

A photograph of a woman from the waist down, wearing a dark blue bikini. She is holding a large bouquet of hydrangeas against her midsection. The background is a solid dark blue color.

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Endometriosis
and how it
Connects to
Larger Issues in
Women's
Healthcare

Women commonly talk about their personal experiences with healthcare. Whether it is with an obstetrician-gynecologist (OB/GYN) or their primary care physician, millions of women have continually struggled to have their symptoms taken seriously (Booth, S. & Booth, S., 2018). This lack of respect from healthcare professionals is especially an issue in the realm of the disease endometriosis, a chronic illness that 176 million people live with. Statistically, one in ten women will develop endometriosis in their lifetime (Endometriosis.org, 2017), and yet most struggle to get the care they need. People with endometriosis deserve affordable, quality treatment options because allowing continued suffering of those with chronic pain is unethical.

What is Endometriosis? How is it Treated?

To begin, it is important to examine exactly what endometriosis is. “Endometriosis is defined as the presence of endometrial glands and stroma outside the endometrial cavity and uterine musculature” (Nardi, Ferrari, & Denny, 2011). To simplify, endometriosis occurs when the tissue that would typically grow inside of the uterus (the endometrium), grows on the outside of it. This is the same tissue that is typically shed during menstruation. Endometriosis symptoms include pain, severe dysmenorrhea (painful menstruation), pelvic pain, deep dyspareunia (pain around the genitals), cyclical or perimenstrual gastrointestinal or urologic symptoms, pain at defecation or micturition, subfertility (a delay in conceiving), abnormal menstrual bleeding, chronic fatigue, and backache (Nardi, Ferrari, & Denny, 2011). These symptoms may seem fairly general, and so to go more in depth, it is important to look at other, more severe medical impacts that endometriosis can have on the body. Pain is a debilitating symptom and decreases quality of life. Other potential side effects of untreated endometriosis include infertility and higher than average links to ovarian cancer, as well as endometriosis-associated adenocarcinoma, another type of cancer (Mayo Clinic Staff, 2019). These symptoms and side effects are nearly impossible to ignore; however, many people with endometriosis fail to get a diagnosis and, thus, are unable to access treatment. A survey of women ages 18-54 reports that the average length of time between the onset of symptoms and official diagnosis is approximately 4.4 years (Soliman, Fuldeore, & Snabes, 2017). This is completely unacceptable and would not be tolerated in many other areas of healthcare, and yet is completely normalized in the case of women’s health--specifically in terms of this disease.



Not all of the blame can be put on the doctors who are treating people with endometriosis, though. The majority of symptoms present are also found in a multitude of other diseases, such as irritable bowel syndrome or pelvic inflammatory disease. It is difficult to achieve a conclusive diagnosis with such common symptoms. However, there are currently multiple ways to diagnose endometriosis conclusively. While a pelvic exam can potentially diagnose endometriosis, it is only effective if the endometriosis lesions have caused a cyst to form. There are three ways to specifically image endometriosis, and those methods are (from least to most diagnostic certainty): ultrasound, MRI, and laparoscopy (Mayo Clinic Staff, 2019). It is abhorrent that there are multiple conclusive tests available for endometriosis, yet it takes years from first consultation for healthcare professionals to decide to administer those tests. Often, women with endometriosis feel ignored by their healthcare professionals. According to a study in 2017, many women with endometriosis feel as if their experiences with healthcare professionals have been “destructive”(Grundström, Alehagen, Kjølhede, et. al., 2017). These experiences should not be so common. If a patient were presenting symptoms of the flu, it would be completely unacceptable to not test that patient for the flu as a diagnosis could lead to proper treatment. It should not be any different for those with endometriosis. Once a diagnosis is rendered for endometriosis, treatments open up.



There are a multitude of treatment options for women living with endometriosis. One of the most accessible treatments, assuming the patient is not trying to get pregnant, is birth control. This works by releasing hormones that control menstruation cycles. If the patient is trying to get pregnant, other hormones may be prescribed. While birth control is a great, accessible option, it is only really effective for cases of endometriosis where the symptoms are not severe (Eisenberg, Britton Chahine, 2019). So, while accessible and affordable, this is not necessarily viable. According to the U.S. Department of Health and Human Services' website on endometriosis, the only other medical treatment option is surgery. During this surgery, a doctor will locate and remove any patches of endometriosis found (Eisenberg, Britton Chahine, 2019). There are, however, nonmedical ways to potentially relieve the pain experienced by those with endometriosis, including acupuncture, chiropractic techniques, various herbs and vitamins, and over-the-counter painkillers. Many of these options are discussed in testimonials to relieve pain, yet these options do not offer long lasting relief. That said, treatments such as acupuncture have a long cultural history of being effective, and according to the Mayo clinic, acupuncture is commonly believed to stimulate different nerves to release

natural painkillers (Mayo Clinic Staff, 2020). Clearly, though, surgery is the preferred treatment method if it is available and safe for the patient.

The Financial Burden of Endometriosis

Another compelling reason for accelerated diagnosis of endometriosis is the financial burden that it has upon those living with it. According to an article from the "Sydney Morning Herald," a newspaper based out of Sydney, Australia, endometriosis "exact-ed \$7.4 billion from the Australian economy" in the year 2018 (Aubussen, 2019). This equates to approximately \$4.25 billion in United States Dollars at the 2020 exchange rate of \$0.77 USD to \$1.00 AUD. Additionally, in the same article, there is a testimonial stating that grappling with endometriosis will cost one individual \$20,000 AUD, or \$15,419 USD, on average. When broken down, these expenses may appear to make sense. The costs include surgeons fees, hospital admissions, and consultations, as well as medications and travel expenses in order to receive treatment at all (Aubussen, 2019). That said, this is not a sustainable way to live. In fact, the 2015 poverty line in the United States for a single person under

the age of 65 was \$11,770. For someone living with endometriosis, these treatments, including surgeries, are critical to quality of life. Care, of course, can be denied to those who cannot afford it due to how expensive it is. And while it is possible to apply for medicaid in situations where healthcare is too expensive, it is also possible for requests to be denied, and payments still do need to be made, as it is not free healthcare (Medicaid, getting started, 2017). This is not to say that all healthcare can or should be free in the United States, but that there needs to be a reevaluation of economic versus humanitarian values in regards to necessary healthcare. Treatment expenses are unsustainable for many women living with endometriosis; while surgery is the most expensive treatment alternative, for many it is the best--or even only--option.

Gaslighting in Reproductive Health Settings

In addition to the financial burden, there is also a common theme of gaslighting throughout women's healthcare, especially within reproductive healthcare. Medical gaslighting is when a medical professional convinces a patient that his or her instincts are incorrect. This can involve the level of pain experienced, or even whether or not a past procedure was really performed (Booth, S. & Booth, S, 2018). In an article published by the BBC, it is stated that one woman was told that her pain, which was really from undiagnosed appendicitis, was from "childhood sexual abuse," despite her informing the doctor that had never happened (Billock, J., 2018). When doctors assert reasons for symptoms that do not align with what the patient knows to be true of her body, doctors exert more power over their patients, whether this is intentional or not. Additionally, doctors can make assumptions about women's lifestyles and behaviors that aren't true.



An article published by the New York Times states that one woman (who is also a doctor) went to her primary care physician because she had lost 10 pounds in a concerning amount of time and thought it may be a sign that an old illness was returning. Her doctor dismissed it and told her that he disagreed for a few reasons, including "you've been on a diet," which was something she had not said or implied during the appointment. Once

she had him run the tests, it turned out the illness was indeed returning, and she had to begin treatment immediately (Pagán, C. N., 2018). Medical gaslighting, which also includes women being told their symptoms aren't real or are "in their heads," can lead to more doubt of a person's future symptoms, disregard for chronic pain, and an overall lack of accurate diagnosis.

To conclude, people with endometriosis often suffer physical, financial, and even emotional burdens from this disease. Many women know the emotional burdens present with even easily diagnosed conditions. As such, they

can also attest to the struggle of being believed without a medical professional altering their thoughts, words, and feelings. The discussion of accessible healthcare is one that has gone on long enough, as people who cannot access the treatment they need continue to suffer from their illnesses. Due to the unmanageable costs, as well as the daily inhibitors placed upon the body from chronic pain, not to mention the battle for symptoms to even be heard, endometriosis care should be both of a high quality and affordable, as this is not just a women's issue, it is a humanitarian one.

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