

SUMMER 2020

Endometriosis Misdiagnosis Report

endo**me**trix



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About Endometrix

The idea for Endometrix sparked at a Design Thinking course in 2017. That philosophy still pumps steadily through our veins. Since that day, we have used the Design Thinking framework to ensure that we are always listening to and learning from the endometriosis community. There's no such thing as having a final product by us because every detail of our app continues to be focused on and tested by our users' adapting needs.

Both our app and our team is constantly learning from the information shared by our users. Most companies will tell you that they have the answer. We know that the answers you seek are already within you, we just want to give you the tools to help you find them.

Our Philosophy

Chronic period pain is not normal and the culture surrounding "period pain" is hurting all uterus carriers. We believe the normalization of "period pain" contributes to the prevalence of misdiagnosis and the seven-year-long average time to diagnosis experienced by people with endometriosis.

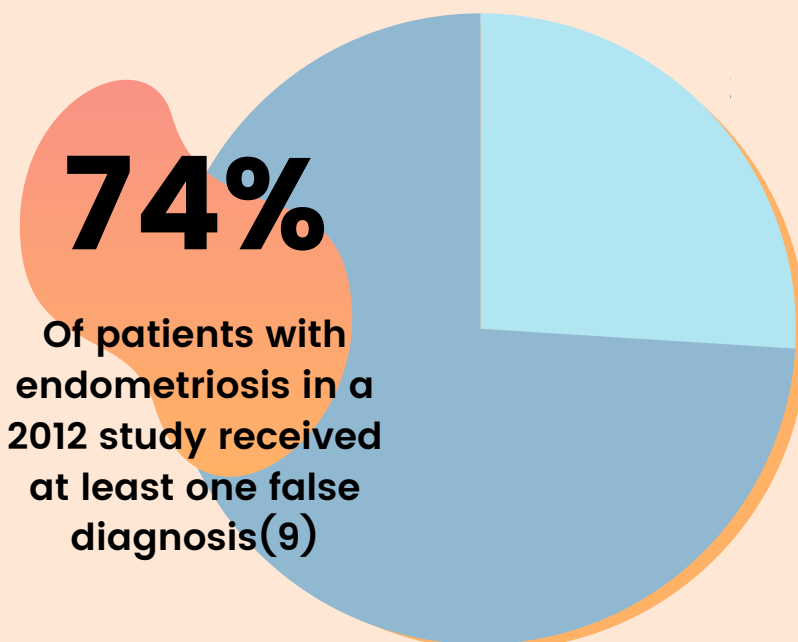
Ultimately, our mission is to empower past and present uterus carriers everywhere to receive the healthcare they deserve. We believe awareness, whether it's within ourselves about how our body functions or throughout the healthcare system, helps achieve this. We want to drive this awareness with data to help our users understand and better communicate their needs with those they seek care from.

Executive Summary

According to today's literature, people with endometriosis can expect a gap anywhere from 4 to 11 years between their onset of symptoms and receiving a diagnosis.

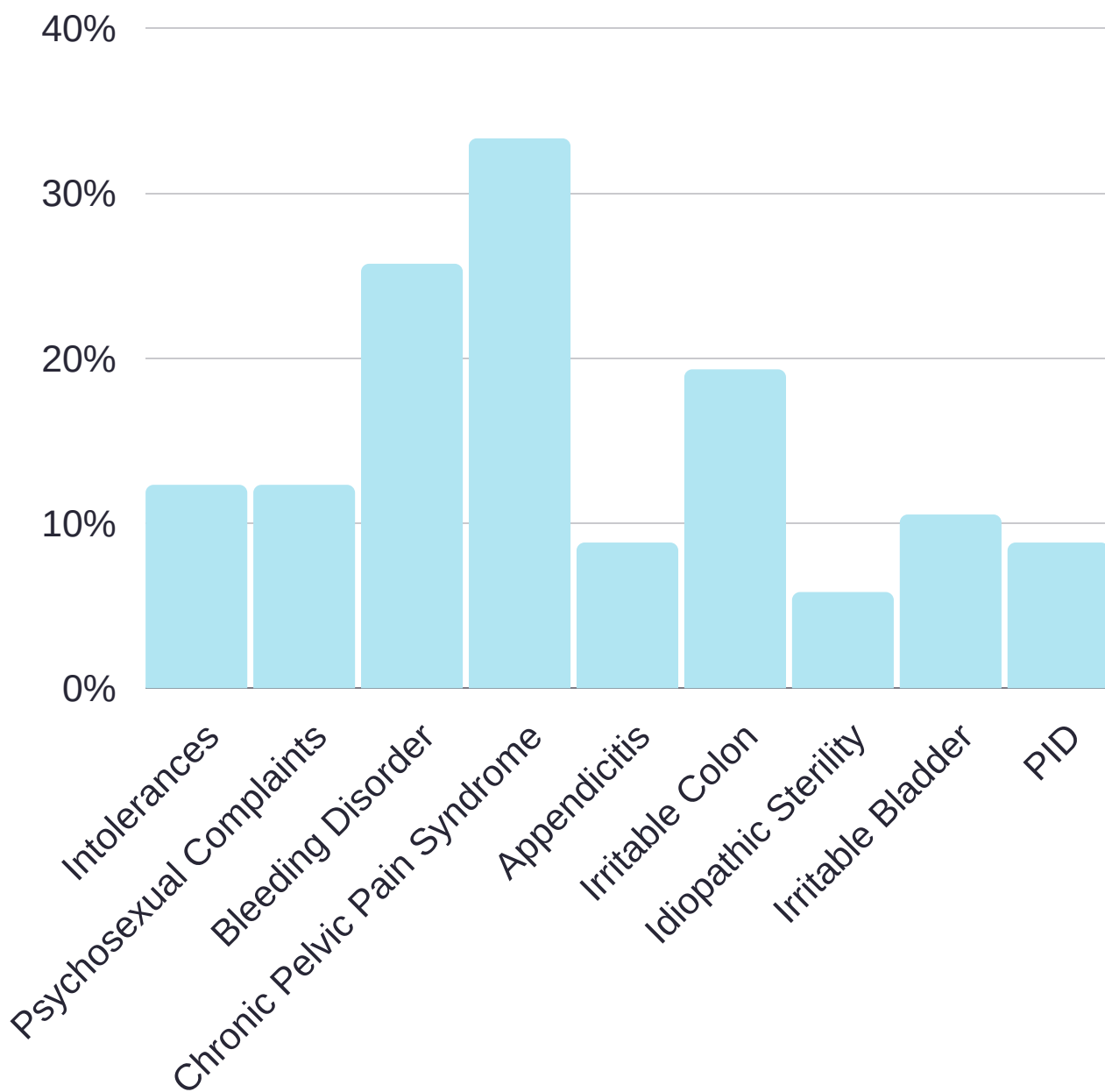
This delay is largely due to a lack of understanding of the condition. Endometriosis diagnosis poses challenges as it can present similarly to other conditions, both on a cellular level and in terms of symptoms. Also, there are no non-invasive ways to diagnose endometriosis, and access to the type of surgery for diagnosis - laparoscopy - is a privilege.

In this report, we explore the current state of the misdiagnosis of endometriosis, and its effects on the individual and society as a whole.



Report Highlights

The most common conditions endometriosis is misdiagnosed with include (9):





Word Bank

Endometrial:

The mucous membrane lining the uterus, which thickens during the menstrual cycle in preparation for possible implantation of an embryo.

Biomarker:

A naturally occurring molecule, gene or characteristic by which a particular pathological or physiological process, disease etc. can be identified.

Tenesmus:

A continual or recurrent inclination to evacuate the bowels, caused by disorder of the rectum or other illness.

Pathognomonic (of a sign or symptom):

Specifically characteristic or indicative of a particular disease or condition

Histology:

The study of the microscopic structure of tissues.

Dysmenorrhea:

Painful menstruation, typically involving abdominal cramps

How Endometriosis is Diagnosed

Endometriosis is a gynecological disease that is mainly characterized by its most common and most challenging symptoms: sub-fertility and pelvic pain (1). People with endometriosis have **endometrial**-like tissue that grows outside of their womb and within their pelvic cavity (2). This is a disease that does not have a cure, though there are treatments available to help manage the pain. However, there is a general lack of awareness around endometriosis throughout society, including patients and even physicians. Without an understanding for the disease, or knowledge of its presence, even these treatment measures cannot be taken.

Endometriosis diagnosis poses challenges as it can present similarly to other conditions, both on a cellular level and in terms of symptoms. It can be difficult to distinguish between endometrioma from a cyst of the corpus luteum, a mass of cells that forms in the ovary; a hemorrhagic cyst, a cyst that

can bleed; or a simple cyst, a cyst containing a straw colored liquid. There is a thick, dark brown color to the cyst fluid in the endometriomas, however this color is not unique to endometriosis (1). The current best diagnostic test for endometriosis is laparoscopy, but it comes with costs and surgical risks. This method involves using a small incision, referred to as keyhole surgery, to enter the body and look for visual evidence of endometriotic deposits within the abdomen. Unfortunately, there are no clinical practices that are non-invasive currently available to accurately diagnose endometriosis (2).

It is difficult for endometriosis to be diagnosed without laparoscopy because it does not have disease-specific features or **biomarkers** that are sufficient for superficial diagnosis. Endometriosis is best identified by use



How Endometriosis is Diagnosed Cont.

4 to 11 Years

Is the gap people with endometriosis can expect between the onset of their symptoms and diagnosis.

of histology, with extrauterine lesions that contain **endometrial** glands, **endometrial** stroma, and/or hemosiderin-laden macrophages, which makes it difficult to catch without laparoscopy. According to today's literature, people with endometriosis can expect a gap of anywhere from four to eleven years between their onset of symptoms and their diagnosis (3). People who experience endometriosis do not only suffer from the direct symptoms of the disease, such as pelvic pain and infertility. Consequentially, they may also experience a lower quality of life, higher rates of depression, challenges in intimate relationships, limited ability to participate in daily activities and socialization and loss of productivity and potential income. Further, those who battle with endometriosis face the burden of health care costs (3). With its ongoing list of obstacles that endometriosis presents to its victims, an accurate and timely diagnosis can make a substantial difference for those who are forced to take on this battle.

Misdiagnosis, delayed diagnosis, and failure to diagnose endometriosis have detrimental consequences, particularly on patients. Without a timely and accurate diagnosis, patients continue to experience persistent painful symptoms of the disease and their quality of life is proportionally impacted by this burden (3). Failure to diagnose endometriosis can be harmful to the patient-physician relationship, and it can even lead to the development of central sensitization. This is a reality in which those who experience persistent pain related to endometriosis develop a heightened awareness for pain both related and unrelated to their lesions (3). Improvements in diagnosing endometriosis need to be made to improve the lives of those who suffer from this disease and to allow them to be active members in society. To do so, it is important to understand who is most burdened by misdiagnosis of endometriosis, for what reasons these inaccuracies occur, and what cost they inflict upon individuals and societies.

Demographics of Misdiagnosis

All people who menstruate are eligible victims of endometriosis. It is prevalent in 6-10% of menstruating people, in 50-60% of menstruating people with pelvic pain, and in 50% of those with infertility. On top of these odds, some individuals fall into demographics that may be faced with higher possibility for misdiagnosis compared to others. Despite some disparities in endometriosis diagnosis, endometriosis still goes undiagnosed even in countries where there is universal healthcare (3).

Commonly, adolescents carry a great burden of living with endometriosis without a diagnosis, misinterpreting their symptoms of endometriosis as abdominal pain related to menstruation.

This association delays seeking help from a health professional by 4.6 years among young people. The process is lengthy, particularly for younger patients, because of misinterpretations of symptoms alongside the need for biomarkers to develop in order to reach diagnosis (4).

It is important to note that the prevalence of endometriosis may vary with the diagnostic method, and laparoscopy is currently the golden standard for diagnosis (5). As a result, individuals with less access to such diagnostic methods may be underrepresented in the prevalence rates, and reported rates of endometriosis are higher among people of affluence. Higher rates among resource rich populations could be associated with earlier and better diagnosis as affluent individuals may have more opportunity to recognize pelvic pain and infertility as important health issues, particularly when they are in a position that allows them to investigate these concerns (5). This can be seen across societies and across individuals. Racial differences in endometriosis prevalence have also



Reported rates of endometriosis are higher among people of affluence.

been speculated to be in relation to greater under diagnosis and misdiagnosis among certain groups. Afro-indigenous people report lower rates of endometriosis compared to African Americans and Caucasians, and part of the reason could possibly be due to under diagnosis of endometriosis. Under diagnosis in African countries may be due to laparoscopy being less accessible (5).

The types of services that are utilized are also relevant to the appropriate and timely recognition of this disease. A study on the endometriosis-related health care usage among Puerto Ricans

found that those who utilized private health care were more likely have diagnostic and medical attention for their endometriosis compared to those who sought medical care in the public sector (6). Among patients with endometriosis between the ages of 14-50, laparoscopy was 3.5 times less likely to take place for endometriosis those in the public sector. Further, individuals using the public sector were more likely to be prescribed opioids or narcotics, and those in the private sector utilized obstetrics and gynecology services more than twice as much compared to the public service users (6). While menstruating people suffer from delayed diagnosis of endometriosis globally, there are recurring factors that may add weight to that burden for people of some demographics. Age, race, and socioeconomic status are parameters for which the likeliness of having the awareness and tools to properly identify endometriosis may fluctuate.

Symptoms that Cause Confusion

Overlap of symptoms with other diseases, along with a limited diagnostic process, present challenges that contribute to the misdiagnosis of endometriosis. The most common symptom of endometriosis is dysmenorrhea, but there are numerous other ways in which the disease can be displayed (7). Like other diseases, there are different types of endometriosis and various ways in which it may present symptomatically.

Intestinal endometriosis can be estimated to be present in anywhere from 3% to 37% of all cases of endometriosis. It is a type of endometriosis that is easily overlooked for diagnosis as endometriosis due to the type of symptoms it presents. For example, those who have intestinal endometriosis may experience diarrhea, constipation, tenesmus and rectal bleeding.



Endometriosis is difficult to diagnose, especially without surgery, as its symptoms can closely identify with those of other intestinal diseases. For menstruating people who experience symptoms of an ambiguous nature and whose radiologic and endoscopic findings are not specific, the diagnostic options should consider intestinal endometriosis (7).

Common Misdiagnosis

People with endometriosis are commonly misdiagnosed with various other conditions, including irritable bowel syndrome (IBS), solitary rectal ulcer syndrome, inflammatory bowel disease, colorectal cancer, ischemic colitis, and metastatic tumor (7).

Intestinal endometriosis can be particularly difficult to diagnose due to the way in which its symptoms overlap with other diseases.

Preoperative evaluation results can lack specificity which emphasizes the importance of defining the

characteristics of intestinal endometriosis (7). Thus, individuals with intestinal endometriosis are commonly misdiagnosed with various other health issues. A study done by the Division of Colon and Rectal Surgery at the University of Ulsan College of Medicine and Asan Medical Center in South Korea retrospectively reviewed 30 intestinal endometriosis patients' pathological reports. All of the individuals were confirmed to have intestinal endometriosis upon surgical screening, however, the study looked at the preoperative diagnosis of the patients.

Of the 30 individuals, 17 were misdiagnosed with other diseases. Eight individuals were diagnosed with a submucosal tumor in the large intestine, 3 were told they had malignancies of the colon/rectum, and three were diagnosed with malignancies of the ovaries (7).



A reason why an endoscopic test that obtains biopsy material may not encourage consideration of endometriosis is that biopsy material may be too superficial. The endometriosis typically exists in the inner layers of the bowel wall that may not be reached endoscopically (7). These various misdiagnoses and the reasons for why they so commonly occur ultimately lead to delayed diagnosis and therefore ill-suited management for people with endometriosis (7).

The Economic Burden of Misdiagnosis

Chronic pain is a burden to the individual who experiences it; besides the pain, they may have a lower quality of life with a variety of physical, emotional and financial consequences. People who suffer from endometriosis are in their most productive years of life, and in return, have the most to lose by being benched by their diseases. Without an explanation, it can be difficult to appropriately manage symptoms.

The Economic Burden of Misdiagnosis Cont.

\$22 Billion

Was the combined costs of endometriosis diagnosis, pain treatment, and infertility in the U.S. in 2002

High rates of delayed and misdiagnosis of endometriosis means that those who suffer from it do not know the true cause of their pain nor how to make it go away. Costs of misdiagnosis of endometriosis to the patient and to society are significant. Some studies have investigated the economic burden of the disease on individuals and on societies. In 2002 in the US, costs of endometriosis diagnosis, pain treatment, and infertility were estimated at \$22 billion (1). The economic burden of endometriosis in Canada, caused by its victims being unable to contribute to society as a result of their disease, was estimated at \$1.8 billion (4).

A national online survey distributed to people who menstruate in Australia in 2017 found that the cost of illness burden fell between \$16,970 and \$20,898 per person annually. These costs are associated with people who experienced pelvic pain irrespective of endometriosis diagnosis, and the majority of the burden was due to loss of productivity (8). Though it is difficult to track economic costs due to misdiagnosis, the largest costs related to endometriosis come from lost productivity that result from pelvic pain (8).

A Need for Awareness

Endometriosis is painful and emotionally draining. It is a sneaky villain that thrives on misconception, commonly being taken for something that it is not. Faulty understanding of the condition causes pain and economic loss to individuals and to society. Awareness around the existence of endometriosis could go a long way in ensuring that more menstruating people gain the important diagnostic status in a timely fashion. With more consciousness around this disease, listening to the symptoms and experiences of the patients could potentially create an atmosphere in which a patient's lived experience can be taken as reason enough for investigating the presence of endometriosis without laparoscopy.



<1%

or \$6 million of the \$41.68 billion NIH 2020 budget goes towards endometriosis research, programs, and services.

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About the Author

Meet our dedicated Community Health Intern



Charlotte Myers is a master's student studying Public Health Sciences at Karolinska Institutet in Stockholm, Sweden. She has a bachelor's degree in Global Studies with minors in Spanish and Public Health. She is passionate about human and ecological wellness, and aspires to engage in community health initiatives that enable a sustainable positive change that creates opportunities for all humans to thrive.