Chapter 2

The Trust Gap

The pain started on an early Friday morning during Maggie’s senior year of college. She’d been fine when she woke up and fine when she went for a run, but about 30 minutes after eating breakfast, she suddenly felt a horrible pain—“the worst I’d ever experienced in my entire life,” she said. Within an hour, almost as quickly as it had started, it stopped, so she went about her day. But the pain, in her left abdomen and radiating up into her left shoulder, returned again, once after hanging out with some friends on the quad, and then in her afternoon class. This time, “it was worse than the first two times.” Leaving class to take refuge in the bathroom, Maggie fainted in the hallway.

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When she came to, the on-campus emergency responders first asked if she might be pregnant. When a test confirmed she wasn’t, their second question was if she was on her period. Unsure of what was wrong and about to close for the weekend, the campus clinic sent Maggie to the emergency room. The doctors did a couple tests and told her they could admit her and run some more; it was up to her. Since the pain had completely abated once again, Maggie, famished and stressed about missing her a cappella group’s auditions, opted to leave. But that night, after she ate a bag of chips and some pretzel M&M’s, the pain returned again. And when it came back the next morning, after eating a

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bagel, even the slightest movement triggered such excruciating spasms that she could hardly breathe. “That’s when I knew something was really wrong.”

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Her roommate drove her back to the ER and wheeled her into the waiting room because she couldn’t walk through the pain. “At this point, there were tears streaming down my cheeks, and I was still gasping for air. The nurse asked, completely unfazed by my appearance, ‘What seems to be the problem?’ In between gasps, I said that I was in so much pain that I couldn’t breathe.” Noting that her vitals were normal, the nurse told her, “You need to calm down. I think you’re having a panic attack.” She said emphatically that she wasn’t. She called her mom and handed the phone to the nurse. She heard him say, “She's a Brown University student and a 21-year-old girl—this is anxiety talking.”

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Maggie would spend the next 48 hours in and out of that hospital before the doctors finally figured out what was wrong with her. Until they did, her report of terrible pain would alternately be blamed on being a stressed-out student, being a “dramatic” personality, and, finally, being a drug seeker looking for prescription painkillers. “I can't even count the number of times I was told to stop ‘being hysterical,’” she said.

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There was a real irony to the charge leveled in the early 1990s that medicine overlooked biological differences between men and women. For most of its history, that was one of the very last things you could have said about Western medicine. On the contrary, for

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centuries, medicine had been obsessed with differences between genders, races, and classes and invoked these differences to justify everything from women's oppression to slavery to eugenics. As sociologist Steven Epstein wrote, "Until recently, medical emphases on differences—such as those between women and men or between black people and white people—were closely linked with social notions of superiority and inferiority. By treating variations between genders and races as something fixed in the body, medical theorists helped to reinforce the perception that social inequalities were a straightforward reflection of the natural order of things."

Certainly, the history of Western medicine is littered with examples of treating the male body as the norm (the most perfect representation of the species) but definitely not because it was assumed that women were so alike; women were their own special inferior subgroup. Women were portrayed as dissimilar to men—weaker, abnormal, inherently sickly—in unalterable ways that stemmed from their obviously different reproductive organs but went far beyond them. "The essence of sex is not confined to a single organ but extends, through more or less perceptible nuances into every part," the French physician Pierre Roussel wrote in 1775. Soon, doctors were measuring women's skulls and pelvises and concluding that women were lower than men on the evolutionary ladder.

Although men may have been the norm, women were imagined as the "typical patient." In the nineteenth century, according to medical historian W.F. Bynum, "more often than not, the abstract patient was referred to as female." And medicine was greatly concerned about women's health. Author Carol Weisman pointed out in her 1998 book, *Women's*

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The roots of this shift that medicine underwent—from obsessing over women's poor health to ignoring it—can be found in the history of the term hysteria. For centuries, it was a label for pretty much everything that went wrong in women's bodies, but by the beginning of the twentieth century, hysteria had come to be considered a mental disorder. The legacy of this transformation has been a persistent assumption that women's symptoms are "all in their heads"—until proven otherwise.

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A Brief History of Hysteria

The doctors and nurses who kept telling Maggie to stop being "hysterical" likely meant it in the modern meaning of the word: to stop being so emotional. But their treatment of her was also rooted in the original meaning of word. Before "hysterical" became an adjective, it was a disease.[ii] The word derives from the Greek word for uterus, *hystera*.

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Although it's a modern myth that ancient Greek and Roman medicine described a single distinct disease called hysteria, early Western medical texts did attribute an array of physical and mental symptoms (including menstrual pain, dizziness, paralysis, and a

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sense of suffocation) to the effects of a restless uterus roving about the body. Treatments were aimed at either enticing or driving the organ back into its proper place in the pelvis. Because, as the philosopher Plato explained, a womb that “remains barren too long after puberty” was thought to be especially prone to wander.[iv] Plato also recommended marriage as another cure. Even as later writers began to doubt the anatomical possibility of a “wandering womb,” they continued to see the organ as the source of many mysterious complaints. As one of the Hippocratic medical texts from the fifth century BC put it, “The womb is the origin of all diseases” in women—a hypothesis that would remain influential in Western medicine for millennia.[vi]

During the medieval period, the uterine theory of hysteria gave way to a demonological theory.[viii] Between the fifth and thirteenth centuries, as Christianity came to the Latin West, most illness came to be seen as a sign of original sin. Symptoms that might have been blamed on a wandering womb a few centuries before were now blamed on possession by the devil. “The hysterical female was interpreted alternately as a victim of bewitchment to be pitied and the devil’s soul mate to be despised,” wrote hysteria scholar Mark S. Micale.[x] Early in the medieval period, a “hysterical female” might have been treated with prayer, incantation, and exorcism. But by the late medieval and Renaissance periods, as the witch hunts swept the continent, she might have been tortured and executed.

As the scientific revolution arrived in Europe, some physicians began to argue that these mysterious symptoms weren’t *stigmata diaboli* (marks of the devil) but a disease that

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should be treated medically. In the early seventeenth century, for example, the English physician Edward Jordan wrote a treatise entitled “A Brief Discourse of a Disease Called the Suffocation of the Mother,” after unsuccessfully testifying in defense of a poor widow standing trial accused of bewitching a young girl. He argued that the alleged victim’s symptoms (contortions, paralyses, tics, and spasms) “which in the common opinion, are imputed to the [Devil], have their true natural causes” as symptoms of a genuine disease.[xi]

When medical men began resurrecting ancient Greek and Roman medical texts in the seventeenth century, they initially echoed their predecessors’ focus on the uterus as the source of nearly all female maladies. As prominent English physician Thomas Willis noted, “When at any time, a sickness happens in a woman’s body, of an unusual manner…so that its cause lyes hid…presently we accuse the evill influence of the womb…and in every unusual Symptom, we declare it to be something hysterical.”[xiii] But by the end of the century, some, including Willis, were laying the blame on a newly recognized system in the body. He argued that “the chief disorder is in the nervous system” in which “animal spirits” released by the brain were carried through the body.

In the eighteenth century, hysteria was increasingly lumped together with various different nervous disorders. No longer linked directly to the uterus, these disorders were diagnosed in both sexes. Still, women were considered more vulnerable because, as one British physician put it, they tended to have “a more volatile, dissipable, and weak Constitution of the Spirits, and a more soft, tender and delicate Texture of the Nerves.”[xv]

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Since hysteria was stereotyped as a women’s disease, male hysterics were often portrayed as effeminate, sensitive, and sometimes homosexual. Doctors also created a different label for male sufferers of nervous disorders. Loosely, the male equivalent of hysteria, also known as “the vapors” or "the spleen", was hypochondria. The two, according to British physician Thomas Sydenham, were as alike “as one egg is to another.”[xvii]

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A plethora of theories and treatments for hysteria proliferated during the nineteenth century. Eventually, doctors developed an influential theory that married the ancient focus on the female reproductive system with the emerging interest in the nervous system. As one doctor explained, “The functions of the brain are so intimately connected with the uterine system, that the interruption of any one process which the latter has to perform in the human economy may implicate the former.”[xix] In short, women were inherently prone to nervous disorders because their reproductive functions (menstruation, pregnancy, lactation, and menopause) took a great deal of energy away from their relatively small brains.

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The new specialty of gynecology, which emerged in the middle of the nineteenth century, was especially fond of this theory, though opinions differed on which specific reproductive organ was to blame. Some maintained that the uterus was “the controlling organ in the female body.”[xx] Indeed, one American physician told a medical society that the uterus’s influence on women’s health was so great it was “as if the Almighty, in creating the female sex, had taken the uterus and built up a woman around it.”[xxi] With the

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discovery of ovulation in the 1840s, others decided that it was the ovaries that “give women all her characteristics of body and mind.”[xxii]

Whichever was blamed, the treatments offered during heroic medicine’s reign were brutal. Almost any symptom in women would get a local treatment of the reproductive organs, which included injecting various concoctions into the uterus, placing leeches on the vulva, and cauterizing the cervix. For a decade in the late 1800s, ovariotomies (the removal of perfectly healthy ovaries) became a popular treatment for hysteria among middle- and upper-class American women. According to one estimate, 150,000 were performed for such afflictions as “troublesomeness, eating like a ploughman, masturbation, attempted suicide, erotic tendencies, simple ‘cussedness,’ and dysmenorrhea [painful menstruation].”[xxiii] The trend came to an end primarily because doctors became uncomfortable sterilizing women—or, as one doctor put it, being “the destroyer of everything that makes a woman’s life worth living.”[xxiv]

In the later part of the nineteenth century, another new specialty competed with gynecologists for the treatment of hysteria and other nervous disorders in the United States: neurology. Disdainful of gynecologists’ methods, early American neurologists experimented with electrotherapy, drugs (arsenic and opiates, among others) and Dr. Silas Weir Mitchell’s infamous “rest cure.” His regime was described by Charlotte Perkins Gilman, who had been a patient of his, in her well-known novella *The Yellow Wallpaper*. For several weeks, the patient would be confined to bed in a dimly lit room, allowed to see only the doctor and a nurse, and forbidden from reading, writing, or doing

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anything else besides eating fattening foods and receiving a daily massage. The theory went that the cure was such “bitter medicine” that when Weir Mitchell commanded the patient to get better at the end of it, she would bend to his will.

The French researcher Jean-Martin Charcot, considered the “father of modern neurology,” on the other hand, felt that nothing could be done to treat hysteria, which he believed was a degenerative neurological disease. In the 1870s, he gave a series of packed public talks demonstrating the bizarre contortions and fits of his hysterical patients under hypnosis. Prominent American neurologist George Beard was responsible for coming up with a new respectable label for men’s nervous symptoms: neurasthenia, or weakness of the nerves. (Hypochondria no longer sufficed since it had gradually come to take on its broader, contemporary meaning.) Neurasthenia’s many symptoms overlapped with the many symptoms of hysteria, and it was eventually diagnosed in women and men with about equal frequency. While women continued to be seen as prone to nervous disorders because of “something fundamental in their nature, something innate, fixed or given,” among elite gentlemen, the same symptoms were often attributed to overwork and the stresses of urban, industrial modern life.[xxvi]

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The uterine-nerve theory of hysteria proved especially useful for keeping women in their proper place; one might even suspect it was designed to. The precarious balancing act between their reproductive organs and brain meant that women were inherently sick or at least had an innate biological predisposition to illness. All the stages of a woman’s life (puberty, menstruation, pregnancy, and menopause) were considered periods of “ill

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health" when their bodies could easily be thrown into dangerous disorder by any activity, but especially by mentally taxing ones. And so, as Weir Mitchell warned, "It were better not to educate girls at all between the ages of 14 and 18, unless it can be done with careful reference to their bodily health."[xxvii] As for pursuing a career, well, "one shudders to think of the conclusions arrived at by female bacteriologists or histologists at the period when their entire system, both physical and mental, is, so to speak 'unstrung,' to say nothing of the terrible mistakes which a lady surgeon might make under similar conditions."[xxviii]

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As the suffrage movement gained ground, women's colleges opened their doors, and women pushed for admission to medical schools. Male physicians stepped up their insistence that this was all very risky—medically speaking, of course. In the midst of the debate about allowing women to attend Harvard, Dr. Edward H. Clarke, a professor at the school, published *Sex in Education, or a Fair Chance for the Girls* in which he reviewed the medical literature and concluded that higher education would cause women's uteruses to atrophy.[xxx] "Women beware. You are on the brink of destruction," another doctor warned. "Science pronounces that the woman who studies is lost."[xxxii]

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The scientific "fact" of a zero-sum connection between women's reproductive functions and their brains was transparently self-serving for the young male-dominated medical profession—and doubly so. As Barbara Ehrenreich and Deirdre English wrote in their 1978 book *For Her Own Good*, "The theory of female frailty obviously disqualified women as healers. At the same time the theory made women highly qualified as

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patients."[xxxiv] The economic self-interest driving doctors' concern was not lost on some of the few female doctors who'd broken into the profession by the end of the nineteenth century. As Dr. Mary Putnam Jacobi wrote dryly in 1895, "I think, finally, it is in the increased attention paid to women, and especially in their new function as lucrative patients, scarily imagined a hundred years ago, that we find explanation for much of the ill-health among women, freshly discovered today."[xxxv]

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But, of course, many women didn't make lucrative patients. Conveniently enough, nineteenth century "science" showed that working class white women and black women were magically resistant to the health problems that plagued well-off white women. As one physician noted, "The African negress, who toils beside her husband in the fields of the south, and Bridget, who washes, and scrubs and toils in our homes at the north, enjoy for the most part good health, with comparative immunity from uterine disease."[xxxvi] In a remarkably lucky boon to the new medical profession, it was only those women who had the time and the money to be treated who were prone to perpetual illness and in need of their services. And it was only those women trying to break into professional work—aspiring bacteriologists, histologists, and surgeons—who faced such dire health consequences from working.

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The Unconscious Mind

As the nineteenth century wore on, doctors' accounts of hysteria and other female nervous disorders were increasingly marked by a note of suspicion and frustration.

Though most continued to insist that it was a physical disease tied to the uterus, nerves, or both, their treatment approaches became more and more punitive. As one physician put it, hysterical women respond best to “fear and the threat of personal chastisement.”[xxxvii]

In part, this attitude seemed to stem from a sense that women were bringing ill health upon themselves by denying their proper role. Historian Ann Douglas Wood explained, “One finds an underlying logic running through popular books by physicians on women's diseases to the effect that ladies get sick because they are unfeminine—in other words, sexually aggressive, intellectually ambitious, and defective in proper womanly submission and selflessness.”[xxxviii] Weir Mitchell, for example, admitted the hysterical woman was the “hated charge” of his specialty, a “self-made invalid” who was “like a vampire, slowly sucking the blood of every healthy, helpful creature within reach of her demands.”[xxxix]

There were also some concerns that hysterical women were just faking it. As one doctor warned, some women "pretend hysteric attacks, in order to excite sympathy and obtain some desired end.”[xl] Another doctor described hysterical women as “performers” who must be convinced by a doctor that “she has nothing at all the matter with her, and is, in reality, in perfectly good health: her ailments being, one and all, fraudulent imitations of real disease.”[xli] Earlier in its history, the profession may have welcomed chronically ill women as a cash cow, but the public increasingly expected their doctors to actually help

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And growing it was. Thanks to advances in anatomy, physiology, pathology, and microbiology over the course of the nineteenth century, the field began to have some success in matching laboratory findings to patients’ symptoms. Gradually, it was adopting the view that all symptoms could be traced back to a particular, visible, measurable pathology—a shift that was solidified with the acceptance of germ theory in the 1880s. The discovery that infectious diseases were caused by specific microbes strengthened the growing belief that all diseases had a specific cause. Previously, diseases were defined as collections of symptoms; “fever” or “pains” were disease categories in their own right. As historian of medicine Charles Rosenberg explained, “Recognizably modern notions of specific, mechanism-based ailments with characteristic clinical courses were a product of the nineteenth century.”[xlii]

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And it led to a fundamental transformation in the way medical professionals thought about symptoms. Before, doctors had no choice but to take patients at their word about what they were experiencing. After all, without any tools to see within the body and without the foggiest notion, really, about what caused most diseases, they usually didn’t have anything else to go on. But as diseases came to be categorized based on the physiological disturbance at their root, symptoms were transformed into clues that could help the doctors uncover their source. The patient’s subjective report of their symptoms (pain, dizziness, nausea, etc.) only became actual symptoms of a disease once the doctor,

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It’s within this context that the final phase in hysteria’s history occurred. In the late 1800s, neurologist Sigmund Freud abandoned the neurological theory of hysteria in favor of a psychological one. In his famous case studies of hysterical women, he argued that psychological conflict, or strangulated affect, was converted into physical symptoms. Describing this process as “the puzzling leap from the mental to the physical,” he left it to others to fill in how it actually worked. Initially, Freud argued that hysteria arose when repressed traumatic memories, usually of sexual abuse, within “the unconscious” found expression in the body in a symbolic manner. Later, backing off from the implications of that assertion, he decided that it wasn’t actual sexual abuse—just fantasies of it—that converted into hysterical symptoms. The symptoms would disappear, he believed, if the patient consciously recalled the psychological distress through a technique of free association within his theory of psychoanalysis.[xliii] As historian Carroll Smith-Rosenberg wrote, “Psychoanalysis is the child of the hysterical woman.”[xliv]

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This was a major transformation. For millennia, hysteria had been considered a physical ailment, which could cause a wide array of mostly physical symptoms. After Freud, it was seen as a mental disorder that caused physical symptoms. After alternately tracing all of women’s unexplained aliments back to a wandering womb or demonic possession or sensitive nerves, medicine finally punted them over to the psyche. As Ehrenreich and English wrote, “Under Freud’s influence, the scalpel for the dissection of female nature

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eventually passed from the gynecologist to the psychiatrist." And "the medical view of women…shifted from 'physically sick' to 'mentally ill.'"

This shift has had incredibly long-lasting effects on what is known about women's health and diseases and how women are treated when they enter the medical system. As hysteria became psychologized, which occurred just as medicine increasingly defined "real" diseases as those it could see and explain, the idea formed that any symptoms medical professionals couldn't yet see and explain, particularly those in women, could be blamed on the unconscious mind. Medicine has liberally utilized this theory whenever it comes up against the limits of its knowledge. It has led to the persistent distrust of women's subjective reports of their own bodies until those reports are backed up by objective evidence.

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The Disorders Formerly Known as Hysteria

One of the biggest myths about hysteria is that it disappeared in the first part of the twentieth century. That's what scholars concluded when they began writing histories of the condition. As one French historian wrote, "Hysteria is dead, that it is certain. It has taken its secrets with it to the grave."[xlv] But most tended to shrug their shoulders and provided few hypotheses about how and why exactly this disease, once supposedly so common, mysteriously disappeared. To the extent that they did, most offered explanations that largely accepted Freud's theory of the condition. One common conclusion was that before the twentieth century, people in the West were more

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psychologically primitive, prone to expressing their mental distress through physical symptoms. As the public became more knowledgeable about psychological concepts, the process of hysterical conversion no longer worked, and they were more likely to develop depression or anxiety disorders instead.

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Even many second-wave feminist accounts of hysteria left something to be desired. They tended to highlight the fact that by the end of the nineteenth century, doctors were labeling as hysteria any behavior in women they disliked, particularly rebellious claims to autonomy and equality. These accounts also emphasized, as Ehrenreich and English did, that the male-dominated medical system seemed to have a clearly self-interested investment in women’s illness. In other words, women weren’t actually that sick; doctors were just saying they were. Or, largely accepting the psychological theory of the condition, they portrayed the “flight into illness” of nineteenth-century hysterical women as an unconscious protest against their oppression in a patriarchal culture. In this analysis, the decline of hysteria was the result of feminist progress: women became more equal and got better.

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But while there’s no doubt some truth to these accounts, they tend to leave out the most mundane explanation for hysteria: that most of the women lumped into this broad diagnostic category were indeed sick. It’s understandable that second-wave feminists would be reluctant to focus on that one. After all, for centuries, medicine had been insisting that women were sick, that they were sick because women were inherently sick, and that this justified their inferior social status. But one needn’t accept the second and

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third conclusions to accept the first. Indeed, if women were in poor health that could just as easily be taken as an indictment of the medical system that was treating them. As Harriot Hunt, one of the earliest female doctors in the United States, pointed out in 1856, "Man, man alone has had the care of us [women], and I would ask how our health stands now. Does it do credit to his skill?"

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While the state of nineteenth-century women's health may not have been quite so dire as a medical system that recommended ovariotomies to treat troublesomeness claimed it to be, some women surely were sick. The medical profession, in its infancy, was incapable of differentiating between a multitude of physical ailments. Physicians didn't have use of germ theory until the 1880s and didn't have the x-ray until 1895. After all, it is not like physicians were diagnosing hysteria in addition to the thousands of diseases we recognize today. Indeed, they were eventually attributing nearly "every known human ill" to hysteria. As Micale wrote, the term "came to mean so many different things that that by around 1900 it ceased to mean anything at all."

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And so to the extent that hysteria disappeared, it was because this bloated diagnostic category inevitably shrank as medical knowledge grew. As Micale argued in the nineties, hysteria didn't so much vanish as it splintered. In a process that he called diagnostic drift, what would have been called hysteria a generation ago was likely to instead fall into one of numerous newly recognized diagnoses, creating only "the retrospective illusion of a disappearance of the pathological entity itself."[xlvi] For example, during the time that hysteria was on the decline, particularly the dramatic fits and paralysis that had so

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captured the medical imagination, doctors were getting much better at diagnosing neurological conditions such as epilepsy, multiple sclerosis, and the neurological effects of syphilis. Many scholars have attempted retrospective diagnoses of the women that Freud had (mis)diagnosed with hysteria; Anna O. likely had temporal lobe epilepsy, a condition that wasn't recognized until the electroencephalogram became widely available in the 1930s, or perhaps tuberculous meningitis; Frau Emmy, Tourette's syndrome; Elisabeth von R, pelvic appendicitis.[xlviii]

But even as many conditions drifted out of hysteria, the Freudian concept of hysteria remained. One of the innovations of Freud's theory was that hysteria was transformed from a distinct disease category with an impossibly long list of potential symptoms into a theoretical process—the conversion of psychological distress into physical symptoms. So while the belief in a specific disease called hysteria may have waned throughout the first half of the twentieth century, the idea that physical symptoms could be produced by the patient's mind never disappeared at all. Hysteria was officially listed in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) as one of the "neuroses" until 1980. And hysterical was retained as an adjective to describe any symptom for which doctors couldn't find a physical cause and deemed due to a so-called conversion reaction.

As the term hysteria gradually entered the popular lexicon with its modern meaning of excessive, uncontrollable emotionality, a less pejorative term was needed. By the 1960s, a few new euphemisms had started to take its place.

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In the 1960s, a group of American researchers rechristened hysteria as Briquet syndrome, after a nineteenth-century French physician who had studied hysteria.[l] According to their diagnostic criteria, a patient would qualify if she (and it was almost always a woman) had at least 25 of 59 possible symptoms in 9 of 10 different symptom areas before the age of 35 and no diagnosis of a recognizable disease that could explain them. Its possible symptoms included essentially every possible symptom under the sun: headaches, blindness, paralysis, fits, fatigue, a lump in the throat, fainting spells, dizziness, chest pain, visual blurring, weakness, abdominal pain, vomiting, diarrhea, menstrual disorders, changes in sexual interest, pains in various parts of the body, breathing difficulties, weight changes, appetite changes, and feelings of nervousness, fear, and depression.

Meanwhile, the concept of somatization was also taking hold. Defined in the 1920s by Viennese psychoanalyst Wilhelm Stekel as the "process by which neurotic conflicts appear as a physical disorder," somatization's definition was expanded in the late 1960s by American psychiatrist Zbigniew J. Lipowski.[lii] Acknowledging that the idea was "related to, if not identical with" the Freudian concept of conversion, Lipowski described it as "the tendency to experience and communicate psychologic distress in the form of somatic symptoms that the patient misinterprets as signifying serious physical illness."[liii] "Somatizing" mental distress, he wrote, was a "common, if maladaptive and largely unconsciously motivated, coping strategy to deal with life's demands and frustrations." But it became a psychological disorder when patients kept insisting they were sick even though doctors had concluded that they were not. "Patients with persistent somatization relentlessly seek medical diagnosis and treatment despite repeated reassurance that

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physical illness is either absent or insufficient to account for their symptoms and disability.”[liv]

Meanwhile, as the influence of Freudian theory on American medicine peaked during the middle of the century, a new subspecialty of psychosomatic medicine was born. Offered as a corrective to a biomedical approach that, with its increasing focus on biological disease, ignored the psychological and social factors that affected health, psychosomatic medicine was looking for the mental states and personality factors involved in a wide range of organic diseases, including cancer and heart disease, at the height of its popularity. Still, the field considered some diseases to be more influenced by the mind than others. So-called psychosomatic disorders included asthma, ulcers, and hypertension, and it was hard to escape the conclusion that these conditions were simply those that medicine didn’t yet know much about in biological terms. The field suffered a blow to its reputation when stomach ulcers, long believed to be caused by stress, were linked to the bacteria *Helicobacter pylori*.

As Susan Sontag argued in her famous 1978 essay “Against Illness as Metaphor,” psychological theories of illness “are always an index of how much is not understood about the physical terrain of a disease.”[lv] Sontag, who was being treated for breast cancer, was writing at a time when psychosomatic medicine had popularized the idea that there was a certain repressed cancer personality. Psychological theories of disease also tend to be “a powerful means of placing the blame on the ill,” she pointed out. “People are encouraged to believe that they get sick because they (unconsciously) want to, and that

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they can cure themselves by the mobilization of will…Patients who are instructed that they have, unwittingly, caused their disease are also being made to feel that they deserved it."

And despite the more narrow definition of psychosomatic used by experts in the specialty, in general medicine (as well as in the popular culture) it often came to be used as a synonym of psychogenic (its origin in the mind) in contrast to organic (its origin in the body); it's another euphemism for hysterical. Though psychosomatic medicine may have been a worthy attempt to emphasize the unity of mind and body in all diseases, medicine more generally just used it to reinforce the duality it was increasingly attached to: if not organic, then psychogenic. If the cause of the symptom can't be found in the body, then by default, it must be in the mind.

"Does the Patient Accept Herself as a Woman?"[lvi]

In the 1970s, women, as both patients and physicians, were beginning to point out that they seemed to be particularly vulnerable to this kind of medical psychologizing. They were more likely to have their physical symptoms dismissed as psychogenic when they presented to their doctors, and medicine seemed especially fond of blaming conditions unique to them on psychological factors.

As historian Shari Munch noted, "there was remarkable agreement among both scholars and lay community that this problem existed," despite the fact there actually wasn't that

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much empirical evidence to support the charge.[lviii] But anecdotal evidence abounded, and in the late 1970s a couple of studies documented it. One study based on a random sample of 336 tape-recorded interactions between physicians and their female and male patients found the physicians were more likely to see the women’s illnesses as psychologically caused.[lx] Another looked at the physicians’ responses to five common complaints (back pain, headache, dizziness, chest pain, and fatigue) in a sample of 104 men and women, and found that for each one, the men received more extensive workups than the women.[lxii]

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In explaining this gender-biased diagnosing, some pointed the finger at differences in how men and women tended to communicate with their doctors. As a 1981 study testing that theory put it, “The open and emotional behavioral style used by women in reporting their illnesses may prompt physicians to react to women’s complaints as though they were expressions of emotional problems, whereas the more stoic style found in men reporting a similar complaint does not elicit a psychosomatic diagnosis from the physician.”[lxiv] But their study, in which 253 primary care doctors read case studies of patients of both genders complaining of either abdominal pain or a headache, offered only partial support for the hypothesis. Men were almost as likely as women to get a psychosomatic diagnosis when they mentioned they were dealing with a personal problem; however, a large gender divide appeared among those patients who didn’t mention a personal problem. “Even non-expressive female patients were judged to have psychosomatic problems,” the authors wrote, “as though women were a priori more emotional creatures than men.”

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Though there were still very few women physicians at the time, they helped expose the problem. In a 1974 article entitled “What Medical Schools Teach about Women,” Dr. Mary C. Howell, the first female dean at Harvard Medical School, wrote: “Following traditional linguistic convention, patients in most medical-school lectures are referred to exclusively by the male pronoun, ‘he.’ There is, however, a notable exception: in discussing a hypothetical patient whose disease is of psychogenic origin, the lecturer often automatically uses ‘she.’ For it is widely taught, both explicitly and implicitly, that women patients (when they receive notice at all) have uninteresting illnesses, are unreliable historians, and are beset by such emotionality that their symptoms are unlikely to reflect ‘real’ disease.”[lxvi]

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In her 1977 book, the *Hidden Malpractice: How American Medicine Mistreats Women*, journalist Gena Corea reported that 72 percent of physicians in one survey referred spontaneously to a woman when asked to describe the “typical complaining patient.”[lxviii] According to a 1973 survey of female students in 41 American medical schools, their lectures were filled with references to women as “hysterical mothers,” “hypochondriacs,” and “old ladies” whom doctors must “manage.” One student described being told by a surgeon that a young woman with abdominal pain “was by definition an 'unreliable

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historian.'" Another student explained, “Often women are portrayed as hysterical or as nagging mothers or as having trivial complaints. Men are almost never pointed to as having a psychological component to their illnesses—this is generally attributed to women." In fact, another noted, “Women's illnesses are assumed psychosomatic until proven otherwise.”

The portrayal of women as particularly prone to psychogenic symptoms was formally taught as scientific “fact” in textbooks too. A 1971 gynecology text warned that “many women, wittingly or unwittingly, exaggerate the severity of their complaints to gratify neurotic desires.” It suggested that doctors be on the lookout for psychological and “personality factors” that contribute to everything from urinary problems to infertility to back pain. The surest way to tell if the source of the symptom was physical or psychological was to consider the question, “Does the patient accept herself as a woman?”[lxix] Accepting herself as a woman, of course, meant adhering to the narrow feminine role of the era: a role that medical textbooks also had quite clear ideas about. A 1978 analysis of 27 general gynecology texts published over the previous few decades found that in nearly all the texts, women were described as “anatomically destined to reproduce, nurture, and keep their husbands happy.”[lxxi]

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If a woman attempted to resist these prescribed roles, this mental conflict could emerge in a number of symbolic ways, particularly in disorders affecting her reproductive system. (Just as in the nineteenth century, women were still thought to bring illness upon themselves by failing to be properly feminine—only now their symptoms were all in their

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heads.) In an influential 1973 article in the *New England Journal of Medicine*, Drs. K Jeane Lennane and R. John Lennane discussed four conditions that—on little scientific basis at all—had come to be considered to be at least partly psychogenic: dysmenorrhea, nausea of pregnancy, the pain of labor, and behavioral disorders in infants.[lxxiii] According to one textbook, dysmenorrhea "is generally a symptom of a personality disorder" and "therefore a thorough study of the women's attitudes toward femininity is often necessary." Nausea during early pregnancy, the morning sickness experienced by the vast majority of pregnant patients, "may indicate resentment, ambivalence and inadequacy in women ill-prepared for motherhood," another textbook explained.[lxxv] Likewise, the pain of labor was attributed to the mother's fear of childbirth, and—in a testament to the truly astounding power of a woman's neurosis—her newborn's colic was blamed on her own maternal anxiety.

The Lennanes offered an astute observation about how such theories became popular, despite ample scientific evidence clearly pointing to organic causes. The reason the psychogenic explanations appeared plausible, at least enough of the time to make them attractive, was that they were simply reversing the causal arrow. Those who experience painful menstrual periods understandably may be less than excited about that time of the month, "this has been reversed to say that fear and dislike of menstruation cause or aggravate the dysmenorrhea." Severe nausea during pregnancy may make the patient ambivalent about the state that's causing it, "this is reversed to say that ambivalence or hostility causes the nausea." Likewise, it's not that the pain of labor causes fear, or that a constantly crying baby makes a new mother anxious; it's the reverse. "Because these

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conditions affect only women," they concluded, "the cloudy thinking that characterizes the relevant literature may be due to a form of sexual prejudice."

From Psychosomatic to "Medically Unexplained Symptoms"

The concept of hysteria has an impressive ability to adjust to changing times. Freudian theory fell firmly out of favor in American medicine in the 1970s. When the third edition of the DSM was published in 1980, it had been scrubbed of all vestiges of it—except, that is, in one section: the new category of somatoform disorders.[lxxvi] With some minor revisions, for the next two decades these disorders described patients whose physical symptoms were "not explained by a general medical condition" and were judged to be caused by psychological factors. Briquet syndrome was renamed somatization disorder and included a simplified criteria that now required a lifetime history of 14 of 37 possible symptoms. (In a subsequent revision, it was further streamlined to require just 8 of 32 symptoms distributed among four symptom groups.) Conversion disorder applied to unexplained neurological symptoms such as paralysis, seizures, and amnesia. Psychogenic pain disorder (eventually revised to just pain disorder) described unexplained chronic pain in any part of the body. Hypochondriasis was reserved for patients with medically unexplained symptoms who also had an intense fear of having a serious illness. A couple residual categories, undifferentiated somatoform disorder and somatoform disorder not otherwise specified, covered any unexplained symptoms that didn't fit neatly into any of the other labels. As Lipowski wrote, "The somatoform

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disorders have been mostly derived from the wreckage of what used to be called hysteria."

With the exception of hypochondriasis, all the somatoform disorders were described as more common among women.[lxxviii] Indeed, somatization disorder, like its immediate predecessor Briquet syndrome, was considered to be almost exclusively a female ailment—ten times more common in women than men. In the mid-1980s, a couple of researchers came up with a screening test for the disorder. While the DSM criteria technically required 13 of 35 possible symptoms at that time, they argued that just 2 or more of 7 "highly suspicious" symptoms indicated a high probability of the disorder: shortness of breath, dysmenorrhea, burning sensation in the sex organs, a lump in the throat, amnesia, vomiting, and painful extremities. The mnemonic aid they offered for remembering them is "Somatization Disorder Besets Ladies And Vexes Physicians."[lxxix] Less consistently, somatoform disorders were reported to be more prevalent among patients with less education, those with lower incomes, and people of color.

Somatization disorder, Zipowski wrote, was the relatively rare "tiny tip of the somatization iceberg."[lxxx] And by the 1980s and 1990s, physicians in various specialties had begun carving up this iceberg in different ways, identifying specific functional somatic syndromes and arguing that they shouldn't be considered the unintelligible symptoms of somatizing patients but physical conditions whose underlying mechanism was simply not yet known. Diagnoses such as fibromyalgia, interstitial cystitis, irritable bowel syndrome, idiopathic low back pain, vulvodynia, and chronic fatigue syndrome

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have all awkwardly straddled the gray area "at the borderland between psychiatry and medicine," known in the former as somatoform disorders and in the latter as functional somatic syndromes.

These functional somatic syndromes are sometimes called contested diseases, a reflection of the disagreement over how they should be understood. Over the last 25 years, thanks to the efforts of individual clinician-researchers and patient advocates, there has been progress made in explaining these conditions. These days there is often a wide discrepancy between how they are viewed by experts who study them (namely, as poorly understood physical diseases) and how they are viewed by the rest of the profession (where they remain shrouded in an air of psychosomatic suspicion). They lack the legitimacy and acceptance afforded to diseases whose underlying pathology can be fully explained.

In a testament to medicine's tendency to attribute to the mind anything it can't explain in the body, the term functional initially did not imply a psychogenic cause, only the lack of a discernible organic one, but it has come to be used that way in practice. As Dr. David Edelberg, an expert in fibromyalgia, wrote in a 2012 article in the American Medical Association's (AMA) *Journal of Ethics*, "Functional" is "the contemporary term for what was 'psychosomatic' 50 years ago and 'hysterical' a century ago."[lxxxi] Or as Lipowski wrote, "The symptoms of somatizing patients have been called 'functional,' 'psychosomatic,' 'psychogenic,' and 'somatoform.' All these terms imply that however

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strongly such symptoms suggest physical illness, they belong to a different realm and are but an imitation of the ‘real’ thing.”

In recent years, the phrase “medically unexplained symptoms” (often abbreviated as MUS) has also been added to that list of terms. It is used to describe the functional somatic syndromes, but also used in medical literature to describe any individual symptom that a doctor has determined isn’t explained by an organic disease. While on its face a neutral description,[lxxxii] in practice, it is often used to imply a psychogenic origin.[lxxxiii] In an analysis[lxxxiv] of 75 articles on medically unexplained symptoms, Annemarie Jutel, author of *Putting a Name to It: Diagnosis in Contemporary Society*, found that half of them used the phrase interchangeably with psychiatric terms such as somatoform disorder and somatization. Less than a quarter of the articles critiqued that tendency. Again, as one article explains, “following a frequently challenged but nonetheless surprisingly resilient dualistic perspective…if no disease is found in the body, it is assumed that the disease is ‘all in the mind’ and that symptoms that are medically unexplained are considered, by default, to be ‘psychiatrically explained.’”[lxxxvi]

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Though the terms, somatoform, functional, and medically unexplained symptoms, are used by researchers and doctors among themselves, very often they aren’t used with patients. Physicians are in the unenviable position of trying to explain to patients why they are having symptoms that they believe to be, by definition, unexplained and ideally to do so without implying that the symptoms are “all in your head,” even though, by and large, that’s exactly how medicine thinks of them.[lxxxvii] In one 2009 study, doctors

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reported that they most commonly reassured patients with medically unexplained symptoms that “nothing’s wrong” in one of three ways: by explaining that diagnostic tests had come back negative, by using metaphors to explain why they might be feeling poorly, and by normalizing the patient’s symptoms, telling them that having symptoms is just a part of life.[lxxxix] Almost invariably patients do not find these explanations reassuring.[xc]

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Patient accounts suggest that physicians often attributed unexplained symptoms to depression or anxiety, causing no small amount of confusion for patients who were under the impression that to have a mood disorder one needed to actually feel depressed or anxious. And, perhaps above all else, patients had their medically unexplained symptoms attributed to stress. In an afterword to his influential 2007 book, *How Doctors Think*, Dr. Jerome Groopman, chief of experimental medicine at Beth Israel Deaconess Medical Center, wrote that, based on the many stories he’d heard from patients since its publication, “It seemed that ‘stress’ had become a catchall term to explain problems that were not readily unraveled.”[xcii] To be sure, depression, anxiety, and prolonged stress can cause specific physical symptoms, but these symptoms are not limitless nor are they actually unexplained. When doctors invoke these labels for symptoms as diverse as rashes to paralysis to severe, unending pain, it is the concept of the somatoform disorders (hysteria dressed up in modern garb) that allows them to do so.

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Meanwhile, when the fifth edition of the DSM was published in 2013, the somatoform category had been revamped significantly. Somatization disorder, hypochondriasis, pain disorder, and undifferentiated somatoform disorder had been replaced with a single disorder, somatic symptom disorder (SSD), which is characterized by one or more "symptoms that are either very distressing or result in significant disruption of functioning, as well as excessive and disproportionate thoughts, feelings and behaviors regarding those symptoms." Previously, the somatoform disorders had involved only symptoms that were medically unexplained, but in the new SSD, the symptoms may or may not be explained by a medical problem. Now the disorder hinges on whether the patient's concern about them is judged—by a doctor—to be excessive. Freud's old conversion disorder is still there, now with the subtitle "functional neurological symptom disorder."

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In a biting critique in the *British Medical Journal*, Dr. Allen Frances, chair of the DSM-IV task force, argued that without even a reminder to attempt to "rule out other explanations" before concluding that a psychological disorder is present, the new label would lead to a missed diagnosis of underlying medical causes, as well as risk "casually mislabeling the physically ill as also mentally disordered." A trial study suggested that 15 percent of cancer patients, 15 percent of patients with heart disease, 26 percent with irritable bowel syndrome, and 26 percent with fibromyalgia would qualify for a diagnosis of SSD, as would 7 percent of healthy people. Women were especially at risk for misdiagnosis. "Millions of people could be mislabeled, with the burden falling disproportionately on women," Frances wrote, "because they are more likely to be casually dismissed as 'catastrophizers' when presenting with physical symptoms."

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“A Disguise for Ignorance and a Fertile Source of Clinical Error”

For a long time, critics have pointed out that there’s a high risk of misdiagnosis inherent in the concept of psychogenic illness, regardless of the disease’s various names: hysteria, somatization, or medically unexplained symptoms due to stress.

In perhaps the most influential discussion of the problem, British psychiatrist Eliot Slater warned in a 1965 editorial that too often a label of hysteria just allowed doctors to believe they’d solved the mystery when, in fact, most of the time they hadn’t.[xcv] After following up with 85 patients who’d been diagnosed with hysteria at the National Hospital in London throughout the 1950s—including by Slater himself—he discovered that, nine years later, more than 60 percent had been found to have an organic neurological disease, including brain tumors and epilepsy; a dozen of them had died. “The diagnosis of ‘hysteria,’” he concluded, “is a disguise for ignorance and a fertile source of clinical error. It is, in fact, not only a delusion but also a snare.”

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It’s such a “snare” because there’s a stark imbalance in the burden of proof needed to make a psychogenic diagnosis versus an organic one. To attribute a symptom to a physical disease, objectively observable evidence of pathology is required, but to label it psychogenic, all a physician needs—indeed, since there’s no test for psychogenesis, the best a physician will ever have—is a strong suspicion. As medical journalist Laurie Endicott Thomas pointed out, this is a uniquely low bar. “The lack of an objective test for psychological disorders is something that hampers the whole field, but the somatoform

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disorders are the only mental health diagnosis that are based not on a description of symptoms but instead about speculation about their cause."[xcvii] And once symptoms are suspected of being psychogenic and the doctor starts looking for some stress that might be to blame, it's usually not hard to find it. As Slater wrote, "Unfortunately we have to recognise that trouble, discord, anxiety and frustration are so prevalent at all stages of life that their mere occurrence near to the time of onset of an illness does not mean very much."[xcix]

Worse still, a patient doesn't even have to show any signs of stress, depression, anxiety or other emotional symptoms to get a psychogenic diagnosis. According to theories of conversion and somatization, psychogenic symptoms are produced when the psychological distress causing them is repressed, pushed deep into the inaccessible unconscious, precisely in order to avoid consciously feeling psychological distress. Consequently, Lipowski explained, "A patient with somatization will often deny being depressed or anxious or will assert that any emotional distress he or she is experiencing results from physical suffering and disability. Neither such explicit denial nor the patient's casual interpretation needs to be accepted as necessarily correct, as either may be misleading."[c] Therefore, a psychogenic diagnosis most frequently involves a doctor telling a patient there is no physical ailment, even though their body feels sick and there is a mental disorder, even though they don't feel emotionally distressed.

In practice, then, a psychogenic diagnosis is what's known as a diagnosis of exclusion. As Jutel explained, "It is a diagnosis that is made not on the basis of what it is, but on the

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basis of what it is not. The absence of explanation, rather than the presence of a well-defined feature, is pathognomonic of the condition. The label becomes a wastebasket diagnosis to use after ruling out all possible organic explanations. But, of course, the doctor could prematurely decide the symptoms are medically unexplained and therefore miss the correct diagnosis for a great many reasons: it's a rare disease, a difficult-to-diagnose disease, the patient has an atypical presentation, a test was inaccurate or misread, or the doctor simply made a mistake (as human beings inevitably do) and didn't think of it. Therefore, it wasn't included in the differential diagnosis.

The danger here is compounded by the fact that a psychogenic diagnosis, while easy to make, is very difficult to overturn. All misdiagnoses are vulnerable to confirmation bias (the tendency to only see new evidence that's in line with your existing theory), but a psychogenic diagnosis is a particularly sticky one, because the only exonerating evidence that could show it to be false—proof of an organic pathology—is exactly what doctors have now stopped looking for. Once doctors have settled on the conclusion that "nothing's wrong," further investigation halts, so they're unlikely to find anything wrong.

Indeed, there's a circular logic built into psychogenic theories that ensures once a doctor has decided the symptoms are psychogenic, pretty much everything the patient does will just reinforce it. Once a patient is labeled an unreliable reporter, particularly by more than one doctor, it is all but impossible to get their credibility back. According to the medical literature on somatoform disorders, one "red flag" that suggests a patient may be suffering from such a disorder is repeatedly seeking medical care (described as "doctor shopping").

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despite assurances that they have no organic disease. This includes denying that their symptoms are psychogenic. In fact, according to one prominent British proponent of psychogenic explanations for functional somatic syndromes, “The vehemence with which many patients insist that their illness is medical rather than psychiatric has become one of the hallmarks of the conditions.”[ci]

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Unfortunately, there’s another patient group who tends to insist their symptoms are medical, and they doctor shop until they get a diagnosis: people suffering from yet-to-be-diagnosed physical diseases. The idea such behavior could be considered a "hallmark" sign that there is in fact no organic disease at all is deeply backward and logically dangerous. The concept of psychogenic illness leads to a system in which trying to get an explanation for persistent or worsening symptoms puts a patient at risk of acquiring a mental health diagnosis right up until the moment the correct diagnosis is made.[cii] Indeed, the actions that are often required to get that diagnosis in a fragmented and inefficient medical system may be seen as abnormal illness behaviors until, finally graced by the legitimacy afforded by a medical diagnosis, they retrospectively become the perfectly rational actions of a sick (and no doubt increasingly desperate) patient. As one patient with chronic fatigue syndrome put it, “The difference between a crazed neurotic and a seriously ill person is simply a test.”[ciii]

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There is remarkably little concern about the risk of missed diagnoses. “In medicine, resistance to the notion of error in somatoform diagnoses is so thoroughly pervasive that there exist no precautions of any kind, no protocols, and no forms of oversight to ensure that as few patients as possible are mistakenly diagnosed," wrote Diane O'Leary, a bioethicist and former director of the Coalition for Diagnostic Rights. [civ] The criteria for the somatoform disorders calls for "appropriate medical evaluation" before concluding the symptoms aren't explained by a medical condition. But in a medical landscape in which there are currently more than 10,000 known diseases, more than 5,000 diagnostic tests, and more than 120 medical specialties and subspecialties, it's entirely up to individual doctors to decide when the search for a medical explanation can be exhausted and the symptoms attributed to the patient's mind by default.

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Such confidence in the average doctor's diagnostic skills is impossible to square with the reality that serious medical conditions are missed all the time. Many millions of people in this county experienced long delays and saw multiple health care providers before getting correctly diagnosed: four years, on average, for patients with autoimmune diseases; seven years for patients with rare diseases; and as many as ten years for those with endometriosis. As we'll see time and time again in this book, surveys, as well as ample anecdotal evidence, suggest that at some point during the search for a diagnosis, female patients in particular find their symptoms attributed to any number of psychological causes: depression, stress, conversion disorder, and more.

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Even if they never got a psychogenic label, their symptoms were, by definition, medically unexplained until they were properly diagnosed. Yet many discussions of medically unexplained symptoms seem to take place in an alternate reality where diagnoses are always made accurately on the first try. Studies have estimated that up to one-third of

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patients in primary care, and up to two-thirds of those in specialty clinics, have symptoms that are medically unexplained.[cv] Approximately 70 percent of them are women. Since a patient has medically unexplained symptoms simply because the doctor didn't find an explanation, at least some of those patients have symptoms that haven't been explained yet—patients who will, in three or five or ten years (after some more doctor shopping), find someone who properly diagnoses them. But an acknowledgement of that fact is conspicuously absent from most articles on the prevalence of medically unexplained symptoms. The problem of medically unexplained symptoms is discussed as a frustrating one for the medical system, but rarely as a cause for reflection. If physicians are unable to come up with a diagnosis for such a large proportion of (mostly female) patients, perhaps they are not adequately equipped with what they need (the time, the diagnostic tools, or the medical knowledge) to do their jobs effectively.

I soon learned that this disconnect is reflective of a bigger problem. According to experts such as Dr. Mark Graber, founder and president of the Society to Improve Diagnosis in Medicine (SIDM), diagnostic errors—diagnoses that are wrong, needlessly delayed, or missed entirely—are a "large and silent problem" that has only begun to be acknowledged in the last decade or so.[cvii] In 2015, an IOM report concluded, "For decades, diagnostic errors—inaccurate or delayed diagnoses—have represented a blind spot in the delivery of quality health care. Diagnostic errors persist throughout all settings of care and continue to harm an unacceptable number of patients."[cviii] The SIDM estimates that 40,000 to 80,000 people die each year due to diagnostic errors in the United States. A 2014 study[cix] concluded that 12 million Americans who see their primary

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care doctor each year experience a diagnostic error.[cx] According to a conservative estimate published in the *British Medical Journal* in 2016, medical errors in general are the third leading cause of death in the United States after heart disease and cancer.[cxii]

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Experts in diagnostic errors had an answer to the puzzle that had been nagging me: how was it possible for missed diagnoses to be so widespread and yet not perceived by doctors as the major problem they clearly are? The problem is that physicians, while generally aware that mistakes happen, greatly underestimate how often they make them. In his talks with doctors on the topic, Graber often asked how many had made a diagnostic error in the past year; typically, only about one percent of the hands go up. "The concept that they, personally, could err at a significant rate is inconceivable to most physicians," he wrote.[cxiii] In short, they think it's the other guy. This overconfidence is not even necessarily their fault. Experts say doctors simply do not get the feedback needed to gain an accurate sense of their success rate. They assume their diagnoses are correct unless they hear otherwise. Since there are few, if any, healthcare organizations in the United States that systematically measure diagnostic error rates, they typically only learn of their mistakes from the patients themselves.

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And that's especially unlikely when it comes to patients whose symptoms were dismissed as being all in their heads. In the case of a patient incorrectly diagnosed with another disease, the patient may stick with their doctor long enough for the mistake to come to light. But if a doctor has concluded that it's "just stress," a patient with persistent symptoms will almost invariably move on to another doctor—if they don't give up

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entirely. Indeed, they have no other option. And the first mistaken doctor usually doesn't get a memo if, down the road, their symptoms finally become medically explained. Consequently, to him, she remains the somatizing stressed-out woman he concluded she was, and missing diagnoses remains a mistake only other doctors make.

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Heartsink Patients

In addition to the already long list of different euphemisms for hysterical, patients with medically unexplained symptoms have acquired some other revealing names over the years.

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"Patients with persistent somatization are not only well-known to physicians but also singularly disliked by them," Lipowski explained.[cxiv] "Their widespread unpopularity is reflected in the mostly derogatory labels they have acquired, such as 'crocks,' 'gomers," "turkeys,' 'hypochondriacs,' 'hysterics,' and 'the worried well.' These labels express the frustration of doctors faced with patients who claim to be physically ill, clamor for medical diagnoses and treatment, tend to be dissatisfied with any therapy they get, and are inclined to 'doctor shop.'" Women with medically unexplained symptoms also made up the majority of the patients that were deemed "heartsink patients"—patients who "exasperate, defeat, and overwhelm their doctors by their behaviour"—in an influential article that coined the term in the late 1980s.[cxvi]

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It's understandable that doctors would feel frustrated when they cannot explain a patient's symptoms. As Dr. Lisa Sanders, who pens the "Diagnosis" column for *The New York Times Magazine*, wrote in her book *Every Patient Tells a Story: Medical Mysteries and the Art of Diagnosis*, "Nobody likes not knowing, but doctors, perhaps, find this state of being even more intolerable because it utterly thwarts their ability to alleviate suffering, which is often the fundamental motivation for their entire career. But a doctor's discomfort in the fact of the unexplained can lead them astray. Rather than accepting a patient's symptoms as real, but unexplained, physicians all too often either dismiss the symptoms as unreal ("all in your head") or, alternatively, read too much into scanty evidence in an effort to banish uncertainty with a crisp diagnosis."[cxviii]

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In fact, as the derisive labels suggest, many physicians not only dismiss the symptoms as unreal but also despise the patient who has them—projecting the frustration they feel onto the patient. As one article on medically unexplained symptoms noted, doctors tend to adopt strategies "deflecting the threat to medical competence posed by medically unexplained symptoms" by "shifting the blame from the limits of medicine to some characteristic of the patient."[cxx]

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There's another reason for this attitude. In theory, medicine considers somatoform symptoms to be unconsciously produced and no less "real" to the sufferer than organic ones. But in practice, those with unexplained symptoms are often treated as though they're willfully staying sick. This is probably because Freud's theory of hysteria introduced the notion of secondary gain, which has been part of theories of conversion

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and somatization ever since. The primary gain patients became ill from unconsciously converting their psychological conflict into physical symptoms to avoid consciously feeling mental distress. But the symptoms were thought to be perpetuated by the secondary gains they received from being ill. Lipowski explained: “The communication of somatic complaints may also represent an attempt by the patient to attain certain personal objectives, such as release from social obligations or an excuse for failure to meet them, resolution of an inner or an interpersonal conflict, securing of support from others, or financial benefit. Any one or any combination of these factors may foster illness behavior and adoption of a sick role.”

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This theory has, at times, led to punitive therapeutic strategies that seem to borrow directly from Weir Mitchell’s nineteenth-century rest cure of hysteria. In a 1978 article on the “often thankless challenge of the hysteric patient,” an American physician described his approach to “managing” patients with Briquet syndrome who made up six percent of the adult women in his practice.[cxxii] Since “symptomatic behavior persists only as long as it continues to be reinforced,” he explained, “withdrawal of the reinforcement must be accomplished to extinguish the symptom.” The patient should not be referred to other doctors to avoid “the secondary gain—attention—the patient experiences each time she retells her story.” Her family should be advised to ignore her symptoms, rather than “cater to her wishes.” In a hospital setting, she could be isolated in a locked room and “given privileges contingent upon symptom reduction.”

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Chloë Atkins’s experience is a chilling illustration of just how far this thinking will sometimes be taken. As a young woman she began experiencing episodes of paralysis that, over the course of a decade, worsened until she was eventually quadriplegic. She frequently had to be hooked up to life support because she was unable to breath on her own. With inconclusive test results, her doctors had decided early on that she was suffering from conversion disorder, a diagnosis they clung to even after evidence began to suggest that she might have an atypical form of the autoimmune neuromuscular disease myasthenia gravis. And even as her mystery disease threatened to actually kill her, she was treated as if she was to blame. “Clinicians behaved as though I wanted to be ill and that I conspired to confuse and frustrate them,” she wrote in her book *My Imaginary Illness: A Journey into Uncertainty and Prejudice in Medical Diagnosis*. “I was treated as though I were a criminal or a juvenile delinquent. Instead of my illness being the problem, I became the problem.”

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The notion of secondary gain inevitably results in some conflation between psychogenic symptoms and those that are simply fabricated. According to the DSM criteria for the somatoform disorders, they must be differentiated from two other diagnoses: factitious disorder and malingering. While a patient with a somatoform disorder is thought to unconsciously produce symptoms, the factitious disorder patient consciously fakes symptoms in order to achieve some internal benefit (e.g., a sense of victimhood). And the malingerer consciously fakes symptoms for an external benefit (e.g., disability compensation, painkillers). Since doctors cannot read patients’ minds (conscious or

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unconscious) it’s not surprising that anyone with medically unexplained symptoms is liable to be viewed with suspicion. Indeed, a 1998 article acknowledging this problem lumped all three together: “Somatizing disorders comprise the variety of phenomena known as somatoform disorders, factitious disorders, and malingering. Indeed, the boundaries between these categories are not as set in practice as the different terms initially suggest.”[cxxiv]

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“Women’s Illness Are Presumed Psychosomatic Until Proven Otherwise.”

In 1999, feminist disability scholar Susan Wendell, reviewing the epidemiological research on somatoform disorders, wrote, “It seems a remarkable coincidence that men of higher socioeconomic backgrounds from the developed Western countries are, in all the world, the people least likely to ‘somatize,’ given that they also happen to be the people who are accorded the most believability and authority in Western scientific settings.”[cxxvi] The fact that women and other socially disadvantaged groups have more medically unexplained symptoms, she suggested, just might have something to do with the fact that “medicine is less interested in explaining their symptoms (both less interested in investigating individuals’ symptoms in the clinical setting and less interested in studying their bodies and diseases in scientific research), because their complaints are assumed to be less believable as evidence of physical illness, and because their authority to describe anything, including their own bodies, is less than that of privileged men.”[cxxvii]

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Indeed, to many of the doctors and advocates who were calling for greater attention to women's health in the 1990s, the fact that so many women were finding their symptoms brushed off as "all in your head" was a clear sign that there was a knowledge gap that needed to be closed. As a young ob-gyn in the late 1980s, Werbinski realized that while she felt pretty well-equipped to deal with her patients' reproductive problems, she was encountering other areas of health for which she didn't have any answers. According to her patients, other doctors were offering an answer though. "Whenever medicine gets into a brick wall that it can't explain, it says, 'Well, it has to have a psychological component.' So a lot of my patients were telling me, 'My doctor told me that this symptom is all in my head.' And the doctor may or may not have said that directly, but the training was telling us that the things we couldn't explain—just put them into that wastebasket. And then we would clap our hands and say, 'OK, I'm done with that; that's not my problem. That's a psych problem, so go see a psychiatrist.'"

But the fact that women have more medically unexplained symptoms, which are labeled psychogenic by default, is not simply a clear reflection of the knowledge gap. The fact that women so readily have their unexplained symptoms attributed to the mind is also a key reason the knowledge gap persists. As Angela Kennedy wrote in her book *Authors of Our Own Misfortune? The Problems with Psychogenic Explanations for Physical Illnesses*, the concept of psychogenic illness has served as a so-called god of the gaps theory. It slips in "wherever there is a vacuum of medical and/or scientific knowledge about somatic conditions."[cxxix] But in continually filling in these gaps, it relieves any need to fill them with actual scientific knowledge.

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As Kennedy pointed out, there’s a dangerous paradox about psychogenic theories of medically unexplained symptoms: by providing an explanation for them—but one that can’t be scientifically proved or disproved—the theories thereby discourage further investigation into them. This is as self-fulfilling on the collective level as it is on the individual one, but perhaps more so. An individual woman can at least go to another doctor if the first, deciding her symptoms are psychogenic, stops looking for another explanation. But if it’s been decided that a condition is sufficiently explained by the long-standing medical “fact” that women are prone to somatizing their distress, there is no reason to do the scientific research needed to provide a medical explanation. There is, in fact, not much reason to study it at all.

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In other words, if the same biomedical community that’s decided (as that medical student in the 1970s put it) that “women’s illnesses are psychosomatic until proven otherwise” is, in fact, in charge of doing the research that would prove otherwise, the proof simply never comes or at least takes decades to accumulate. As Werbinski summed it up, “OK, I’m done with that; that’s not my problem.”

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For decades, functional somatic syndromes have been caught in this maddening trap. The assumption that these conditions were psychogenic (just modern labels for women’s age-old hysterical tendencies; as one article put it, “old wine in new bottles”[cxxx]) meant there wasn’t much interest in studying them within the biomedical community. But only scientific research to uncover their precise biological mechanisms could rescue them

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from the wastebasket of the medically unexplained. As one researcher on multiple chemical sensitivity lamented, “We are in a catch-22 situation. It is difficult to attract research money for a controversial condition and it is difficult to resolve the controversy without the necessary research.” In the meantime, skeptical doctors would point to the absence of consistent biological abnormalities in these conditions as proof that there was “nothing wrong” with the patients, but finding such abnormalities would have required research to look for them.

Meanwhile, a good deal of what little research has been done on functional somatic syndromes has been looking in the opposite direction: trying to confirm their psychological roots. On the whole, the marshaled evidence to attribute a psychogenic cause to such conditions is as speculative in the aggregate as it is on the individual level. Countless studies have been done showing that patients with functional somatic syndromes have higher rates of depression and anxiety than healthy people. But this is true of patients with explained chronic diseases too. Such studies rarely include a control group of patients that are similarly debilitated by an organic disease. They also rarely pay more than passing lip service to the possibility that being ill, particularly with a poorly understood and therefore poorly treated condition, could be the cause, not the consequence, of mental distress. In other words, the tendency to simply reverse the causal arrow, the same “cloudy thinking” the Lennanes warned of decades ago, has remained a common problem. Research also points to higher rates of childhood sexual abuse or other early-life stresses in patients with functional somatic syndromes to imply a psychogenic cause. But, again, such findings are common in a range of diseases.

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Indeed, one reason the evidence that has been used to back up psychogenic theories looks so weak is that there is an ever-growing body of research showing how mental and physical health is utterly intertwined. We know that chronic stress (living in poverty, experiencing discrimination, etc.) is linked to a higher risk of conditions as diverse as heart disease and viral infections. We know that sexual abuse and other kinds of adverse childhood experiences increase the odds of poorer health (autoimmune diseases, type 2 diabetes, depression, etc.) later in life. These connections aren't due to some near-magical abstract process like conversion or the victim-blaming theory of secondary gain, but to the physiological effects of elevated stress hormones on a great many bodily systems.

But medicine has had a tendency to highlight these mind-body links the most when it comes to unexplained syndromes that affect mainly women, and, further, assign them a casual status that simply can't be backed up. In a 2016 article, for example, two researchers from New Zealand's Victoria University of Wellington reviewed the evidence in favor of psychogenic explanations of two functional neurological syndromes: so-called psychogenic movement disorders and psychogenic non-epileptic seizures, which are both about three times more common in women.[cxxxii] Noting that "we see no reason why a lower standard of evidence should apply to a psychological [explanation] than to a medical explanation," they decided to evaluate the evidence just as rigorously "as one would demand for any other causal explanation" and concluded it wasn't sufficient. They suggested the medical community accepted psychogenic theories of these disorders by "default" and "may need to retire those overworked psychological explanations that are

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commonly invoked in the face of uncertainty and instead adopt a completely fresh perspective.”

“One of the great puzzles of the psychogenic literature,” wrote Dr. Martin Pall, a researcher on medically unexplained conditions, “is how do so many bad papers get published?”[cxxxiv] He called the publication of such research with poor scientific standards “by far the largest failure of the peer-review system that I am aware of,” and he noted, “I cannot help wondering whether it is based on the fact that most victims of these illnesses are women. There is a long history of sex discrimination in medicine, and while I would like to think we are more enlightened in the twenty-first century, this pattern suggests that perhaps we are not.”

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Another puzzle is how medicine has managed to retain a belief that everything it currently can’t explain is psychogenic, even as the list of diseases that were formerly attributed to psychological causes keeps growing. As Jutel wrote, “It is not unusual for physical diseases to be incorrectly attributed to psychiatric disorder either early in the disease history of an individual or in the history of the disease itself.”[cxxxvi] At this point, the pattern has repeated itself again and again: a step forward in medical knowledge and—*poof!*—yesterday’s mysterious, psychogenic-by-default conditions became explained. Nearly all the diseases mentioned in this book were at one point attributed to women’s neurosis, repressed anger, or hidden traumas. The dynamic that’s all too familiar to individual women—of symptoms dismissed as “all in your head” until

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Yet despite this record, each generation of medical practitioners has been remarkably confident in the theories and technologies of the current era, treating what is currently medically unexplained as if it is, in fact, unexplainable—even to a doctor in the future with greater knowledge and more precise technologies. As Jutel wrote, assigning a psychogenic cause to "medically unexplained symptoms" presumes not only "the infallibility of doctors" but also "the omniscience of medicine." In her analysis of articles on medically unexplained symptoms,[cxxxvii] she also found that even when the phrase wasn't conflated with psychogenic labels, it was nearly always discussed "as a unified condition that could be considered under one light," implying that "all physical complaints without explanation" (lower back pain, irritable bowl syndrome, fibromyalgia, so-called psychogenic seizures, etc.) "can be viewed in the same way."[cxxxix] In short, medicine resorts to "creating a catchall diagnostic category in which it can place the unexplained."

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Sound familiar? Hysteria, in its many modern day cloaks, remains, as French physician Charles Lesegue wrote in the mid-1800s, "the wastepaper basket of medicine where one throws otherwise unemployed symptoms."[cxl] Or, as Weir Mitchell put it, "hysteria is the nosological limbo of all unnamed female maladies."

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It's long past time for medicine to abandon this concept. The only reason it exists to begin with is that at the end of the nineteenth century, the same year the x-ray was invented, a German nerve doctor suggested that hysteria (a label that undoubtedly covered hundreds of yet-to-be-recognized diseases affecting mostly women) could be attributed, through some mysterious, occult process, to "the unconscious mind." This concept was passed down, grandfathered into each successive generation of medicine, even as more and more conditions previously believed to be hysterical were removed from the category as medical knowledge grew. As Atkins put it, the idea of psychogenic illness appears to be "a cultural artifact masquerading as a medical truth." And it's a cultural artifact that continues to powerfully shape women's experiences with the medical system.

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Women Dismissed: A Self-Fulfilling Prophecy

By the 1990s, most doctors were surely no longer determining whether symptoms were organic or psychogenic by considering whether the patient "accepts herself as a woman." But studies showed that women continued to be especially likely to have their symptoms psychologized. The AMA's Task Force on Gender Disparities in Clinical Decision-Making, reviewing a national sample of patients, found that men were 8.6 times more likely to receive catheterization for heart disease, 30 percent more likely to receive a kidney transplant, and 60 percent more likely to receive a test for lung cancer than women with similar symptoms. The task force concluded that the most common reason for the disparities was

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that women’s symptoms were more likely to be attributed to “overanxiousness” than organic pathology.[cxli]

Patient surveys also found this type of dismissal was a pervasive feature of women’s relationships with their doctors. According to a national poll by the Commonwealth Fund, 17 percent of women, versus 7 percent of men, had been told their symptoms were all “in their head.” More than 40 percent of women had changed doctors due to difficulties in communication, compared to 27 percent of men.[cxlii] A survey commissioned by the National Patient Safety Foundation found that 42 percent of the respondents said that they or someone close to them had experienced a medical mistake, and 17 percent of the women, compared to 8 percent of the men, said that the mistake could have been prevented if the health care professionals had simply listened more.[cxliv]

There’s no indication this pattern has improved today. Women remain especially at risk of this type of misdiagnosis in large part simply because they’re known to have more “medically unexplained symptoms.” That’s the problem with a diagnosis of exclusion; all a doctor has to do to land on it is stop searching for another explanation, a call that’s inevitably influenced by how likely they think it is they’ll find one. In a self-fulfilling prophecy, then, those patients who are profiled as being prone to having medically unexplained, psychogenic by default, symptoms will be most likely to be judged to have them.

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Women do have higher rates of functional somatic syndromes, which affect many millions of people in the United States. They make up the majority of the six million with fibromyalgia, with its widespread pain and fatigue, and the one to four million with so-called chronic fatigue syndrome. They're five times as likely to have interstitial cystitis, now sometimes more aptly called painful bladder syndrome, and at least twice as likely to experience the abdominal pain of irritable bowel syndrome and the jaw pain of temporomandibular disorders. The list goes on. Much of the rest of this book will explore how these conditions, and those who suffer from them, have been neglected by the biomedical community.

And their neglect creates ripple effects that impact all female patients. The reality that women are more likely to have these functional diagnoses for which no objective tests exist yet (and which too many doctors continue to view as psychogenic) means women are also more likely to get misdiagnosed with them or to get even looser labels such as depression, anxiety, or stress for their unexplained symptoms. For example, a woman with an autoimmune disease gets initially misdiagnosed with fibromyalgia; one with ovarian cancer gets misdiagnosed with irritable bowl syndrome. Yet, ironically, women who *actually* have functional somatic syndromes face delays in getting properly diagnosed too, often encountering physicians who prefer to say "nothing's wrong" or to offer mental health labels, concerned a more specific label will just "reinforce" a somatizing patient's mistaken belief that they have an organic disease.

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The danger that women will be profiled as having medically unexplained symptoms is heightened by the fact that doctors believe it is possible and preferable to identify such patients quickly. Incredibly, the medical literature on somatoform disorders contains more discussion on the risks of doing a thorough investigation into medical causes than of not. As one article explained, “Out of a fear of overlooking a serious disease, many physicians give their patients full physical examinations and interventions, thereby incorrectly confirming the somatic nature of their condition.”[cxlvi] The American Association of Family Physicians, for example, advises doctors to consider the possibility of a somatoform disorder “early in the evaluation process” in order to limit “unnecessary diagnostic and medical treatments.”[cxlviii] To be sure, there are real risks to over-testing that should be minimized in any patient, but the idea that doctors could determine if symptoms are medically unexplained before attempting to explain them would seem to be a contradiction in terms.

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And yet, many do apparently believe that they can somehow intuit—rapidly—whether a patient’s symptoms will turn out to be medically unexplained. In a 2016 Dutch study, family physicians reported that they suspected patients’ symptoms were medically unexplained symptoms if they had many symptoms and had lots of previous doctor’s visits and referrals. (Again, the red flag of doctor shopping means the longer a patient has been searching for a diagnosis, the harder it becomes to get one.) They also considered the subtle feelings the patients provoked in them to be a clue. One of those feelings was confusion. As one doctor explained, “I believe I know what is going on within 30 [seconds], like many of us. When I think within 2 [minutes] ‘I do not have a clue of

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what is going on here', then I start to think 'This can be [medically unexplained symptoms].'' The other feeling was irritation at the patient. "Most FPs," the study explained, "stated that when they did not feel empathy for their patients, they were more often inclined to recognize symptoms as [medically unexplained symptoms]." A 2000 British study, one of the few to explore the possibility of misdiagnosis of medically unexplained symptoms, found a similar pattern: of the cases that the doctors had provisionally diagnosed as unexplained, 17 percent were later found to be explained, and the single biggest factor that increased the likelihood of misdiagnosis was if the physician felt the interaction with the patient had been negative.[cli]

If doctors are going with their gut instincts about whether patients' symptoms are psychogenic, it is no wonder that women, who've been considered the "typical patient" with psychogenic symptoms for a century, so often find themselves dismissed. In a 1986 study, researchers looked at a group of patients who'd been diagnosed with hysteria or a functional disorder and were subsequently found to have a serious organic neurological disorder.[cliii] Concluding that a "diagnosis of hysteria is usually wrong," they identified the characteristics that seemed to make patients especially vulnerable to a hysteria misdiagnosis: being a woman, having a prior diagnosis of a psychiatric disorder, offering a plausible psychological explanation for the problem, and embellishing their symptoms, which, the researchers suggested, stemmed from patients' fear that their doctors would not believe them.

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With two strikes against them, women who have previously been diagnosed with mental health problems have an especially hard time getting physicians to take their physical symptoms seriously. Indeed, women's higher rates of common mental health conditions is, in and of itself, likely one reason that women are more vulnerable than men to psychogenic misdiagnoses. Women are twice as likely than men to have a diagnosis of depression or anxiety disorder. In the United States, 1 in 4 women is prescribed a psychotropic medication, compared to 1 in 7 men.

But this gender disparity may be as much a reflection of the tendency to dismiss women's symptoms as "all in their heads" as it is a reason for it. While women may indeed have a higher risk of depression and anxiety disorders, for cultural or biological reasons or some combination, many have argued that the difference in prevalence rates is at least partly the result of overdiagnosis in women and underdiagnosis in men. One sign that men don't get the mental health care they need is they have four times the rate of suicide as women. Studies in the 1990s suggested that up to 30 to 50 percent of women diagnosed with depression were misdiagnosed.[clv]

Since depression and anxiety are stereotyped as "women's diseases," doctors may be more likely to attribute the physical symptoms that can accompany these conditions (heart palpitations, shortness of breath, fatigue, insomnia, etc.) to them rather than considering the many physical conditions that can cause such symptoms. Furthermore, depression and anxiety are themselves symptoms of other diseases. In their 1997 book, *Preventing Misdiagnosis in Women: A Guide to Physical Disorders that Have Psychiatric*

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Symptoms, Elizabeth Klonoff and Hope Landrine reviewed dozens of conditions (including endocrine, neurological, and autoimmune disorders) that are more common among women whose primary symptoms are psychological.[clvii] They warned their fellow mental health professionals that the "the misdiagnosis of these physical disorders as psychiatric in part accounts for women's higher rate of depression, anxiety, and somatization disorders." And just to really complete this self-fulfilling circle—the stress of suffering from an undiagnosed, and therefore untreated, disease often takes its mental toll. As one article pointed out, "Ironically, medical misdiagnoses of physical conditions may induce depressive reactions in female patients."[clix]

Whether women truly do have a primary psychological disorder or have been misdiagnosed with one, once listed in their chart, it heightens the risk that any other physical symptoms they have in the future may be automatically dismissed as psychogenic. Dr. Pat Croskerry, director of the Critical Thinking Program at Dalhousie University and a leading expert on diagnostic errors, has dubbed this particular type of mistake a "psych-out error," in which medical conditions may be "overlooked or minimized" in patients with psychiatric diagnoses.[clxi]

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Lindsey had been familiar with the psych-out error for years. She'd been taking antidepressants off and on since she was a teenager, when her primary care doctor prescribed them after she teared up about a recent breakup while at a check-up for

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something else. At different points over the next several years, she'd seen doctors about various symptoms including, dizziness, fatigue, and a bizarre vision problem. "But the second my antidepressants came up, it was always brushed off as 'stress,'" she said. She tried to insist that, "I know what stress feels like and I'm being treated for that, which is why I know that this is not stress." But the doctors generally just recommended therapy and getting her medications adjusted. "I walk into one of those rooms, and I know that doctors think, 'All right, here we go; she's fine and we just have to tell her she's fine."

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Finally, a few years ago, she saw a doctor who listened to her complaints of exhaustion and unexplained weight gain and said, "Let's figure it out." "She tested really aggressively, which no one had really done before." It turned out she had thyroid cancer. As Lindsey acknowledged, it's not clear that the earlier symptoms were due to the cancer. They may indeed have been related to stress, or they may have simply been "unexplained." Regardless, there's no excuse for a history of mental health problems to be a reason to immediately discount new symptoms. People with depression get cancer too. (People with mood disorders tend to have higher rates of many diseases.) "I'm troubled by the fact that a cancer diagnosis almost felt like good news because it validated the more mysterious symptoms and made me feel less 'crazy,'" Lindsay said.

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And it's not just patients with clear-cut mental health diagnoses, such as depression, that may be vulnerable to the psych-out error. Since, to many physicians, medically unexplained symptoms continue to be seen as psychogenic by default, patients with functional somatic syndromes may find their reports distrusted as doctors assume new,

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unrelated symptoms must be unexplained as well. In *How Doctors Think*, Groopman told of a young woman, Maxine, with irritable bowel syndrome, who nearly died of a ruptured ectopic pregnancy after three doctors missed it. They assumed it was a flare up of her irritable bowel syndrome, even as she insisted the pelvic pain she was suddenly experiencing was different from her usual IBS symptoms. The self-fulfilling circle never ends.

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The Girl Who Cried Pain

The psych-out error may have played a role in Maggie’s experience too, though she didn’t realize it at the time. Her mother had managed to convince the nurse that Maggie, who didn’t have a history of anxiety, wasn’t having a panic attack. But she found out later that the campus clinic’s notes on her case may have biased the ER doctors’ thinking. Maggie had fainted once during her freshman year, and the doctor she saw at the campus clinic afterward said she thought Maggie had an eating disorder. Maggie didn’t and denied it. For the next three years, she’d been healthy and hadn’t been back to the campus clinic. But she later saw in her medical chart the intake instructions the campus clinic had sent along with her to the ER included a note from the campus doctor saying she still suspected Maggie had an eating disorder and that the cause of her pain may be “trying not to eat.” “I think that colored some of the views that the doctors had toward me in the beginning,” she said.

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Certainly, her pain wasn’t taken very seriously once a chest x-ray, blood tests, and a CT scan came back normal. The ER doctor was ready to discharge her. First, though, she wanted to see if Maggie could eat something without pain. She couldn’t; the pain came back worse than ever. The doctor admitted her for observation overnight, but said she doubted further testing would reveal anything really wrong. In the morning, once again, Maggie was given graham crackers and saltines, and “once again, the pain returned with such intensity that I could not stand up or move.” But a nurse reported the doctor had already discharged her without waiting for the results of the cracker test. As the pain worsened, Maggie begged the nurse to call a doctor. “She refused, said that my tests were normal, that I should stop being dramatic and told me, ‘You were not in pain until you were told you were being discharged.’”

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Figuring they had no choice, she and her mom, who’d gotten on a plane to join her in the hospital by this point, left. Once discharged, Maggie spent the next 14 hours in so much pain she couldn’t speak, stand up, or eat. “According to my mother, at times I was silently rocking back and forth, totally withdrawn—as if in a trance. I only remember being certain I was going to die soon and what a shame that would be, but I didn’t have the energy to explain or fight or even be afraid.”

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In an influential 2001 article□ entitled “The Girl Who Cried Pain: A Bias Against Women in the Treatment of Pain,” Diane E. Hoffmann and Anita J. Tarzian reviewed a number of

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studies that had accumulated showing gender disparities in the treatment of pain.[clxiii] The gap could be seen in a wide range of clinical contexts. In the hospital setting, one study showed that women received less pain medication than men after abdominal surgery.□[clxiv] Another found that after a coronary artery bypass graft, men were more likely to receive narcotics, while their female counterparts were more likely to get sedatives.☐[clxv] (Open-heart surgery apparently leaves men hurting and women just a bit wound up.) Their review indicated the difference started early: in a study of postoperative pain in children, more codeine was given to boys than girls, and the girls were more likely to be given acetaminophen.[clxvi] And it persisted when it came to more long-term pain management too. Studies of metastatic cancer[clxvii]☐ and AIDS□ patients found that women were overrepresented in the disturbingly large proportion of patients (42 and 85 percent, respectively) who were undertreated, according to guidelines, for their pain.[clxix] Surveys of patients at specialty pain clinics revealed the women tended to get more minor tranquilizers, antidepressants, and non-opioid analgesics, while the men got more of the stronger opioids.

As Hoffmann and Tarzian pointed out, this differential treatment could be justified if, on average, women reported less pain than men but, in fact, the opposite was true. In the late 1980s and early 1990s, pain researchers, spurred by the calls for greater attention to sex/gender differences in all areas of biomedical research, had begun exploring differences in pain perception between men and women.[clxx] The research suggested that women tend to be more sensitive to pain and/or more likely to report it. Given that, they

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wrote, “it seems appropriate that they be treated at least as thoroughly as men and that their reports of pain be taken seriously.” At the very least, they shouldn’t get less treatment. “The data do not indicate that this is the case. Women who seek help are less likely than men to be taken seriously when they report pain and are less likely to have their pain adequately treated.”

They considered various potential reasons for this bias, ultimately concluding that the main one seemed to be that women’s complaints of pain are less likely to be trusted. “The subjective nature of pain requires health care providers to view the patient as a credible reporter,” they wrote. “Women are more likely to have their pain reports discounted as ‘emotional’ or ‘psychogenic’ and, therefore, ‘not real’”—“at least until there is objective evidence for the pain's cause. Medicine's focus on objective factors and its cultural stereotypes of women combine insidiously, leaving women at greater risk for inadequate pain relief and continued suffering.”

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In the years since, the research on gender disparities in pain treatment has been somewhat more mixed. Some studies have found women are undertreated; some have not. One reason for the inconsistency may be that while pain is always subjective, a willingness to trust the patient’s report is more important in some clinical contexts than others. As Hoffmann and Tarzian pointed out, women are at greatest risk of having their pain reports discounted before the pain’s source is discovered. And research continues to suggest that, like Maggie, many women find their pain isn’t taken seriously when they first enter the ER. A 2008 study of nearly 1,000 people who arrived in a Philadelphia emergency room

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with acute abdominal pain found that while men and women had similar pain scores, the women waited longer to get pain medication: 65 minutes, on average, compared with 49 minutes for men. They were also significantly less likely to get any kind of pain medication and were 13 to 23 percent less likely than men to get opioids. (And, as we'll see in Chapter 5, when it comes to chronic pain, which is often unexplained or at least poorly correlated with objective abnormalities, women also face barriers to getting adequate treatment.)

One interesting thing about this bias is the way women's reports of pain are received seems to be greatly and confusedly influenced by cultural stereotypes about men. The stoicism expected of men is cited as one the reasons they are taken seriously when they enter the medical system; their reports of pain are less likely to be doubted because it's assumed they're more reluctant to make them in the first place. But there's no rational reason that men's assumed stoicism should result in women's pain not being taken seriously. As Hoffman and Tarzian pointed out, if men are indeed more reluctant than women to admit they're in pain, "this reluctance on the part of men does not lead to the conclusion that women, as not reluctant, must therefore be less in need of adequate treatment." If women, spared from the cultural pressure put on men to tough it out, are more free to express their pain, their reports would seem to be not overreported but simply more accurate. Instead, women tend to be treated like they're the unreliable reporters.

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In fact, it’s not even clear that men actually are more reluctant to seek medical care than women. Public health researcher Kate Hunt and her team pointed out that an assumption that men are reluctant to seek medical care has become “deeply entrenched” in both medicine and the public at large.[clxxiii] And it tends to come with a corollary assumption that women are not reluctant, which “may result in health care providers assuming that women have a lower level of symptom severity” when they enter the medical system. But these contrasting stereotypes, so thoroughly unquestioned that they’ve been accepted as commonsense knowledge, aren’t actually that well supported.

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While there is certainly plenty of research based on interviews with men that show they commonly say they’re reluctant to see a doctor, and that damaging masculinity norms that discourage admitting vulnerability and asking for help often play a role in that, few studies directly compares men’s and women’s thinking on the matter. In other words, men may indeed be reluctant, but women may be just as reluctant—for different reasons. As we’ll see, one of the common reasons women give for delaying getting medical care is a fear of being seen as a hypochondriac. It seems that these contrasting stereotypes may drive us all to a similar spot: in attempting to adhere to the stoic male stereotype, men may hesitate to get the care they need; in attempting to avoid playing into the hypochondriacal female stereotype, women may do the same.

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Indeed, when it comes to studies that look at what patients experiencing similar symptoms actually do, women are not, as a general rule, any quicker to seek help. Overall, women do consult their primary care doctors more frequently than men do during most of their adulthood, which is part of the reason for the stereotype, but this seems to be largely because they have more of a need to. There is relatively little research that has explored whether men and women with the same condition or the same similarly debilitating symptom differ in whether and how quickly they seek medical care, and it has yielded mixed results: studies found that for some conditions, gender isn't a factor; for others, men delay longer; and for others, women do. (For example, as we'll see in the next chapter, women tend to wait longer than men to get help when they're having a heart attack.) As Hunt and her colleagues concluded in a 2011 review of studies on help-seeking for two common symptoms, headache and back pain, the evidence that women sought medical attention more readily than men was, given the strength of the stereotype, "surprisingly weak and inconsistent." [clxxv]

But, again, even if women were, on average, more willing to seek medical attention than men, it wouldn't justify not taking their symptoms seriously when they do. Indeed, what's fascinating is that men's assumed greater reluctance to seek help is seen as a *problem*—their "underuse" of medical care portrayed as a barrier to improving men's health. Consciously, then, there's a recognition that men should be less reluctant—should, it is implied, be more like women. Yet, Hunt and her colleagues pointed out, it seems to lead, unconsciously, to a contrasting assumption that women seek care not only more readily but too readily, "sometimes for trivial symptoms which are self-limiting or amenable to self-management."[clxxvi] These stereotypes operate, illogically, as if they're necessarily on a seesaw—if men are stoic, women must be overly emotional; if men

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underreport their pain, women must exaggerate theirs; if men are reluctant to seek help, women must be too quick to; if men underuse medical care, women overuse it.

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A Double Bind: You're Either Hysterical or Nothing's Wrong

It is always tempting to imagine that women can avoid sexism by acting more like men. In this case, it's easy to think that perhaps women would be taken more seriously if they were just a little more stoic; if they bit their lip and held back their tears; if their voice betrayed no hint of emotion that could be used against them. In short, if they weren't so hysterical in the colloquial sense of the word, then maybe they wouldn't be treated like they were hysterical in the medical sense of the word.

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That's certainly how Maggie felt. "Being told to 'calm down' is just the most infuriating thing when something is actually really wrong," she said. But she nevertheless attempted to do so. "I tried really, really hard with all the doctors to act very serious and even-toned and to temper my voice, but as soon as the pain would start, it was hard to maintain that." She even felt like her mom's display of emotion would be held against her. At one point, "she was getting so worked up and starting to cry. I remember thinking that I needed to be even more serious because now they weren't going to take me seriously because she was freaking out."

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But gender stereotypes have a tendency to put women in double binds, and this one is no exception. Since women are expected to have an overly emotional response to pain, they are at risk of having their reports not taken seriously whether they adhere to the stereotype or break with it. Dr. Vicki Ratner brought a unique dual perspective to the problem as an orthopedic surgeon and an advocate for patients with interstitial cystitis (more on that in Chapter 5). She's blunt about the dilemma female patients face, "It's very difficult for a woman to present in a doctor's office. Because if she's very stoic—if she talks about the problem in the tone that I'm talking to you—then the doctor's going to think, 'Oh, there's nothing really wrong with her.' And then if she gets very emotional, he's going to blame it on, 'Oh, she's a psychological mess blah blah blah.' You get judged right away because you're female: you're either stoic and nothing's wrong or you're crying and you get labeled hysterical."

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Conversely, the expectation that men keep a stiff upper lip when they're in pain serves to ensure that they're likely to be taken seriously no matter what: if they're stoic, they're just being a typical "macho" guy; and if they're emotional, well, then it must be really, really bad. However, just how much leeway men have to break with the stoic male stereotype and still be taken seriously may depend on how closely they adhere to masculine norms in other ways. In a 2014 study that found female heart attack patients weren't tested and treated as quickly as their male counterparts in the emergency room, the researchers also gave the patients a personality test gauging how closely they conformed to gender stereotypes. They found that both men and women with more traditionally "feminine" traits experienced a greater delay than patients with more "masculine" traits.

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Take Lauron’s experience. At first, the 26-year-old figured it was food poisoning—those fried clam strips at Red Robin perhaps?— but after a few days of terrible abdominal pain, no appetite, and a slight fever, she knew she should get checked out. Having just aged out of her parents’ health insurance into her own not-that-great plan, she found the one urgent care center that was in-network. The doctor she saw said there was a stomach virus going around and that was almost definitely what she had. She told him the pain was excruciating and asked if she could get something to alleviate it. But he said no, explaining that, if it turned out it actually was appendicitis, the pain would get much worse and she would need to notice that and seek treatment right away. In retrospect, it was a little concerning that he hadn’t done much of a physical exam besides briefly feeling her abdomen. But at the time, Lauron figured, “OK, he’s the doctor—someone I’m supposed to be able to trust. And I didn’t want to be hysterical. I assumed that if he had given me the OK, then it was probably OK.” She went home intending to take his advice to go to the ER if it got worse.

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What Lauron didn’t know then was that if it was appendicitis and she were already at the peak pain level (a possibility the doctor apparently discounted completely) then the pain would actually first lessen when the appendix ruptured—and then get really bad. A couple days later that’s what happened. “All the pressure that I had been feeling—the pain from it being inflamed—was relieved because it finally burst. I didn’t know that I was in a dangerous situation.” Then the pain returned with a vengeance. After a night of

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throwing up with a high fever, her partner sent her to the ER. Her ruptured appendix had formed an abscess and was infected. The ER staff told her that if she had waited just three hours more before coming in, she probably would have died. “The infection was so bad that they couldn't operate; they could only insert a drainage tube and fill me with painkillers and antibiotics.” Several delirious days and one collapsed lung later, she was released from the hospital. Over the next several months, she was in and out of the ER as the tube was removed and then reinserted when the infection returned twice. It was eight months before she was finally well enough to have surgery to remove what was left of her appendix.

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Lauron said this nightmare has made her less trusting of doctors, a refrain I heard from nearly every woman I interviewed for this book. “Now I see how fallible doctors are. If I have a serious situation like that again, I’d be more willing to seek out a second opinion, and if something didn’t feel right about an interaction with a medical professional, I’d be more likely to trust myself about why that is.” Still, she knows that she was as firm as she could have possibly been with that urgent care doctor about how much pain she was experiencing—he simply didn’t seem to think it could be as bad as she said it was. “I was really honest—like, ‘This is a pain level that I have never experienced before in my life.’” With a mom who worked in health care, she felt especially well-equipped to communicate with doctors; she’d learned how important it is to not downplay your symptoms. “But I wasn’t hysterically sobbing.” And she thinks because of that, he didn’t believe her account. “Because I’m a woman he didn’t think I had that pain tolerance, so he probably thought I was overexaggerating the level of pain I was actually in. I could

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not have done more to advocate for myself in that moment because I was really clear about it. That’s the frustrating thing—even if you do know the words to say, you’re not always heard.”

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By the time Maggie returned to the hospital yet again near dawn on Monday, she’d been moved into the malingering category. In the ER for the third time in just a few days for pain and no diagnosis to show for it, the doctors clearly suspected she was inventing her pain to get prescription painkillers. “No one would give me any pain medication, despite my complaint that my pain was, on a scale of one to ten, a ‘bazillion.’ In the hallway, the ER doctor told my mother that she thought I must be ‘narco-savvy.’” In fact, Maggie had reacted terribly to the opioid medication she’d received while she’d been admitted before. “It was awful. The implication seemed to be that I wanted more of that, even though I definitely did not.”

Maggie just wanted them to figure out what was wrong with her. Unfortunately, the only clue they had to go on was her “own claims of indescribably horrific pain.” And yet none of the doctors had asked for more information about the nature of that pain, like the fact that it had shifted from the left to right shoulder or that she felt like there was a sandbag shifting about in her abdomen when she moved, information that might have led them to the right diagnosis. At this point, they no longer seemed to believe in her pain at all.

Commented [92]: This could use a brief definition. I assume it means drug-seeking behavior, but it's also out of the ordinary.

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But as the day wore on, tests finally starting coming back supporting what Maggie, readmitted to the hospital but still denied pain relief, had been saying—something was really, really wrong. A high white blood cell count pointed to an infection somewhere in her body. And then another chest x-ray showed a telltale blob that meant there was air in her abdomen that shouldn't be there. The switch was flipped: before she'd even been told of the new development, a nurse was in her room administering pain medication. Indeed, the medical professionals' entire attitude toward her changed immediately. "The nurses and doctors began treating me with compassion and sympathy."

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It was clear that an organ had ruptured, but since Maggie was starting to go into septic shock, there was no time left to find out which one; she was rushed into emergency exploratory abdominal surgery. There the doctors discovered and repaired a hole in her stomach, caused, she would later learn, by an especially fast-growing ulcer. The pain she'd been experiencing for the last 72 hours—the final 6 of which she'd spent in the hospital without pain medication—was from air and fluid leaking into her diaphragm. "I have a six-inch scar on my belly, suffered extreme malnutrition, and underwent a difficult recovery," Maggie reported.

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Unlike in many non-acute cases, Maggie's doctors did ultimately learn what was actually wrong with her. She heard that her doctors were asked to answer questions and justify their decisions to their colleagues at a hospital conference for morbidity and mortality. Someone who was there reported that they would be "kicking themselves for the rest of their lives" for taking so long to determine the correct diagnosis. Every doctor who'd

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been on her case visited her room as she recovered from surgery, often offering up this defense: a perforated ulcer is just so rare, especially in someone her age. "For them, considering a perforated organ as the explanation for my pain was nearly inconceivable." But, as Maggie pointed out, in the interest of not putting lives at risk, for doctors (particularly in the emergency room) there probably should not be any diagnoses that are considered "outside the realm of the possible."

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Indeed, the unjustifiable error was not in failing to more quickly determine a very unlikely diagnosis but in not taking Maggie's report of extreme pain seriously (and eventually deciding it wasn't real at all) until they had. There is always a gap between when a symptom begins and when it is medically explained. It is unreasonable to expect that doctors, who are fallible human beings doing a difficult job, to close this gap instantaneously—and, given that medical knowledge is, and probably always will be, incomplete, they may at times not be able to close it at all.

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But it shouldn't be unreasonable to expect that, during this period of uncertainty, the benefit of the doubt be given to the patient; that the default assumption be that their symptoms are real; that their description of what they are feeling in their own bodies can be trusted, and, if it is medically unexplained, the burden be on medicine to explain it. Such basic trust has been denied to women for far too long.

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