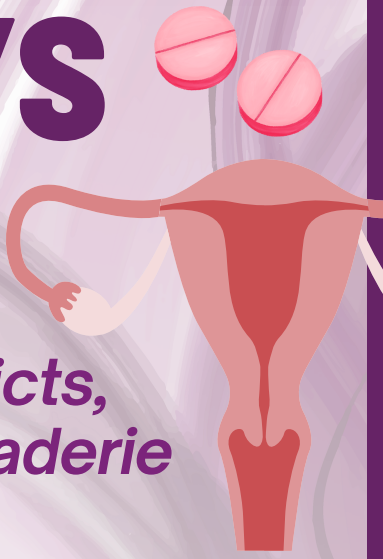
MISOGYNY IN MEDICINE'S MARGINS



Patient-Physician Conflicts, Challenges, and Camaraderie in Endometriosis Care

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BACKGROUND

- Endometriosis is a chronic, painful, inflammatory illness that usually affects women
- Diagnosis takes 7-10 years on average, only currently possible via surgery
- Care-seekers in pain are often disbelieved and dismissed by medical professionals

OBJECTIVE

To explore care-seekers' and physicians' experiences navigating patient self-advocacy and resolving disagreements

METHODOLOGY

38 semi-structured **interviews** with physicians and care-seekers w/ endometriosis in the US

3 weeks of **clinical participant observation** in a Mid-Atlantic tertiary medical center

CENTRAL CLAIM

Misogyny and *capitalism* in medicine undermine patient-physician relationships in endometriosis care, harming both care-seekers' and physicians' goals and well-being.

Chapter 1 calls attention to **gynecologists' challenges**, investigating how their **work conditions** and experiences of **systemic misogyny and capitalism in medicine** influence their ability to be mentally, emotionally, and physically present with patients.

Chapter 2 explores how patients and physicians use various strategies to promote or undermine patients' **credibility**, and either recognize or dismiss patients as valid sources of **knowledge**, in the context of factors like mental health, substance use, online research, and identity.

Chapter 3 delves into how patients and physicians balance their **rights and responsibilities** in **medical decision-making** around procedures and treatments. We took a special interest in how physicians' duty to "Do no harm" aligned or clashed with patients' need to have agency over their own bodies.

KEY FINDINGS

1 Systemic barriers in gynecology hamper strong patient-physician relationships

- **Institutional/Cultural Issues**
  - Little **research funding** is devoted to endometriosis care
  - Hospital admins often motivate physicians to see more patients via **quicker appointments**, leading to rushed patient care
  - GYN surgeons get low priority in **operating room (OR) scheduling**
  - Endometriosis can be neglected in **medical training**, even in OB/GYN/family medicine/internal medicine residency
  - The **insurance reimbursement system** compensates physicians more highly for procedures on male patients, as is clear when comparing similar urology and OB/GYN procedures
  - Non-OB/GYN physicians may hold **negative stereotypes** about female patients with chronic pelvic pain, and thus, avoid them by referring them out
  - Endometriosis can be medically complex and emotionally traumatic for care-seekers, imposing a greater demand for **emotional and mental labor** on the gynecologists treating it
- **Impact on Patient Care**
  - Physicians feel **physically & emotionally drained**
  - Harder to provide **empathetic, trauma-informed care**
  - Leads to **fewer medical trainees** choosing GYN surgery
    - Results in: Fewer specialists, overbooked surgeons, shorter, rushed appointments, poorer communication with patients
- **Implications**
  - Patients may be inclined to attribute **rushed or dismissive care** encounters to their physicians being **apathetic or uncaring**
  - Yet, patient care, while shaped by the doctor's personal qualities, is also limited by **systemic factors** like time constraints, the medical education system, insurance reimbursement, and more
  - **Policy changes** & better **work conditions** can:
    - Improve surgeon well-being
    - Enhance careseekers' interactions with clinicians
    - Strengthen trust and communication

PHYSICIAN QUOTES

"[W]e see on average like 24-ish patients per day, like 24 different sets of emotional conversations[...**I]t's exhausting**."

—Dr. Jameson*, female OB/GYN generalist (Mid-Atlantic)

"I think there's always a push to be **more efficient** in the clinic setting, depending on how much time is allotted for the appointments. So, **that's always in the back of your mind [...] going through clinic**."

—Dr. Miller*, female OB/GYN generalist (West Coast)

"I feel like I am **always running behind**. So, I feel like part of me feels like I want to ask those open-ended questions, [but I] only have a certain amount of time."

—Dr. Evans*, female gynecologic surgeon (Mid-Atlantic)

"I do think you should get better at [performing emotional labor] with time, but **sometimes, you get worse with it with time**. I've experienced that [...] at the hands of the healthcare system."

—Dr. Kennedy*, female urogynecologist (Mid-Atlantic)

KEY CONCEPTS

- "Gyneconomics" and the Medicare Resource-Based Relative Value Scale (RBRVS) (physician reimbursement policies)
- Physician burnout and its effect on worsening patient care

***** = *pseudonym***

KEY FINDINGS

2 Patients & physicians enact strategies to promote & undermine patients' credibility

- **Why Trust Matters**
  - Physicians currently lack **clear diagnostic tools** to identify endometriosis, short of surgery (laparoscopy)
  - Thus, they must rely heavily on **patient-reported symptoms** for diagnosis
  - When physicians **dismiss** patients' testimonies, it can:
    - Delay diagnosis and treatment
    - Force care-seekers to painstakingly advocate for further testing or seek second opinions
    - Prolong and complicate care journeys
- **Who Gets Trusted—and Why?**
  - **Physician trust** is subjective, shaped by characteristics like **gender, health literacy,** and **perceived mental stability**
  - Patients seen as more "**credible**" receive more validation and faster care
- **Core Themes**
  - Mental Fitness & Well-Being
    - **Mental health** is relevant to endometriosis care, but can be weaponized by physicians, even unintentionally, to **discredit** care-seekers
    - Patients feel dismissed when doctors frame **physical pain as purely psychological** and treatable via psychiatric treatments
  - Online Research as a Double-Edged Sword?
    - **Online health information** empowers patient health literacy and self-advocacy
    - Yet, it can undermine trust if physicians feel that their **authority is challenged**, or that care-seekers are unable to detect **misinformation**
  - Performing Trustworthiness
    - Care-seekers modify their **appearance**, **language**, or **tone** to be taken more seriously by physicians (e.g., dressing older, avoiding crying)
    - Feeling obliged to **perform credibility** undermines care-seekers' abilities to be **vulnerable and genuine** in expressing themselves to their physicians
- **Implications for Better Care**
  - Patient-physician relationships can benefit from physicians avoiding **prematurely judging** care-seekers' credibility due to suspicions about mental health, substance use, etc.
  - Findings highlight the need to use language and behaviors that signal **belief and respect**, not suspicion
  - Encouraging physicians to remain **open to patients' knowledge and online research** can lead to: Mutual willingness to listen, stronger patient-provider relationships, more timely diagnoses, and effective care

PATIENT QUOTES

“When I have an appointment where I want to discuss something important, I feel like I have to **emotionally remove myself**. I have to write things down or take that part of myself that might have an emotional reaction out of the equation.”

—Claire*, Social Security Claims Specialist, in her thirties

“I'm not a doctor, but, you know, I do read medical things from my work. And so, **I feel like it gives me a bit of validity in the room where they're like, “OK, she isn't coming in trying to prove she's smarter than me.** She's coming in with, like, genuine questions.”

—Nadia*, young PhD student in a STEM field

“[For] a lot of females in their 20s and 30s and so on, the way you appear in an appointment affects how you may be perceived. So, **there’s making sure you dress nice, but not too nice, or not too run down** and all those things, which is just insane. But there [are these] subconscious ways that providers may [...] interpret the visit.”

—Tanya*, physician assistant in her late twenties

“**[Patients] educate themselves and [...] each other with authoritative fact-based information**, whereas before, if we read an article, there was nowhere to go from there. If we read a news article that said, “You know, it's a misplaced endometrium. You’ll get pregnant, it’ll cure you,” we had no outlet. Now we can contact, in real time, the author of that article/that feature and say, [...] “You've got all these facts about the disease wrong,” and really make sure that we're propagating the right information. **[...T]he Internet has, by leaps and bounds, changed the game.**”

—Yvonne*, healthcare advocate/program director of an endo care center

PHYSICIAN QUOTES

“[P]art of the reason I follow so many GYN and OB things on social media, is [to] stay [up-to-date] on what my patients might be seeing. **[T]he majority of times when patients come in and said, “I read something about this,” first thing I always ask is, “Where did you see that, and how did you see that?” because oftentimes it's something like Instagram or TikTok, which is not a reliable source of information**.”

—Dr. Jameson*, academic OB/GYN generalist (Mid-Atlantic)

“I try not to be defensive if patients bring that. In fact, I'm like, “Oh, let me look at that. This could be a new piece of information that very well could be applicable.” [...] **I don’t sit here and say that I'm the encyclopedia on endometriosis and endometriosis care. Nobody can be that, right?** [...] We’re all learning new things every time.”

—Dr. Smith*, experienced female gynecologic surgeon (West Coast)

KEY FINDINGS

3 During medical decision-making, patients & physicians have a hard time balancing agency & authority

- **Core Tension**
  - Conflicts often arise around **procedures or interventions that the patient may prefer or wish to avoid, while the clinician disagrees**
  - Physicians' commitment to "**Do no harm**" can clash with patients' right to choose their own care
  - "**Harm**" may be perceived differently by patients and their physicians - for ex: It can mean **a poor health outcome, or a violation of bodily autonomy**
- **Identity & Power**
  - Patient participants asserted bodily autonomy by:
    - **Voicing disagreement** with physicians' recommendations
    - **Seeking second opinions**
    - **Leaving physicians** who refuse or pressure them
    - **Leaving negative reviews** or **making formal complaints**
  - Physician participants wielded medical authority by:
    - Counseling patients by persistently **raising pros and cons that may change their minds**
    - **Refusing procedures they see as unnecessary**
    - **Referring patients when values clash**
  - Both **gender** and **education** shape the patient–physician power dynamic
    - For ex, many gynecologists and patients with endometriosis tend to be women, and thus, are often dismissed or undermined in the clinical space - thus, they may try to compensate by holding more rigid stances during decision-making, intensifying conflict
- **Implications for Care**
  - Trust-building actions ease tension and enable shared decision-making - **without trust, both sides become more rigid** and communication breaks down
  - Findings can help patients and physicians understand each other's perspectives and reconcile **a shared vision for the best outcome possible, in terms of health & bodily autonomy**

PATIENT QUOTES

“We only get one body. This is all that we have. We need to find people to help us shepherd it through our journey. And if the doctors aren't doing that, or the nurses aren't doing that — I say it from a place of reverence for the profession, they're saving lives every day — but at the end of the day, I have to stand up for myself. **[I]nformed consent is a sacred construct, and we are not just objects of that consent and that care.**”

—Yvonne*, a healthcare advocate in her early fifties

“As someone with endo, I like to have a lot of control over my body and I like my decision to all be my decision and not any other doctor’s, even if it might not be the best thing for me. **You know, there's just such a loss of control when you have endo, you know, your insides are just turning against you. [...] If [my doctor] couldn't [respect that], I would seek other care.”**

—Jenni*, a young woman with endometriosis

PHYSICIAN QUOTES

““I think we have to be careful to not assume that we [physicians] don't have any expertise in anything. **I think that we should value the patients’ goals and preferences, but that doesn't mean that we would just do anything that the patient wants, right?”**

—Dr. Williams*, a female academic OB/GYN generalist

“If I have a complicated medical patient and they say, “When someone did surgery on me, I felt better for a year, [...] I had a better life with my family and my husband,” I will probably [operate on] that patient. [...] **I will err on the side of, if you can improve somebody's quality of life, even if it's six months to a year, it's worth it.** [T]he easiest thing we can do is say yes to the person and bring them to the operating room, right? [Then] no one’s upset.”

—Dr. Atkins*, an older male academic gynecologic surgeon

“I feel like as a young female physician, [seeing...] patients that are, you know, my age or older than me—it's easier to just have [the patient] say what they wanna do and be like, 'Whatever you want, we'll do that.' But I think what I'm gaining is the “**physician recommendation hat**” from my older male colleague. **He has an easier time [giving strong recommendations] because he's a male, he's older, he has a lot of experience, and people are like, 'Yes, Sir.'”**

—Dr. Evans*, a young female gynecologic surgeon

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