

ENGL 1014: Experiences of Chronic Illness
Professor Claire Crow

By submitting this essay, I attest that it is my own work, completed in accordance with University regulations. —Emunah Garmaise

Beyond the Lesion: The Histories of Women's Pain and Endometriosis
by Emunah Garmaise '28

“I can't get up,” Rachel says, “the way of women is upon me” (Genesis 31:35).

In a riveting episode in the Old Testament, the Biblical matriarch Rachel and her husband Jacob steal the idols from Rachel's father Laban's home because, as early monotheists, they reject idolatry. Laban, Rachel's father, chases after them through the desert. When he catches up with them, he demands that his daughter rise from her camel so he can search for his missing idols, but Rachel refuses to stand up, citing period cramps. Despite his rage at the thievery, Laban backs off. He does not ask more questions. He searches around her, but to no avail. Eventually, Jacob and Laban make a pact for peace.

It is not immediately clear whether Rachel truly suffers from such severe pain that she does not want to get up for one moment, or if she knows that just by referencing her period, her father will back off and allow them to escape scot-free with the idols. Either way, this biblical episode is telling— the taboo of menstruation is so uncomfortable, it is enough to defuse a serious conflict. Beyond this offhand biblical reference to menstrual pain, I am interested in how taboos, stigmas, and thinly-veiled misogyny have delayed biomedical progress in conditions like endometriosis, where the presenting problem is often menstrual pain.

Endometriosis is a condition that occurs when “tissue that is similar to the lining of the uterus grows outside of the uterus” (Mayo Clinic, “Endometriosis”). Its characteristic endometrial-like lesions can sometimes evade even MRI, ultrasound imaging, or even diagnostic laparoscopy without histological confirmation (Gubbels et al.), making it difficult to diagnose.

Yet its symptoms are blatantly obvious: severe, cyclic pain on periods or during ovulation, with using the bathroom, with movement and exercise of any kind. Endometriosis lesions respond to a woman's hormonal cycle— so when a woman bleeds, so do the lesions, but this bleeding cannot escape the body. This trapped blood can lead to scarring, adhesions, chronic pain, inflammation, and infertility. We still do not fully know why this happens (Johns Hopkins Medicine, “Endometriosis”).

Society views severe reproductive pain as “just part of being a woman” even when it is disabling, stealing days and weeks of women and girls' lives— and not a concerning malady worthy of non-invasive diagnostic tools and treatment options. By analyzing archival medical research, newspaper articles from the mid-20th century, and contemporary nonfiction by women (experts and patients) about the disease, I will show how representations of endometriosis in literature and history reflect the history behind a disease whose diagnostic complexity is not merely pathological.

Uterus Insanity

The uterus has long been discussed as the seat of all women's maladies, not just reproductive conditions like endometriosis. Ancient Egyptians blamed a “misplaced womb” when women experienced frightening symptoms like choking, mutism, and paralysis. In Ancient Greece, Hippocrates— the founding father of modern medicine, whose oath medical students recite at their white-coat ceremonies— placed the blame for women's unhappiness specifically on a process in which “at the time of their menstruation, blood collects later in the uterus so it may flow out ... When the blood has nowhere to flow, it rises up toward the heart and the diaphragm. When these organs are filled, the heart is desensitized. From this transformation it becomes numb. Madness overtakes women because of this numbness” (Hippocrates). Interestingly, in

attributing menstruation to emotional instability, Hippocrates unwittingly describes retrograde menstruation, a theory for the pathogenesis of endometriosis which many doctors still believe today.¹ Hippocrates attributed similar physical and psychological disturbances to a “dry womb rising toward the throat in search of moisture.” He called the phenomenon “hysteria” (Edwards 1).

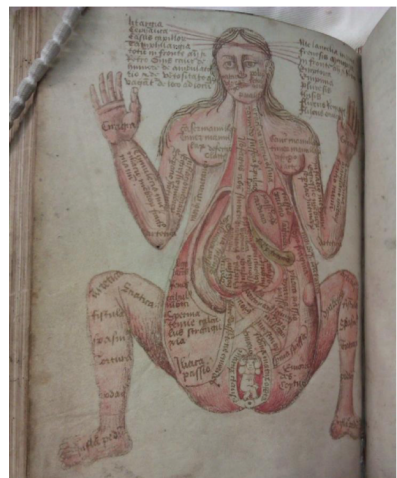
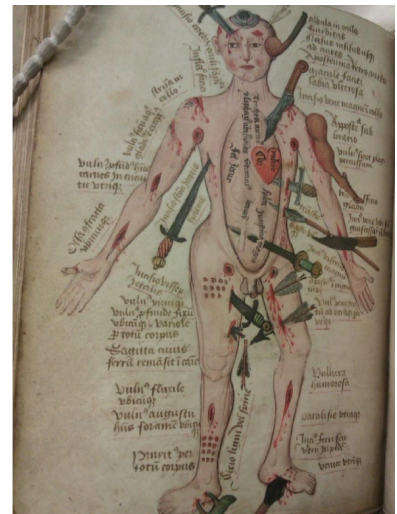
Hysteria comes from the Greek word for uterus, *hysteria*. Initially, hysteria started as a physical illness in women believed to be caused by a “wandering womb,” or the uterus shifting to different organs, causing symptoms across the body. Anushay Hossain writes in *The Pain Gap*, a book about gender- and race-based health disparities, “It is hard to think of a word in the English language with roots more sexist than this ancient Greek (word)” (Hossain XVI).

As late as the latter half of the 19th century, medical lectures included references to symptoms of a gender-inclusive but still predominantly female-affecting form of hysteria, including “headache, nausea, (and) pain in the back” (Skeye). Horatio Storer, a 19th century anti-abortion activist and physician, linked women’s mental states to their reproductive organs: “the various forms of insanity in women...(can be attributed to) functional or organic diseases of the uterus and its appendages; in other words, they are of a sexual character” (Storer, qtd. in Comen 297). Now, hysteria has been removed from medical textbooks and lexicon, but the phenomenon “has merely changed to reflect the preoccupations of society” (Edwards 1). Ironically, despite male physicians’ preoccupation with the female body, women’s conditions remain vastly understudied.

¹ In retrograde menstruation, menstrual blood defies gravity to flow upwards, toward the diaphragm, which is below the lungs, rather than out of the body (Cleveland Clinic, “Retrograde menstruation”).

Historically, men in the public sphere – whether philosophers or physicians – have looked at women’s bodies as mutant or deviant from the norm. Aristotle believed that the female physique was a departure from the standard of maleness: “We should look upon the female state as being a deformity, though one which occurs in the ordinary course of nature” (Aristotle, qtd in Comen 269). Horatio Storer, a 19th century medical lecturer, told a class of midwives in Philadelphia, “Women’s reproductive organs are pre-eminent, they exercise a controlling influence upon her system...everything that is peculiar to her springs from her sexual organization” (Witbank, qtd. in Comen 293). Whether a “deformity,” or a “peculiarity,” healthy female anatomy became pathology in the eyes of men. Ironically, this line of thinking assigns a level of legitimacy to women’s health complaints even when using stigmatizing rhetoric– that because the female body was believed to be anatomically disfigured, the resulting pain could not be imagined.

A look into medieval surgical textbooks provides even more insight into how these views on the female body evolved: for example, Wound Man is a medical motif from surgical anatomy books, first depicted in the fifteenth century (Hartnell 1). It depicts a man with various daggers inserted into his limbs (Strådal 1) and remains ubiquitous today. The female equivalent, Disease Woman, is less known, but sets up a contrast between perceptions of the male versus female body in illness.



The pain of Wound Man is external and inflicted by another, an enemy. In contrast, the afflictions written in Latin across Disease Woman's body are internal and notably, reproductive. "Beating heart" is written across Wound Man's chest, while Disease Woman dons "pain and suffering" over her heart (Strådal 15). The implication of the woman's cardiac label, dating all the way back to Eve's punishment in the Garden of Eden of a fate of reproductive suffering (Genesis 31:6), is that women are destined for pain, whether psychological or physical— where a man has a heart muscle, a woman has the physical embodiment of pain. In Disease Woman, the female body is anatomized by splitting it open to reveal the uterus with a growing fetus inside of it. She is pregnant. While Wound still has "clearly-defined viscera," he is not "reduced to (his)... interior," (Strådal 15) at least not the way Disease Woman has been, with her reproductive organs amplified in pregnancy, to the exclusion of women who are not presently pregnant or may never be.

In the past, a diagnosis like hysteria overpathologized women's symptoms, linking these symptoms to "taboos" like unruly sexual desire and even her supposed promiscuity (Comen 298). Today, however, I argue that medical institutions chronically underpathologize experiences deemed to be part of womanhood, such as cyclic pelvic pain. Beyond surgically examining the endometriotic lesions of patients, society needs to take a closer look at how medical history reflects and contributes to endometriosis' characteristic delay in diagnosis and how ironically, the normalization of women's pain represents a shift in medical culture.

From Mystifying to Mundane: The De-medicalization of Female Pelvic Pain

Now, the medieval view of the female body as an anomaly has been replaced by a medical system which struggles to acknowledge when the reproductive system has gone awry. The average time to diagnosis of endometriosis is 8-12 years (Puglsey et. al) in part because a

common presenting symptom of the disease is debilitating menstrual pain. Jaipreet Virdi, a medical historian at the University of Delaware, writes, “My pain was simply the pain of my body growing, a marker of my journey towards adulthood that began with menarche.” The pain eventually turned severe, leading her to “cry as I bled... It was just cramps, I told myself” (Virdi 1). With every other body part, we view pain as an ominous signal of inflammation, infection, or injury². But because menstrual pain is so common, women are expected to grin and bear it, even when it results in a loss of functioning.

Even female physicians who themselves experience periods can participate in medical gaslighting about pelvic pain, because of the legacy of misogyny that still persists in medical education. In *Diagnosis Female*, a book about gendered health disparities, Emily Dwass describes how a young female doctor dismissed her severe chronic pain. The doctor shrugged noncommittally and said, “‘Some women get cramps because they don’t like having periods.’ And that was the extent of her exam, diagnosis, and treatment” (Dwass 1). When doctors fail to pathologize women’s diseases, women often shoulder the blame, to the point that they feel relief when diagnosed with a chronic, incurable condition: “I cried, and cried, and cried. For most of my life I’d doubted myself, feeling second-rate, weak and flaky, only to realise ... I wasn’t. I had to reimagine myself, and it wasn’t easy” (Jackson 5). While medieval doctors aggrandized women’s reproductive systems, blaming the uterus and its affiliates for every and any symptom or emotion, modern doctors look at women’s reproductive dysfunction with dismissal. Rather than providing women with relief, this dismissal forces women to internalize their pain.

²According to Yale endometriosis expert Hugh Taylor, MD, “menstrual pain is the only type of pain that is commonly accepted as normal” (Yale School of Medicine).

Medicine for Women, By Men: The Professionalization of Obstetrics

Even female physicians can dismiss their patients' pain, because the professionalization of midwifery into obstetrics and gynecology excluded women from the space of women's health, a realm that had once been entirely their own.

In ancient times, women provided each other with herbal and other non-invasive remedies for gynecological concerns. The earliest reference to period pain is in the Kahun Gynecological Papyrus from 1800 C.E, in which a woman is treated by taking "1 qd of chufa, 1 qd of fruit, 1 hin of boiled cow milk" for four mornings in a row (Lopes et al. 13). The text does make reference to a "wandering womb," a statement echoed later by Ancient Greek doctors and thinkers, but it does not attribute a mental state to the misplaced organ; in the absence of modern medical imaging, the Kahun Papyrus uses the "wandering womb" as the imagination of pain pathogenesis, rather than the crux of every issue a woman has. The combination chufa and boiled milk may not have been studied in a double-blind experiment, but women have provided each other gentle, supportive care for millenia. When medicine professionalized midwifery into obstetrics, women were quickly pushed out of the field. In the 16th to 18th centuries, midwives or female healers were often accused of witchcraft and killed (Ring et al.).

Michel Savonarola, a 14th century Italian physician, said it succinctly: "I leave such treatment to male physicians, for it is not the work of women" (Savonarola, qtd in Green 246). The Italian doctor "repeatedly advised his female audience, both laywomen and midwives, to leave certain, more serious tasks to the male physician or surgeon: the prescribing of medicines, surgical intervention in obstructed birth, treatment of postpartum fever" (Savonarola, qtd in Green 246). What had previously been taken for granted as solely "the work of women" became

the purview of the same men who drew women with exaggerated sexual organs, like the Disease Woman, and continued to regard the female reproductive tract with morbid fascination.

The Modern Politics of Endometriosis

Even as awareness of endometriosis grew throughout the 20th century, the disease continued to be politicized and moralized, cast to be a moral failing of the white career woman who delayed having kids. A 1948 New York Times article interview features Dr. J.V. Meigs, a Harvard-affiliated gynecologist who had a novel idea for endometriosis treatment: parental subsidy of early marriage and childbearing. By delaying childbearing, Meigs hypothesized, careerwomen experienced more uninterrupted menstrual cycles than women who become mothers early, thus increasing their risk of endometriosis: “by training and education, (they) attempt to plan their marriage on the basis of security from financial worries...” By causing infertility to women in the upper-class, “the ailment pointed to the eventual displacement in the social dominance of healthy and intelligent people by the weak and unintelligent but fecund class who had produced history’s leading dictators” (Meigs qtd in Hill). In the aftermath of World War II and its devastations, Meigs pointed at women with endometriosis as the ones to blame for the rise in tyrannical dictators, such as Hitler and Mussolini.

Aside from its eugenicist bent, the paper presents several inaccuracies. Meigs infers causation when there is merely correlation: endometriosis is not the result of delayed

SOCIAL ILL IS LAID TO ENDOMETRIOSIS

**Women's Ailment Restricting
the Propagation of Intelligent
Class, Says Dr. J. V. Meigs**

By GLADWIN HILL
Special to THE NEW YORK TIMES.

LOS ANGELES, Oct. 20 — The increasing incidence of endometriosis, one of the commonest ailments of women which leads to sterility and many other disorders, is a social rather than a medical phenomenon foreshadowing a decline in our civilization, the American College of Surgeons was told tonight.

Associating endometriosis with delayed marriage, contraception and delayed child-bearing, Dr. Joe Vincent Meigs, one of the nation's leading gynecologists, said that, unless checked, the ailment pointed to the eventual displacement in social dominance of healthy and intelligent people by the weak and unintelligent but fecund class which had produced history's leading dictators.

procreation—it's the leading cause of infertility. Furthermore, women of every class have and had endometriosis—upper-class, white women were and are simply more likely to receive a diagnosis. Tracey Lindenman tracks this trend in *Bleed*, quoting an endometriosis specialist Dr. Kitsner who reported that most of his patients were “higher socio-economic” women with a “specific body type and psychic demeanor are frequently found: mesomorphic but underweight, overanxious, intelligent, egocentric and perfectionist” (Kitsner qtd in Lindenman 14-15). Kitsner's demographic data suggests that women who were proactive about their pain were stereotyped as nervous or even egocentric. Personality stereotypes about women and girls with endometriosis persist well into the 21st century—Abigail Anthony, a graduate of Princeton, describes how she was finally diagnosed with endometriosis as a senior in college. Before that, even her parents chastised her for the dawn of a devastating chronic illness that they felt was rooted in neurotic tendencies:

I couldn't remember the energetic girl I used to be, and I couldn't imagine a desirable future... My parents told me I was suffering from *perfectionist* tendencies and an obsession with good grades. They instructed me to “stop being *hysterical*” and “pull myself together.”³ (Anthony 1)

Women who don't advocate for themselves will likely not receive a diagnosis until they present with infertility, but the patients who return again and again to the doctor's office will be labelled “neurotic.” Similarly to personality stereotypes, racial and socioeconomic stereotypes prevail as barriers to endometriosis diagnosis. A 1976 paper in the American Journal of Obstetrics and Gynecology reported endometriosis in 21% percent of Black women who had previously been misdiagnosed with pelvic inflammatory disease (PID), which is caused by a sexually-transmitted infection (Chatman et al.). In the US today, up to 72% of women diagnosed with endometriosis

³Italics mine. Anthony's parents use almost identical language to Kitsner.

are white, despite the fact that there is no definitive evidence Black women are less prone to the disease (Bougie et al.).

The diagnostic delays Black women face are inherent to modern gynecology, which is rooted in sadistic racism towards enslaved Black women in Alabama. This history is reflected today in racial disparities in endometriosis treatment and other health outcomes, including maternal morbidity. In the mid-nineteenth century in an Alabama overrun by the Cotton Belt industry, James Marions Sims performed painful gynecologic surgeries on enslaved women without anesthesia or consent (Cooper Owens, qtd in Zellars 1). Sims is known as the progenitor of modern gynecology, but Anarcha, Betsey, and Lucy suffered at the hands of a man who partially legitimized these barbaric surgeries because of his ideas about Black women's decreased capacity for pain.

Sims pioneered a new technique for the repair of obstetric fistula, a complication after childbirth. He operated on Lucy thirteen times before he deemed the experiment "safe enough to perform on white women" (Equal Justice Initiative). Modern gynecology has evolved significantly since, but acknowledging how its tarnished history contributes to contemporary medical disparities is crucial.

Sims' cruelty lies in stark contrast to a millenia-long legacy of midwifery, during which women provided each other dignity and support in childbirth and for other women-specific health needs. While most obstetrician-gynecologists are now women, gynecology was initially formed as the clinical, objective alternative to midwifery, when it quickly turned cruel and exploitative.

Seeing the Invisible Illness

Endometriosis is the “final frontier” of hysteria because it is so difficult to visualize using modern medical imaging. In medieval medicine, the pain of marginalized people was often met with disbelief because of the lack of diagnostic tools. With the advent of modern medicine and the associated imaging tools, women could no longer be accused of hysteria and the phenomenon disappeared into oblivion.

Endometriosis, whose characteristic lesions are often invisible until a surgeon performs laparoscopy, facilitates doctors’ all-too-easy return to medieval conceptions of the female body in pain. Lena Dunham writes in *Vogue*:

In August, the pain becomes unbearable. I am delirious with it, and the doctors can’t really explain. The ultrasound shows no cysts, no free fluid, and certainly no baby. But that doesn’t help the fact that it hurts so bad that the human voices around me have become a sort of nonsense Teletubbies singsong. With pain like this, I will never be able to be anyone’s mother. Even if I could get pregnant, there’s nothing I can offer. (Dunham 1)

Dunham’s imaging is clear despite horrific pain, so she must beg⁴ for the surgery she feels will help her feel better: a hysterectomy. In a witty essay, she explores the bitter irony that women with endometriosis are often told to have a baby to cure their menstrual pain, but endometriosis can make it harder to get pregnant. Women with uncontrolled chronic pain often do not want to become pregnant— as Dunham says, “there’s nothing I can offer.”

Dunham eventually gets her answers, but at the cost of her fertility: after surgery, the doctors tell her that her uterus looks terrible, riddled with “endometrial disease, an odd humplike protrusion, and a septum running down the middle... I have had retrograde bleeding, a.k.a. my period running in reverse, so that my stomach is full of blood. My ovary has settled in on the

⁴ Notably, Dunham is a white woman with a net worth in the millions, and even she is not immune to medical dismissal.

muscles around the sacral nerves in my back that allow us to walk” (Dunham 1). By the time Dunham, a wealthy white woman, was believed, it was too late. She lost the chance to fulfill her dream of being a biological mother and carrying a pregnancy— but perhaps the outcome would have been better had doctors listened earlier.

The Research Gap

The lack of proper diagnostic tools for conditions like endometriosis does not exist in a vacuum: it’s merely another symptom of hundreds of years of excluding women from clinical trials. For much of medical history, the exclusion of women from biomedical research has been systemic due to fears of how female hormones or potential pregnancy might interfere: “all of the cells, tissues, animals, and people being studied were male.

Unbelievably, women were excluded as medical research subjects until 1993, meaning that most of what is known now about drugs and diseases is based on findings applicable to only half the population” (Dwass 2). A 2020 research paper published in *Fertility and Sterility*, a scientific journal published on behalf of the American Society for Reproductive Medicine, was entitled “Attractiveness of women with endometriosis: a case-control study.” The finding was that 31% women with (posterior pelvic) endometriosis were viewed to be “attractive or very attractive” while only 8% of the (abdominal) peritoneal endometriosis group received that designation (Vercellini et al.). While this paper has since been retracted by *Fertility and Sterility* (7 years after its publication), the study was funded by the University of Milan and published in America’s leading reproductive medicine journal. Similar studies, like those about the toll of endometriosis on the sufferer’s intimate partner (Santulluni et. al) eschew the opportunity to research a cure for this devastating disease in favor of prioritizing the men surrounding these patients.

Today, only 5% of global research and development (R&D) is allocated to women's health research, of which 4% is designated to women's cancers. Endometriosis is not malignant and therefore receives *a share of* the remaining 1% of global funding (.038%), or \$2 per patient. (Kirk et al.). Perhaps we would have better diagnosis and treatment options if the government poured more resources into research about women's healing. Research articles like the *Fertility and Sterility* publication that focus on the sex appeal of women with endometriosis are included in this fraction of 1%.

While endometriosis has pathology that is difficult to visualize and thus diagnose, endometriosis has only remained an enigma because of a stunning lack of research, which is rooted in period shame, which is rooted in the earliest history of Abrahamic religion and perpetuated by an unspoken code of silence. Even when women's doctors become invested in their quality of life, the lack of biomedical research leaves even the best doctors with their hands tied— and the less capable doctors to ironically de-pathologize women's pain as inherent to femaleness, in contrast to medieval and ancient doctors who pathologized normal female anatomy.

By analyzing the history of women's healthcare across thousands of years to the present day, it is clear that the disenfranchisement of women's pelvic pain is based in medicine's historical grotesque fascination with the female organs and tainted by the field's involvement in both eugenics and racism, coupled with poor global investment in endometriosis research. While modern medicine has improved and saved the lives of countless women, only when we acknowledge the ambivalent history of male providers in women's medicine and redirect medical funding toward this common, painful condition (and other similar ones) can we begin to find a path forward for the hundreds of millions of women globally who live with endometriosis.

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