calls the *Trust Gap*. Why did her doctor diagnose Reasoner with anxiety when he heard her rapid heart rate, reported on her murmur, ran objective tests that indicated there was a physical problem with her heart? He knew her; he respected her; but he never considered there was an organic problem. This is a good example of a common complaint; female patients often report feeling dismissed or ignored.

That is the essence of how the *Trust Gap* impacts women, Dusenberry reports. Since the beginning of medicine (see **Roaming Uteruses** below), women patients have not been considered trustworthy reporters of their own symptoms. This goes far beyond what Dusenberry calls "women's general lack of authority in a sexist culture." While sexism is a factor, it is not the root cause of the problem.

The *Trust Gap* is a direct result of the *Knowledge Gap*. It is due to generations of theories that say women's bodies are ruled by their emotional state. Much of Dusenberry's well-researched book, [DOING HARM](#), is about why doctors consider female patients to be unreliable reporters of their own symptoms. In short, some of this may be due to a doctor's growing frustration and irritation when his healing efforts fail. Some of it is due to the historical and current state of medical education.

Accurate diagnosis requires [teamwork](#). When doctors are trained that female patients are unreliable reporters of their own pain or other symptoms, it affects the quality of

communication. When they view women as emotional rather than rational and objective, it damages their respect for the patient's ability to make decisions about their own care. The clinician needs to accept that the patient is being honest and listen to all of their symptoms and concerns. The patient needs to know the doctor or nurse is also being forthright in their analysis of their symptoms and the risk of disease. Without mutual respect and trust, the risks of misdiagnosis, and then inappropriate treatment, rise.

### **Roaming Uteruses**

The *Trust Gap* has deep historical roots. When medicine was in its infancy, they had a lot of weird ideas about how women's bodies worked. For example, Dusenberry writes, "early Western medicine texts" believed many of women's health problems were due to "the effects of a restless uterus roving about the body." Years later, when they realized that our wombs didn't actually wander, it was still believed that the womb was the source of many diseases in women. Centuries later, unrecognized diseases were blamed on women's "tender and delicate Texture of the Nerves." Dusenberry puts a fine point on it when she states, "In short, [it was believed] women were inherently prone to nervous disorders because their reproductive functions...took a great deal of energy away from their relatively small brains."

Many medical texts still used to train new doctors use the male pronouns (he, him) when they discuss physical illness and the female pronouns (she, her) when they discuss mental health illnesses. While it isn't the same as stating that women's illnesses tend to be in their head, there is a cumulative effect that can impact overburdened doctors' thinking.

As recently as July 20, 2018, there was a social media uproar over a practice question for medical students. It was titled "A 36-Year-Old Woman in Undetermined Pain" and wanted the students to answer, "Which of the following diagnoses characterizes her unexplained physical symptoms?" In the details of this woman's case, it included the information that she was "quick to suggest treatment options and listens intently whenever any medical professionals are in the room." To our ears, she sounds like an engaged patient who is knowledgeable and involved in her care.

Not so to the medical text the question came from. All of the multiple choice answers, all of the possible diagnoses, suggested she was crazy. The "correct" answer was Munchausen Syndrome, a mental illness in which the patient pretends they're ill when they know they're not. Few medical students or doctors protested the question. It took a couple of days before the posted question reached the general public and the reactions exploded on social media. The company who posted it quickly pulled the test question, apologized, and promised to review their whole question bank. They referred to it as an example of "medical misogyny, a huge problem women face when seeking treatment from medical professionals."

## **A Presumption of Mental Illness**

In 1995, Lorraine Johnson was a corporate attorney at a high profile entertainment company in Los Angeles. Her work required her to operate on multiple levels simultaneously. Slowly, she noticed she was no longer able to work at the top of her game. She began to “lack the energy to engage in life” and developed brain fog. “I couldn’t think my way out of a paper bag,” Johnson says. “It’s like I was sitting in a room and the lights were going out one by one.”

While those symptoms sound alarming and could be caused by a long list of organic illnesses, her doctor never explored that list. Instead, she was diagnosed with major depression disorder. Once Johnson was tagged with a mental health diagnosis, no one looked for a cause, just treatments.

Johnson was forced to quit her job. She was unable to be fully present for her two children. Over the next seven years, she tried 52 different drugs for depression and none worked. Finally, she realized she needed a physician who would take a fresh look at her health and partner with her to find a cause and a solution. Even then, it was hard for her to do. “I felt it was a betrayal to leave a physician,” Johnson says. She interviewed doctors until she found one who was open-minded and determined to help her find an answer.

Two months of testing resulted in the correct diagnosis. Blood tests showed her immune system wasn’t working well and follow up tests indicated she had been fighting a serious infection, Lyme Disease. A [brain SPECT scan](#) explained her symptoms. The Lyme bacteria were blocking her brain from getting the proper blood flow. The images from her scan supported her description because the lights *had* been going out one by one. The scan image was dark. Two years of treatment and she was retested. The new brain SPECT scan showed a healthy brain, the images light and colorful.

Lorraine Johnson has taken the skills that had once made her a successful attorney and applied them to help others battling Lyme Disease. As the CEO of [LymeDisease.org](#), she has led them to become one of the most trusted sources of information, education, research, and advocacy. Like Lyn Behnke, Johnson is also a Patient Partner for SIDM’s [Patients Improving Diagnosis in Research \(PAIRED\) initiative](#). You can read the rest of her story [here](#).

## **Looking Ahead**

While organizations like SIDM and authors like Dusenberry are bringing attention to these issues more needs to be done to address the *Knowledge and Trust Gaps*.

The good news is that most new medical research includes female subjects. A [2016 paper](#) discovered that more women than men were included in published surgical studies conducted in the U.S. in the previous two years. Sue Sheridan, Director of Patient Engagement at SIDM, says that the major grant organizations who fund medical and clinical research now require a

better balance of patients as study subjects. “Some are even requiring that patients serve as co-designers of research,” Sheridan says. That is a goal that SIDM shares and encourages (See **What You Can Do** below). Sheridan adds that along with defining the research question and the patient outcomes, patients are also helping decide who is included or excluded in research studies offering a more “real world” sample of the population, including women. Moving forward we expect to learn more about how women’s symptoms and reactions to treatments differ from men’s.

The disappointing news is that the published results often don’t separate the data by sex. The [same 2016 paper](#) found only 37 percent reported the results by gender. That’s important because lumping results for men and women means that we could be missing essential differences.

### **What Women Can Do**

In the short term, you can try to choose doctors who listen to you and give you their time and attention when you are feeling ill. That is harder than it sounds because of the external pressures on most primary care physicians. That includes the new digital record-keeping methods and the demands and limitations from insurance companies and Medicare/Medicaid. At the very least, be prepared to discuss your symptoms and insist on having time to ask questions. (See [Dx IQ #1: The most important medical issue ever](#) for details.)

Trust your gut. If you feel that your symptoms are being ignored or dismissed as emotional rather than organic, try to get the doctor or nurse to consider other options. Ask, “What else could this be?”

Dusenberry knows how hard it is for most patients to disagree with a medical expert. She hopes that women will feel more empowered to “push back” and say, “You’re wrong. I know my body and I’m going to trust myself over you.” Many of the women she interviewed for the book said they got the best quality care when they brought a man, like a husband or father, into the doctor’s office. She said that makes her sad. However, your health is more important than your pride. Bringing a patient advocate, if you can afford one, or an organized friend, might also encourage you to ask more questions. Plus they can take notes and remind you of questions you wanted to ask.

You can also switch medical practices. Talk with your friends, your co-workers, and family members, and ask who they recommend. Tell the appointment nurse you are seeking a new primary care doctor. Ask for a brief initial appointment (10 minutes) to meet the physician and team before switching. There may be a fee since insurance companies rarely cover this but if you can swing it, do so. There is no reason to stay with a primary care provider who doesn’t respect you.

You can also help improve your chances that the medicine you take will be helpful, not harmful. When you are given a new prescription, ask the doctor or nurse if it has been tested on women and if you can see a list of side effects by gender. If you're on birth control pills, ask specifically about potential side effects of the two medicines combined. Don't be surprised if they don't have the answer at their fingertips or if they haven't even considered the question before. If we all do this routinely, eventually they will. Ask your pharmacist the same questions before you get the prescription filled. They should be able to answer your question. If the new medicine hasn't been tested on women, ask for a suggestion of a similar drug that has been and read the insert so you can know if any new symptoms are side effects or a different problem.

In the long-term, you can help change the way that medicine views women's bodies and improve the quality of medical research. The easiest way to start is by [sharing your story](#). SIDM collects and shares patient stories to ensure that the patient voice is heard in their efforts to improve diagnostic quality and safety.

You can offer to join your local medical care organizations' [Patient and Family Advisory Council](#). There you can advocate for women's health care.

If you have an ongoing condition, you can volunteer to serve on clinical studies or drug trials in your area of experience. Most new studies need to have a knowledgeable patient advocate on the team of experts involved in planning and designing. You don't have to have an MD or PhD after your name to do so but it is helpful to learn how to work with researchers first. Check out SIDM's [PAIRED \(Patients Improving Research in Diagnosis\) Program](#) and contact us [NEED AN EMAIL ADDRESS HERE] for more information.

Together, we can help transform medicine's blind spot into wisdom about women's health.

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**The Society to Improve Diagnosis in Medicine (SIDM)** catalyzes and leads change to improve diagnosis and eliminate harm from diagnostic error. We work in partnership with patients, their families, the healthcare community, and every interested stakeholder. SIDM is the only organization focused solely on the problem of diagnostic error and improving the accuracy and timeliness of diagnosis. In 2015, SIDM established the Coalition to Improve Diagnosis, to increase awareness and actions that improve diagnosis. Members of the Coalition represent hundreds of thousands of healthcare providers and patients—and the leading health organizations and government agencies involved in patient care. Together, we work to find solutions that enhance diagnostic safety and quality, reduce harm, and ultimately, ensure better health outcomes for patients. Visit our website at [www.improvediagnosis.org](http://www.improvediagnosis.org), and follow us on [Twitter](#) or [Facebook](#).

**Helene M. Epstein** writes about patient safety and family health. Her goal is to help readers apply important new information to their own lives. [Subscribe](#) to her posts, visit her [website](#) or follow her on [Twitter](#) or [Facebook](#).

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