

# ENDOMETRIOSIS

AN AUTOETHNOGRAPHY ON THE EFFECTS OF A CHRONIC CONDITION  
ON PERCEPTION OF TIME AND THE FUTURE  
BY KIARA LAURIA

“IT’S ALL  
PART OF  
BEING A  
WOMAN.”

This is the simple phrase millions of women around the world are told daily when they express their pain from menstrual cramps. This is the simple idea millions of women around the world are convinced to believe when they reach out to medical professionals about the excruciating pain that comes along with a condition like endometriosis.

Endometriosis is defined as a chronic condition in which a woman’s endometrial tissue grows abnormally both in location and behavior. Interestingly, some women with endometriosis never experience symptoms and are discovered to have it only incidentally during a procedure. On the other hand, some women experience painful cramps, chronic pelvic pain, and, in many cases, eventual infertility, disrupting quality of life and the path toward adult-

hood that society pressures us to follow. I am a part of the latter group.

The normative passage into adulthood includes five objective life events: “completing education, entering the labor force, becoming financially independent, getting married, and becoming a parent,” which according to Pamela Aronson, “are based on outdated assumptions about class and gender” (quoted in Jaffe, 2018). But when I begin to think about the timeline I have set for myself based on society’s expectations I can’t help but wonder if my diagnosis will get in the way.

I plan on graduating from the University of Florida with a Bachelors in Behavioral and Cognitive Neuroscience within the next few years. While working towards this, I want to continue working so that I can enter and pay for my medical school with as little debt as possible. I plan on taking a gap year to work full time and strengthen my medical school applications. Medical school will then be four years long followed by a minimum three-year residency. I also want to get married but I want

to start a family once I have a stable job as a medical professional. There is a small problem with this timeline, though. My endometriosis diagnosis threatens my dream of becoming a mother. After speaking to numerous doctors, the consensus is the same: the longer I wait to have a child, the less likely it is for this dream to come true.

This realization and the consequent anguish and disappointment is shared amongst the approximately 190 million women that have endometriosis around the world, according to the World Health Organization. How can something like getting pregnant- which is so simple for others it happens “accidentally,” possibly be so difficult for so many women? My endometriosis diagnosis, coupled with the fact that female physicians have higher rates of infertility, miscarriages, and complications, (Stentz et al. 2006) I feel I will have to choose between two dreams. If I don’t choose, I will eventually run out of time and be left without the latter of the two.

In this autoethnography, I will explore the effects

of an endometriosis diagnosis both from medical and personal perspectives on mental health, physical health, quality of life and impact on the future. There is not yet a cure for endometriosis. By educating others and sharing the stories of women like me, I hope to bring empathy and respect to the millions of women around the world that are ignored because of a pain that cannot be physically seen.

that it can “cause pain during intimacy, bladder dysfunction, urinary frequency, bladder pain, pain with urination, and intestinal dysfunction which could be constipation [and] pain with bowel movements.” (Dr. Sprague, personal communication, November 2, 2023). In short, endometriosis can grow into other organs and can affect how they behave.

For many women, endo-

“A DEBILITATING AND  
CHRONIC DISEASE”

(DR. SPRAGUE, PERSONAL COMMUNICATION, NOVEMBER 2, 2023)

Endometriosis occurs when endometrial-like tissue grows outside the uterine cavity. Most commonly, this tissue affects the fallopian tubes and the ovaries, but it can also impact the bladder and the intestines. The endometrial tissue that grows within the uterus is ordinarily shed during a woman’s monthly menses. Yet when the endometrial tissue grows beyond where it’s supposed to, it is not broken down but rather built up, resulting in irritated tissue, scar tissue, and pain beyond the days of the standard menstrual cycle.

I interviewed Dr. Sprague, an obstetrician-gynecologist in Weston, Florida, about endometriosis and its impacts. When I asked about the disease’s effects on other areas of the body, he explained

metriosis entails the experience of waiting- waiting for providers to acknowledge their pain and waiting for the clarity of a diagnosis. Because endometriosis is currently only officially diagnosable through laparoscopic surgery, millions of women around the world suffer in silence for years before they are heard for their pain. Because laparoscopic surgery is an invasive and expensive procedure, many women have no choice but to forgo an official diagnosis that can get them the help they need. Left untreated, endometriosis can continue to overcome surrounding organs and cause debilitating symptoms. In many cases, it affects a woman’s fertility and can prevent a woman from becoming pregnant. According to Massachusetts General Hospital, infertility is experienced by

30-50% of people with endometriosis. Additionally, women without endometriosis have a 10-20% chance of getting pregnant each month, while those with surgically documented endometriosis have a chance of only 1-10% (Massachusetts General Hospital). These are already alarmingly small statistics- but in my case, I must reckon with the fact that female physicians in the United States are known to have greater difficulty than non-physicians in achieving and sustaining a pregnancy.

From 2012 to 2013, Stentz et al. (2016) studied perceptions of fertility and their impacts on decision-making. They found that many female physicians have dealt with infertility and have regrets about the way they planned their future. Considering the fact that medical school and training interfere with a woman’s prime reproductive years, it is not entirely surprising that, paired with the demands of a medical career, those with existing reproductive difficulties, such as endometriosis, have even greater difficulty with pregnancy. It is surprising, however, that there is “a substantial chance of infertility among the American female physician population—a rate twice that of the general population, with nearly a third of that infertility related to age” (Sobotka and Martinez et al., 2012). Keeping in mind that fertility rates decrease significantly after age 35, many women choose to have

children before beginning their residency training, but this is a feat in itself (Cleary-Goldman et al., 2005). The demands of residency pose a unique risk to a woman's physical and emotional health during pregnancy, with "an increase in gestational hypertension, placental abruption, preterm labor, and intrauterine growth restriction" having been reported in female residents of the study (Phelan, 1988). Having to choose between facing risks with pregnancy before residency or not being able to sustain one at all afterwards, female physicians are faced with a difficult, life-altering decision.

## “ARE MY DREAMS CRUEL FOR SHOWING ME A WORLD THAT MIGHT NOT BE POSSIBLE DESPITE MY GREATEST EFFORTS?”

It is in our human nature to look to the future, to dream of the possibilities of what

our ideal world can be. Millions of women dream of living free from the effects of endometriosis; free from the excruciating cramps that send us doubled over in pain, causing us to miss school, work, holidays; free from the financial burden of taking expensive hormone medications to manage our symptoms; free from the social stigma that comes with openly discussing a woman's menstrual cycle; free from the pressure of telling our partner that we might

not be able to deliver on one of the most intimate aspects of a relationship; free from the pressure society places on us to have children by a certain time. Our dreams serve as the motivation to work harder, to study more, to become better versions of ourselves because we know there is hope. But what of those dreams that are beyond the scope of our capabilities? What of those dreams we physically cannot work for and must leave up to the chances of life?

In their 2011 graphic novel *Daytripper*, Fábio Moon and Gabriel Bá examine the fragility of life and the uncertainty that

what my life can be once I open my eyes. My dreams tell me who I am” (p. 223).

For women with endometriosis, our dreams and our reality conflict. Our dreams trick us into imagining a life in which our goals are all achieved if, according to Moon and Bá, we simply open our eyes. But the real world can be cruel and unforgiving—the burden that comes with a chronic condition is heavy, and balancing the consequences with goals and society's expectations is exhausting. Despite our greatest desires, the reality that women with endometriosis might have to choose between having children and starting a career in the medical field is terrifying.

I interviewed a fellow

(KIARA LAURIA, PERSONAL COMMUNICATION-JOURNAL ENTRY, NOVEMBER 10, 2023)

student with endometriosis, “Katie,” who shared her worries about being able to balance her career and her dream to start a family. Currently on the pre-PA path, she said, “I also worry, if I wait until I'm out of PA school, and if I wait until I'm a few years into my career and established, is that going to be too late? And I feel like I shouldn't be worrying at 22 years old...if I'm going to be too old to have kids.” (personal communication, November 2, 2023). In a constant race

against time, it is difficult to accept that our dreams could have to be put aside to give way to the reality of life.

Touching upon some of the most unique aspects of

## “ONLY OVER TIME DOES HAVING A CHRONIC CONDITION BECOME BEST UNDERSTOOD.”

(DR. SPRAGUE, PERSONAL COMMUNICATION, NOVEMBER 2, 2023)

the women's experience, endometriosis impacts reproductive health, physical health and mental health. Excluding the small subset of women that do not have symptoms, endometriosis significantly affects a woman's quality of life and her perception of her future, as well as the past.

In his obituary, Brás continues, “I can't really tell how old I am, only that I'm too young to wonder if I asked the right questions in the past, and too old to wish the future will bring me all the answers” (p. 223). Similarly, Dr. Sprague says so many women question themselves when

they are diagnosed with endometriosis. He explains that so many women, ignored for their pain for so many years, come to discover they have endometriosis when they have difficulty conceiving. At this stage in life, assisted reproductive therapies may be required to even attempt achieving pregnancy. He shares that so many women question themselves at this stage in their life, wondering, “If I took care of this earlier, maybe I would be able to have children, maybe I would've been able to manage the pain a little bit differently, maybe

my life would have progressed in a different way” (personal communication, November 2, 2023). This continuous scrutiniz-

ing has a significant impact on mental health. In my conversation with “Katie,” she shared the role guilt plays in her life, explaining, “I worry that I'm not gonna be able to have kids and then I also worry that I'm not gonna be good enough for somebody because I can't have kids...I feel like I would be disappointing somebody else” (“Katie,” personal communication, November 2, 2023). Fearing what the future entails is mentally draining, especially when there is a high risk of disappointing someone else—despite our greatest efforts.

Negatively affecting reproductive, physical, and mental health, among other areas,

## “SUFFERING IN SILENCE... BECAUSE I THOUGHT IT WAS JUST NORMAL.”

(“KATIE,” PERSONAL COMMUNICATION, NOVEMBER 2, 2023)

endometriosis has a way of making women rethink their dreams and reevaluate their goals. Although it may be easy to succumb to a diagnosis of such gravity and let it alter the way we view ourselves and our future, we must not let a diagnosis define us. We have the power to create change and reduce the stigma around women's menstrual health so as to increase education on conditions like endometriosis and their impacts on daily life.

By learning from both personal and medical perspectives, we can truly understand how endometriosis affects women around the world— and how we can support women with endometriosis. Perhaps there will be a cure for this disease, but in the meantime, we can be more compassionate and respectful of others' pain so that no woman will ever again hear the words, “It's all part of being a woman.”