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PATIENT EMPOWERMENT IN MODERN MEDICINE: A PERSONAL ACCOUNT OF
ENDOMETRIOSIS AND BEING AN EQUAL PARTNER IN MY HEALTHCARE

A Thesis

presented in partial fulfillment of requirements

for the degree of Master of Arts

in the Department of Journalism

The University of Mississippi

by

Jacqueline Schlick

May 2019

ABSTRACT

This work outlines my personal experience with a diagnosis of stage three endometriosis and partial oophorectomy surgery along with the subsequent medical opinions I received by my primary OB/GYN and other doctors. This thesis seeks to discuss the issues surrounding patient empowerment, and specifically, laws that support patients in their exploration of the truths behind their conditions and the importance of self-education in order to be better equipped in conversations with their physicians. The work includes testimonials from women about their levels of knowledge into their own medical needs upon the time of their prescription to pharmaceutical medications, and how patients can improve their healthcare through utilizing pharmacist opinion. Readers should take away tools and best practices for securing a better patient outcome through their empowerment and education of this topic.

DEDICATION

This work is dedicated to
any woman told what her body can and cannot do,
and to all medical patients taking back their healthcare.

ACKNOWLEDGMENTS

I thank Professor Joseph Atkins for his tireless positivity, encouragement, and love for the written word which he has demonstrated throughout my graduate school career. Thank you to Professor Vanessa Gregory for reviewing my initial proposal and suggesting a deeper exploration into hormonal birth control. And Dr. Debora Wenger, thank you for knowing exactly how to push to the center of what I had been trying to articulate all along and for supporting me in my writing and reporting throughout the pursuit of my master's degree.

To Dr. Tanya Nichols, my most wonderful surprise and my fiercest advocate. Thank you dearly for your research into my disease and your continued advocacy. You have poured into my life the particular brand of confidence one only knows when she has an ally of your magnitude, compassion, and servant's heart.

Thank you endlessly to the surgeon who restored my health. Thank you for every after-hour phone call to check in on me, secondary appointments to hear my fears, and your relentless warmth and empathy. You made this journey lose its darkness.

And to the University of Mississippi, which has watched me grow these six years and has challenged me in ways that have shaped who I am and have set a foundation for who I will become. I could never thank you enough.

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CHAPTER I
PRE-OPERATIVE APPOINTMENT

The metal chair beneath me is chilling, even through the sanitary paper between my skin and its surface. The room smells of dusty latex gloves and for some unmentioned reason there is an invisible sound machine playing ocean waves on a loop so small it sounds more like static. I cannot forgive the two walls in an L-shape in front of me, one ketchup red, the other mustard yellow. Who chose the hideous combination for an OB/GYN examining room? More importantly, who selected the heavy black and grey curtains keeping out the light?

This was supposed to be a haven for new life and hope.

Then I remember: not for everyone. This is the room where women are told all the time that their bodies don't work like other women's bodies. That they are failing at starting new life.

It's where I might be told the same.

Dr. Barnes knocks twice and enters. He hugs me tightly, his smile wide. I attribute that smile to the fact he arrived at work today at a late 1 p.m. so he could see his youngest son perform as "Lizard #2" in the elementary play. The nurse at the front desk apologized, saying the doctor would be a few minutes late to our appointment. "He always prioritizes family," she said.

Dr. Barnes is young, energetic, and handsome. He's so kind that it sounds as if he's offering me an umbrella in the rain when he says, "So, surgery tomorrow! We've waited a year

for this day. You should be relieved we're finally taking care of you."

He goes on to explain the procedure, that he'll make three incisions, two below my hip bones, one in my naval. The scope will move through my pelvis, hunting the 10 cm cyst that tore and bled the year before, the fluids with nowhere to go.

"I still doubt it's endometriosis," he says. "You don't have it in your genes, you're asymptomatic and you're healthy and fit. It seems unlikely. It's probably just a simple cyst that grew too large."

"Will you explain what endometriosis is one more time?" I ask.

He tells me that this chronic disease results from endometrial tissue that is supposed to be confined to the uterine cavity growing, for an unknown reason, outside of that cavity. Because the endometrial cells and tissue buildup have nowhere to go, the body responds with inflammation that triggers hormonal imbalances that lead to scarring, adhesions, infertility or subfertility (difficulty in becoming pregnant). Endometriosis "implants" look like small circles of gunpowder when spotted on the uterus, bladder, ovaries and other surrounding organs, but the disease can also form pockets of old blood called endometriomas, or "chocolate cysts" that will not decrease in size without surgical intervention.

The study "Management of endometriosis in general practice: the pathway to diagnosis" published in the *British Journal of General Practice*, states, "The prevalence of endometriosis is estimated to be around 10%. Diagnosis is through visualization of the lesions, mostly via laparoscopy. Studies reveal that there is an average delay in the diagnosis of endometriosis of between 8 and 12 years. Little is known about the reasons for delays in diagnosis."

"We've followed this cyst for a year now and it has only grown," I say.

“Well, yes, that could be a sign that it’s an endometrioma,” Dr. Barnes says. “But I’ve seen simple cysts stubbornly remain large once they pass the five cm mark.”

I nod, knowing what he will say next. Knowing, because he has repeated it to me throughout the past twelve months, as if conditioning me to accept it.

“Your left ovary is likely gone, Jacquee. I doubt it could survive a cyst so large. But I’ll do everything I can to save it... You’re so young. Only 23.”

He adds that last thought so softly that the sound of his disappointment makes my hands begin to shake.

I ask questions, I know I do, because I realize after all of them I am only left with more, but I can’t remember what I have asked and what I need to because all I can keep hearing is, “You’re so young.”

He hugs me again.

It’s just a simple cyst, I tell myself.

The man who skips work to cheer on Lizard #2 would not lie.

CHAPTER II

ENDOMETRIOSIS

Ten percent of the world's population of women has endometriosis, but there is not much known about this disease that is capable of robbing women of their fertility. Since a woman goes eight to 12 years from the onset of symptoms before receiving a diagnosis, it is common for women to find it after dealing with issues related to infertility or subfertility.

In today's scientific advancements, there is only one solution: hormonal birth control to stop the body from ovulating and menstruating. During ovulation, the body prepares the woman for pregnancy, creating a thick uterine lining capable of providing support for a fertilized egg. If fertilization does not occur, the uterine lining sheds in the process known as menstruation. Both pose a risk to people with endometriosis. The trigger inside the body to begin thickening the lining cannot discern where the lining is ending up, allowing that lining to grow outside of the uterine cavity and within organs that cannot dissolve the tissue. When it is time to shed the lining, any tissue outside the uterine cavity has nowhere to go and causes inflammation that leaves permanent scarring on the affected areas.

Birth control is not a distinctly effective medication for the treatment of endometriosis and its precision is more akin to chemo treating cancer. Chemotherapy cannot target only mutated cells and must also kill healthy ones. Similarly, hormonal birth control cannot target

uterine tissue outside of the cavity and instead can only work to prevent ovulation and the subsequent thickening of the uterine lining, leaving behind potential side effects as it rewires the body's natural hormones.

“As for birth control suppressing endometriosis, I don't think it's an ideal treatment but there's also not many better options available, which is an awful answer to a very profound problem in the female community,” Pharmacist in Mobile, Alabama Katie Godlewsky said. “Endometriosis, in short, is the presence of endometrial tissue outside the uterine cavity where it shouldn't normally be. This can be influenced by genetic factors and some combination of environmental factors, and the presence of this abnormal cell growth where it shouldn't be prompts a woman's body to react via inflammatory markers and hormone dysregulation that leads to the hallmark pain and infertility issues we see in women with endometriosis; however, there's currently no drug product available in the U.S. market that will reverse or directly treat this root cause endometriosis. So, we're unfortunately left with controlling symptoms related to endometriosis instead. And for the hormone dysregulation, we're left with birth control and the more potent hormone-regulating products that are generally used to adjunctively treat hormone-related cancers that carry a much more severe side effect profile than hormonal birth control. So, I don't personally think that hormonal birth control products are an ideal treatment for endometriosis by any stretch, but I think it's just the medical community's way of doing the best with what is currently available in the drug market.”

In a study published in the *European Journal of Obstetrics, Gynecology, and Reproductive Biology*, 136 women who had confirmed endometriosis as diagnosed by laparoscopic surgery between the years 2009 and 2015 were put into two categories: those with a

history of hormonal contraceptive use and those with no history of hormonal contraceptive use. The study sought to find if a connection between the use of hormonal contraceptives and the occurrence of ovarian endometriomas could be made. Among the 93 women with a history of using hormonal contraceptives, 17 had ovarian endometriomas (18.3 percent). Among the non-users, 21 out of the 43 women studied were found to have an endometrioma (48.8 percent). The rate for endometrioma occurrence was lower for women on some form of hormonal birth control, but it was not a cure nor was it an infallible line of defense, only a suppression of symptoms.

In spite of its less than perfect outcomes, hormonal birth control was prescribed with optimism to me by three different doctors. A doctor in Tupelo who looked at my ultrasound pre-surgery and wanted to perform robotic-arm surgery on me said, “Your cyst is huge. You’ll need to start birth control right away after surgery. You should have already been on it. That way we can make sure your endometriosis doesn’t come back.” When I asked questions about potential natural treatments, I was talked down to, like a father explaining to his child not to rest her hand on a stove.

At a second opinion appointment, a woman OB/GYN at Memphis Obstetrics & Gynecology Association (MOGA) looked at the same ultrasound image and wrote me a prescription for depo-provera, a form of synthetic progesterone in the form of an injection that is administered every three months.

“The depo-provera will shrink your current cyst,” she said as she handed me a small white piece of paper with my new prescription.

Upon researching on my own, I found that depo-provera has no effect whatsoever on current cysts and instead works only to hinder the formation of new cysts by stopping the body

from ovulating (at which time an egg leaves behind a small cyst where it escaped the ovary). Depo-provera causes a loss in bone density, which makes it an even more peculiar choice for me considering my strong family history of osteoporosis (mother, maternal grandmother and maternal grandfather), which I had indicated on MOGA's paperwork. Even the depo-provera patient insert warns against people with a family history of osteoporosis taking the medication.

Three doctors, three different ways of saying hormonal birth control would rid me of my disease long enough for me to have children, but I wasn't satisfied with the answers I was being given. They were vague, they were without scientific evidence, and when met with counterarguments, they resulted in my physicians stammering and demonstrating impatience.

I did not give in, and eventually, I did find a thorough explanation of exactly why and how birth control could help or harm me. The issue was never that the information was not out there or that medical professionals had some nefarious reason to withhold the truth. Instead, it was simply a matter of finding a medical expert who could explain in detail the processes of hormonal treatments with my particular family medical history in mind.

I finally found what I was looking for in the arena of pharmaceutical sciences.

“Ovulation is essentially survival of the fittest for your ovaries every month because only the best egg is put forth for potential fertilization, and your uterine lining gears up to make your uterus a hospitable place for conception,” Godlewsky said.

“When you use low doses of hormones to suppress ovulation (as found in hormonal birth control), the survival of the fittest and uterine changes shouldn't happen. But breakthrough ovulation can occur when taking hormonal birth control, and that's usually presented as cramps, mood changes, spotting, etc. and will hopefully prompt your provider to change birth controls to

a hormonal regimen that would better suppress ovulation. And this is why the efficacy rate for hormonal birth control isn't at 100 percent. It's very close to 100 percent, but it doesn't always completely stop ovulation, so there are still some hormonal changes that will happen while you use hormonal birth control. For this reason, I don't fully support hormonal birth control for the sole treatment of endometriosis, but like I said, it's unfortunately the best of our dwindling options for now. And with your family history of breast cancer, that only makes it more complicated because hormonal birth control is no longer the best of the worst options."

Further research supported her medical advice.

The article "New Developments in the Medical Treatment of Endometriosis" published in the *American Society for Reproductive Medicine* states, "Ideally, medications for endometriosis should be curative rather than suppressive. In addition, they should effectively treat pain and have an acceptable side-effect profile. Long-term use should be safe and affordable. Moreover, *they should not be contraceptive and not interfere with spontaneous ovulation* and normal implantation of the endometrium to enhance spontaneous conception" (emphasis mine).

I had never had an operation before. My body had never struggled for health in any way. Researching what could be gave me a comfort and a strength for surgery.

CHAPTER III
DAY OF SURGERY

I wake up on a flat bed, my feet tucked inside ridiculous hospital-issued socks that are several sizes too large and more scratchy than warm. The anesthesia wears off slowly. My mother is beside me, silent.

An hour later, Dr. Barnes appears by my bed. He smiles down at me and says, “Welcome back!”

He’s happy. It must have been a simple cyst.

“It was endometriosis,” he says.

I blink. The fog is difficult to push through.

“The endometrioma was larger than the ultrasound showed us. It wrapped towards your back.” He holds up his hands in the shape and size of a butternut squash.

“Your Fallopian tube was mangled,” he continues.

“Mangled,” I think. “Mangled” is a word I used in creative writing workshops. It is a word I have used dramatically and sometimes humorously. It is not a real word for real events. It is not a word for my body.

“I stood over you for thirty minutes trying to decide what to do, but I knew if I left it and it wasn’t functional, it would eventually cause an ectopic pregnancy,” he says. “I finally decided

to remove it, too.”

My mother is quiet. She has not been quiet a moment in her full-blooded Italian life.

“Also, your uterus and bladder were spotted with endometriosis implants. I had to burn some of both off,” he says.

My uterus is burned. My Fallopian tube is mangled. My feet are still pricked in these damn socks.

He says, “Of course, I tried to keep the ovary, but when I drew the blood out of the cyst, there was no ovary left. Not even a piece. It was probably absorbed entirely years ago.

“Your right side is beautiful. Yes, ovaries can be beautiful! Squeaky clean. We’ll get you on some birth control so the implants are suppressed and you will be good to go.”

It is quiet for a moment. I wait for him to tell me he is joking or to ask me to wake up, that this is a dream and that the real doctor would like to tell me how the surgery went.

I say only, “Did you take pictures?”

He winks, “You bet.”

CHAPTER IV

PATIENT EMPOWERMENT

As I healed and researched endometriosis, I traveled down a rabbit hole of different female diseases with corresponding testimonial discussion boards, comment sections, YouTube videos, and magazine articles. These health struggles and the women navigating them were all different, coming from different pockets of the world, but one thing was particularly common throughout.

Patients were coming to the internet to ask questions.

Patients were pinning to discussion boards their experiences in telling their doctors no.

Patients were creating videos on social media to warn other people about a medication they were prescribed that inflicted more harm than good.

These were individuals who had already sat on a doctor's examining room chair, in a flimsy paper smock, and asked questions about their healthcare.

Then why were they desperate for answers? Why were they claiming they were not aware of a medication's adverse effects?

The groundwork for conventional medicine has been a thing of scrutiny for me since I was in first grade, when my mother was diagnosed with stage two breast cancer. She was administered four rounds of chemo and when she thought the several-month journey was over,

she went to her final consultation with her doctors.

“You will now need to start on a drug called tamoxifen,” they told her. She was confused. There had been no discussion of this drug prior to her chemo completion.

“I have already taken poison. What more do I really need to put my body through?” she asked.

Tamoxifen, they explained, is a selective estrogen receptor modulator. In layman’s terms, it blocks estrogen from changing breast cells into cancer cells. My mother’s cancer was estrogen-positive and the protocol was to automatically prescribe the drug to all hormone-receptor-positive patients and direct that they be on the pill, taken every single day, for exactly five years.

She went home and researched what they did not tell her.

Firstly, the medical journal *The Lancet* compiled multiple studies following 30,000 breast cancer patients. Half were given tamoxifen for five to six years. Half did not take tamoxifen at all. Those who took the drug had a 74.4 percent survival rate compared to a 70.9 percent survival rate for the non-takers. Not only was the difference marginal, but the tamoxifen-takers were left with common side effects of hair thinning, bone mass loss, weight gain, memory loss and severe anxiety and depression.

To make matters worse, tamoxifen users might have had a 3.5 percent leg-up on the women who did not take the drug, but they were at greater risks for other cancers. The study reported, “Experimentally, tamoxifen has carcinogenic potential. In some strains of rat, tamoxifen can cause liver cancers at doses as low as 5 mg/kg per day.”

The drug goes further to damage other parts of female reproduction. “At a dose of 40 mg/day, there is a reported increased risk of endometrial cancer, this accords with an unopposed

oestrogenic effect of tamoxifen on the postmenopausal uterus.”

If the usual, lower dose of 20 mg/day is prescribed, women are still not in the clear.
“Oestrogenic effects on the postmenopausal vagina have been reported.”

Yet, even after all of this data, the study concludes, “I believe that the results of our pilot program, together with safety data from adjuvant tamoxifen trials, indicate that the potential benefits of using tamoxifen in a prevention trial in healthy women with a strong family history of breast cancer far outweigh the potential risks.”

Ironically, the study also includes this paragraph, “The issue of risk to healthy women is compounded by that of overtreatment—i.e., most women who take tamoxifen would not have developed breast cancer anyway. Overtreatment has always been a part of medical practice: in public health interventions, such as immunization or water fluoridation, the healthy population at large is exposed to possible hazards for unidentified individual benefits. Similarly, in treatment of primary breast cancer, most patients do not require mastectomy or radiotherapy after excision of the primary cancer, either because they were already cured or because they will die anyway of the disease. Likewise, use of tamoxifen for adjuvant treatment of primary breast cancer is mostly overtreatment, especially for women with good prognosis primary disease, for whom the risk of dying from breast cancer is similar to that of high-risk women in our prevention program.”

When my mother returned to her oncologist with her research, he smiled and said,
“You’re a smart one. I’m glad you’ve done your research. Under hospital protocol, I have to suggest tamoxifen, but what you’ve found is correct. Now let’s talk about what we’re going to do that’s actually going to help you overcome this disease forever.”

They decided on a double oophorectomy as the ovaries create most of the estrogen in a

woman's body.

It's 18 years later, and she is cancer free.

Growing up, I did not have a name for my curiosity of the sciences behind doctor recommendations. Today, after my necessary dependence on the medical community, I've learned of something called patient empowerment.

The Danish Committee for Health Education defines patient empowerment as “putting the patient in the heart of services. It is about designing and delivering health and social care services in a way which is inclusive and enables citizens to take control of their health care needs.” The committee defines an empowered patient as someone who:

- Understands their health condition and its effect on their body.
- Feels able to participate in decision-making with their healthcare professionals.
- Feels able to make informed choices about treatment.
- Understands the need to make necessary changes to their lifestyle for managing their condition.
- Is able to challenge and ask questions of the healthcare professionals providing their care.
- Takes responsibility for their health and actively seeks care only when necessary.
- Actively seeks out, evaluates and makes use of information.

In the article “Patient Empowerment in the United States: A Critical Commentary” published by *Health Expectations*, an international journal for healthcare, Dr. Kathleen Roberts explains, “Some patients simply want to be given information about their conditions whilst others want to have full control over all medical decision-making. Some evidence suggests that

active patient participation in health care is associated with better patient outcomes.”

Anatomy, physiology, biology, and pharmaceutical sciences are daunting topics for people unexposed to their details, but to take back some of the power in the doctor’s office, it’s necessary for patients to equip themselves the best they can with independent research and take back their healthcare.

However, the only barrier to being successful in this endeavor is not just being unfamiliar with medical terminology. In Leslie Jamison’s essay “Grand Unified Theory of Female Pain,” she suggests that women’s pain throughout history, literature and the medical community has been viewed as something that is usually made up, though a man’s pain is taken seriously. In her book *The Empathy Exams*, she includes an interview in which she speaks of a friend being admitted to the emergency room with excruciating pain from an ovarian torsion (when an ovary flips over on its Fallopian tube, blocking off blood supply and dying inside the body) and being told to wait. She says, “That to me felt like this deeply personal and deeply upsetting embodiment of what was at stake. Not just on the side of the medical establishment—where female pain might be perceived as constructed or exaggerated—but on the side of the woman herself: My friend has been reckoning in a sustained way about her own fears about coming across as melodramatic.”

Women, perhaps more than men, bring into the doctor’s office a fear of being judged, dismissed as whiny, or seen as carrying unrealistic worries about potential outcomes. Race, ethnicity, socioeconomic status and other characteristics that are individualized throughout patient experience are also in effect. According to a study of personalized strategies for patient empowerment published by *Health Education & Behavior* in 2015, “Research suggests that

patient engagement levels differ by race and ethnicity with African Americans and Latinos demonstrating lower engagement levels compared to Whites.” The study goes on to say, “Variables that mediate patient activation and empowerment, such as self-efficacy and patient-provider relationship, are usually less favorable among minorities than among others” and that “studies also show that minority patients are less likely to have opportunities to ask questions during provider visits, receive less information on their treatments, and are less likely to be consulted their preferences in treatment decisions.”

To overcome these generalizations and personal self-doubt in the doctor’s office, women can look to the seven components of patient empowerment, as published by the Patient Empowerment Network: information, health literacy (degree to which individuals have the capacity to understand basic health information, digital literacy (ability to find, evaluate, share, and create content using information technologies and the internet), self-efficacy (belief in your ability to create change in outcomes for your healthcare), mutual respect between doctors and patients, shared decision making, and a facilitating environment.

If access to a personal computer is not possible, patients can utilize the local library system for free computers and internet access to obtain information. Digital literacy, if not already learned, can be supported by librarians who are trained to understand the library’s computers and their programs.

Patients can also go to a local pharmacy to speak with the pharmacist for free. They are experts on medications but also have incredible insight into how the body works in general and how different diseases affect the body. If a second opinion doctor’s appointment is not covered by insurance, too far away geographically, or impossible for other reasons, a local pharmacy is

an excellent option to gain knowledge from a licensed medical expert without the added cost or inconvenience.

Patient education is only the beginning. According to a study published in the medical journal *PLoS One*, there are three proactive approaches that complete a patient's role in their autonomy. "The first is a process of continuous learning that allows them to acquire experiential knowledge about their health, as well as scientific information and technical know-how. The second involves their assessment of the healthcare they receive, in terms of its quality and how it aligns with their personal preferences. It includes their assessment of the quality of their relationship with the health professional and of the latter's scientific knowledge and technical know-how. The third type, adaptation practices, builds on patients' learning and assessments to compensate for and adapt to what has been perceived as optimal or non-optimal health or healthcare circumstances."

Which is to say that patients must self-educate, assess the healthcare they are currently receiving, and based on that information, make an informed decision on how to proceed.

Described another way, Leana Wen, M.D. defines best patient strategies in her article, "Five Ways to Make Your Doctor Your Partner." They are 1) to find a physician who supports shared decision making, 2) state your intentions, 3) help your doctor help you, 4) understand each test, and 4) make decisions together.

Dr. Wen says some doctors rely on "cookbook medicine," following one recipe in which symptoms and complaints lead only to an array of tests to rule out certain conditions. Patients should interrupt this routine by investigating if the doctor becomes impatient when challenged. If so, it's possible the physician has become accustomed to passive patients and will require a little

more effort in getting the answers needed.

As for her second point, stating intentions, patients should state they plan to be involved in the diagnostic and treatment processes. A helpful question, she says, is to ask, “I know what it is that I am worried about. Can you explain to me what it is that you are worried about?” This can work to welcome a doctor’s perspective if he or she is trying to quietly calculate possible causes and treatments without patient input.

To help your doctor help you, Dr. Wen says to communicate on what is most worrisome to you and not to strain to use medical terminology if you are unsure of exactly what it might mean. If the doctor is only asking yes or no questions, refrain from responding with one word and answer in a narrative-format instead.

Fourthly, understanding each test means to ask the doctor what it is he or she is looking for and what the potential risks are to taking that specific test. Some scans emit radiation, involve drinking dyes and chemicals, or can even increase lifetime risk of cancer (such as a CT scans). If the doctor is unable to thoroughly answer these questions, discuss your concerns with a nurse and have her educate you on the details.

Lastly, Dr. Wen advises patients to make decisions together. “If a potential diagnosis doesn’t make sense to you, ask for more information. Assure your doctor that you don’t need 100 percent certainty, you just want to know what he or she knows. Sometimes, doctors don’t share information because they’re unsure if a patient can handle uncertainty. What they don’t realize is that being told nothing often brings about even more uncertainty than an honest, open discussion.”

CHAPTER V

POST-OPERATION APPOINTMENT, EIGHT DAYS AFTER SURGERY

I feel well enough to shuffle along, though moving my legs past my hips seems like a foreign luxury.

Dr. Barnes knocks twice and hugs me.

“So, you look good! Let’s talk birth control.”

He holds up an orange and yellow box I’ve never seen.

“That isn’t what you suggested a few months ago,” I say.

“That was before I knew you had endometriosis. This is probably my favorite for that disease. If you’re not going to do the Mirena IUD, that is. The IUD is the only birth control actually tested to control endometriosis implants and proves most effective. But you’re a very small person and the insertion will definitely be painful.”

The Mirena IUD is an intrauterine device that contains 52 milligrams of levonorgestrel, a progestin (synthetic progesterone), and releases about 20 mcg per day. The Mirena IUD’s supply of progestin can last up to five years.

I say, “I’ve read about perforation of the uterine wall with the IUD and about infertility. My mother had breast cancer before she even turned 40. I’m at greater risk already and there are competing studies about whether prolonged use of hormonal treatments can cause female

cancers.”

He looks at me straight in the eye and says, “I’ve never heard one of my patients complain of any of those. You really have little to no risk of anything going wrong. There is support to say hormonal birth control actually protects against breast cancer by lowering your natural estrogen.”

He pulls out a reinforced Styrofoam chart of a woman’s hormone levels within a 30-day span. He explains that estrogen and progesterone move up and down, usually not together, and that all birth control does is make sure that both hormones keep each other in check and prohibit spikes in either.

“Is that healthy for the body though? To trick it into thinking I’m always pregnant?” I ask. “If my body naturally wants the hormones to be at totally different levels and peaks in order to satisfy the needs of my other systems and organs, am I supposed to force them to level out? Your hormones are responsible for so many functions of your body that have nothing to do with reproduction. Can’t that cause your period to disappear?”

“It can, yes! But many women see that as a great thing. No more periods means no more discomfort,” he says.

“Don’t you think it’s problematic that I’d just skip a part of my body’s routine that is as natural as menstruating?” I ask Dr. Barnes.

My jovial doctor becomes a little frustrated now. The perpetual grin vanishes.

“Jacqueline. It’s your best bet. It’s fine.”

He extends his hand towards me, the birth control pack on his palm.

I don’t like “it’s fine” as a medical explanation. I don’t like that the various questions

I've raised have not been addressed and I certainly don't like the thought of a plastic T-shaped intrauterine device living inside my cervix for half a decade, to only be replaced by another one, then another, poised to puncture my womb if given the opportunity. I don't like that synthetic hormones will dictate the rhythm of my body all the way to menopause.

But then I remember "mangled" and "burned" and I remember that I walk now with this image of being lopsided, having only a right reproductive system that lives in chronic risk of my hormones misbehaving. I remember that friends of mine have been on birth control for years and have only complained of acne or weight gain. I can handle those.

I have been told by medical professionals that these little pills in foil are the savior to my fertility. They alone can quiet my inflammation, trick my body into thinking it doesn't have to produce its own natural estrogen and progesterone anymore. It doesn't know how to correctly anyway.

So I take the yellow and orange box and a second hug.

CHAPTER VI

THE HISTORY OF BIRTH CONTROL

Birth control's history is wrinkled, to say the least. When sexually active partners had grown tired of using protection made from fish bladders, linen sheaths, animal intestines and vulcanized rubber, the first oral contraceptive was approved by the U.S. Food and Drug Administration in 1960. In just ten years, women were challenging the safety of oral contraceptives at congressional hearings after a book titled *The Doctor's Case Against the Pill* by journalist Barbara Seaman was published. Seaman interviewed physicians, medical researchers and women using the pill and published their experiences. In January 1970, experts gave their testimonies of the hazards of the pill in the Senate chamber. Not a single woman testified. Instead, women audience members sat hushed as experts detailed the health risks that doctors never mentioned when prescribing oral contraceptives. The D.C. Women's Liberation, a group of "radical feminists," finally spoke up and began rapidly firing questions. "Why are women being used as guinea pigs?" they asked.

After the hearings, the pill's hormone levels were considerably lowered from the original dosage and the U.S. government began to require a patient information sheet included in birth control packages.

Did matters improve?

Just four years after the hearings, seven women died after using the Dalkon Shield IUD produced by the family-owned pharmaceutical giant A.H. Robins Company in the United States. The nylon string attached to the shield's end was not sealed, causing it to fray over time and draw vaginal bacteria into the uterus. This caused septic infections throughout the body, septic pregnancies, pelvic inflammatory disease and loss of fertility.

By the time the Dalkon Shield was banned by the Planned Parenthood Federation of America in 1974, 18 users in the United States alone died—15 from septic miscarriages. More than 400,000 lawsuits were filed against the A.H. Robins Company before Robins filed bankruptcy in 1965.

Lawsuits against other IUDs on the market became so expensive that other companies began to slowly remove their products from the market. In 1990, Norplant, the first contraceptive implant that featured six matchstick-sized silicone rods that released levonorgestrel was introduced. The rods were implanted in the upper arm.

From the beginning, women using Norplant complained of sudden missed or frequent periods, intense headaches, nausea and scarring from botched insertion or removal from doctors. Lawsuits poured in, claiming women were not properly informed of the risks. More than 1 million American women used the device. The FDA advised all women using Norplant to discuss with their doctors a new option for contraception. Wyeth Pharmaceuticals agreed to pay the cost of the removal procedure if it was completed by the end of 2002.

In the 2010s and today, lawsuits against birth control companies still run rampant. According to Justin M. Lovely's law firm based out of Myrtle Beach, South Carolina, the complaints are often the same: migration of IUD and perforation of the uterine wall, ectopic

pregnancies, pelvic inflammatory disease, ovarian cysts, depression, lost period or too-frequent period, weight gain, decreased libido and blood clots. Top contraceptives facing lawsuits include Yaz, Yasmine, the Mirena IUD, Skyla and many others that are widely used.

According to *Hormones and Balance*, just three of the known side effects include estrogen dominance within the body which exacerbates endometriosis, ovarian cysts and fibroids, permanent damage to the body's natural hormone production by manipulating its method of homeostasis, and irreversible infertility by both significantly lowering the body's number of immature eggs in a woman's ovaries and shrinking the ovaries themselves by 29 to 52 percent.

Natalia Cabrera, a 24-year-old digital content creator at Purple, Rock, and Scissors in Downtown Orlando said, "I began taking birth control at 17 to calm the heavy periods I was having. Between the ages of 17 and 23, I tried nine different birth control pills because no matter which one I was on, I would experience breakthrough bleeding. I was on my last pill for almost two years and stayed on it because I was in a serious relationship at the time. For the last 1.5 years of that time, I was getting my period biweekly. They were light, but my body would experience the same emotions, same bloating, same cravings, same backaches every two weeks. It wasn't until three months after I decided to get off of the pill that I realized its negative impacts. My mind feels clearer and I feel like I have more control over my emotions since being off of it. I feel like I wasn't 'myself' for those seven years because I feel like an entirely different person now. I feel happier, lighter, and more stable all around."

New research is being published each year that finds new side effects of hormonal birth control. In February 2019, a study published in *Frontiers in Neuroscience* confirmed that healthy

women taking hormonal birth control pills might lose their ability to recognize complex facial emotions such as pride and contempt. The study says, “Despite the widespread use of oral contraceptives (OCs), remarkably little is known about the effects of OCs on emotion, cognition, and behavior.” If little is known, even less is told to women upon prescription.

The official FDA “Brief Summary Patient Package Insert” for hormonal birth control pills states, “Most side effects of the pill are not serious. The most common such effects are nausea, vomiting, bleeding between menstrual periods, weight gain, breast tenderness, and difficulty wearing contact lenses.” It then continues straight into blood clots in the legs and lungs, rupture of a blood vessel in the brain (stroke), heart attack, and blockage of blood vessels in other organs of the body, benign but dangerous liver tumors and high blood pressure.

“There is a conflict among studies regarding breast cancer and oral contraceptive use. Some studies have reported an increase in the risk of developing breast cancer, particularly at a younger age. The increased risk appears to be related to duration of use,” the FDA says.

According to the Centers for Disease Control and Prevention, in the United States alone, 23.9 percent of women between the ages of 15 and 44 use either a hormonal birth control pill or an intrauterine device. The Center for Young Women’s Health says that beyond pregnancy prevention, birth control pills are prescribed for polycystic ovarian syndrome, acne, painful menstrual cramps, premenstrual syndrome (PMS) symptoms, primary ovarian insufficiency and endometriosis.

A closer look, however, begs the question if the widely prescribed hormonal birth controls really are superheroes capable of delivering all they promise.

In an article titled “What Happens to Endometriosis When You’re on the Pill” and

written by three professors in the department of obstetrics and gynecology at the University of Melbourne, they write, “There is a shortage of good evidence-based science around the use of the pill to treat endometriosis symptoms. Much of what we know is based on an understanding of how hormones drive endometrial growth, coupled with practical clinical experience and observation. We presume that long-term suppression of menstruation with the pill halts the progression of endometriosis. Unfortunately, a good clinical trial investigating this would be impossible to run since it would include doing laparoscopies on some women who don’t have symptoms, which would be unethical. We also suspect, but don’t know for certain, that once significant scarring and damage has occurred due to ongoing disease, the pill is much less likely to be effective in suppressing symptoms.”

Hormonal birth control is an excellent contraceptive option that can protect women from unwanted pregnancy and the equally as daunting complications that come with a natural pregnancy. According to the U.S. Department of Health and Human Services, some of the complications include anemia, depression, ectopic pregnancy, preeclampsia (high blood pressure and problems with kidneys and other organs) and blurred vision.

However, birth control independent of unwanted pregnancy concerns is being prescribed without an upfront approach to its realistic capabilities and disappointments for fighting female diseases.

CHAPTER VII
A PATIENT'S RIGHT TO KNOW

Medical treatment must be a shared decision, one that is equal parts a doctor's recommendation and a patient's education concerning on what science the recommendation is built.

The American Medical Association's Journal of Ethics says, "Patients must have adequate information if they are to play a significant role in making decisions that reflect their own values and preferences, and physicians play a key role as educators in this process."

Being "educators in this process" was not clearly defined until the 1963 court case *Canterbury v. Spence*, in which 19-year-old Canterbury complained to Dr. Spence, a neurosurgeon, of back pain and was recommended a laminectomy (excision of the posterior arch of the vertebra). The physician knew that a laminectomy included a one percent chance of paralysis but did not mention it to Canterbury. After the procedure, Canterbury fell from his hospital bed and was deemed paralyzed. He sued Dr. Spence for neglecting to provide information pertinent to his decision of treatment and the court ruled that physicians are required to disclose the following: condition being treated, nature and character of the proposed treatment or surgical procedure, anticipated results, recognized possible alternative forms of treatment, recognized serious possible risks, complications, and anticipated benefits involved in the

treatment or surgical procedure, as well as the recognized possible alternative forms of treatment, including non-treatment.

This was not a complete fix and subsequent court cases did arise that involved other topics of disclosure including personal or economic interests that could influence a physician's judgment (*Gates v. Jenson*), information that a patient would find important to his or her condition (*Nixdorf v. Hicken*) and benefits or risks that are specific and significant to a particular patient, such as a risk of injury to a patient's hand being important knowledge for a professional baseball pitcher.

Disappointingly, these requirements are not always met by the physicians we trust.

Carissa Pauley, a senior psychology major at the University of Mississippi has a 33-year-old sister. When her sister was 32, she was diagnosed with stage four cervical cancer, as cancer cells were also found in the fluid surrounding her liver, lungs, and other major organs.

"The cancer doctor asked her if she had ever taken birth control," Pauley said. "When she told him that yes, for 12 years, he said, 'I'm sorry, but that is likely your culprit. There is much research that supports a link between prolonged use of birth control pills and cervical cancer.' She had six rounds of chemo and a hysterectomy with double oophorectomy."

Pauley said that over the course of her sister's 12 year relationship with hormonal birth control, the main priority was preventing pregnancy. Her sister had not thought to ask about a heightened risk of cancer because she didn't realize there was one.

"Her initial doctor had never mentioned that birth control can be linked to female cancers," Pauley said.

According to the American Cancer Society, consumption of birth control pills over a

prolonged period does pose an increased risk of cervical cancer. “Taking birth control pills for five or more years might make you more likely to get cervical cancer. The longer you use them, the higher your risk. The risk tends to go back down over time when you stop taking the pills.”

However, competing research states that the intake of hormonal birth control can actually decrease the risk of certain female cancers.

The MD Anderson Cancer Center states, “Taking the pill may help cut your risk of ovarian cancer and endometrial (uterine) cancer. That’s probably because women who take the pill ovulate, or release eggs from the ovaries, fewer times than women who don’t take the pill. The more times you ovulate over your lifetime, the more hormones you’re exposed to.”

Self-educating on prescription medications is therefore not a perfect science and should instead be a method patients can use to bring that research into conversations with their doctors.

“I think the debate of benefit vs. risk should most definitely be weighed on a patient-by-patient basis,” Godlewsky said. “When conducting clinical trials to approve medications, the process of collecting information on side effect profiles is all-encompassing (and with good reason). What that means is the researchers will make a list of *every* side effect a woman experiences while taking the trial medication (whether they believe it’s directly linked to the medication or not). This allows researchers to find trends in side effect profiles and potentially stop a trial if they notice that a particular side effect is immediately dangerous to the women. The downside of this process is the dauntingly lengthy list of all reported side effects that you read about on the package insert of a medication. Once a medication is approved, side effects are continually monitored on a more long-term basis (which allows us to look into more long-term health concerns such as infertility, female cancers, and cardiovascular disease).

“The problem is that we know that women experience infertility, cancers, cardiovascular disease, etc. even without ever taking a synthetic hormone product. Which isn’t to say that taking a synthetic hormone product won’t increase that natural risk, but it’s important to know the research before we start making important health decisions about it. While there’s been significant research on the side effects of birth control, there’s still very little we can definitively say about the cause/effect relationship of synthetic hormones and their long-term effects. But we can use trends in the research to help us make personalized health decisions for women.

“For example, if you have a woman with no family history of illness and no current health problems, it’s reasonable to say that she would benefit more than she’d be risking by taking a hormonal birth control. However, if you have a woman with a significant family history of cardiovascular disease and/or breast cancer the benefit may pale in comparison to the potential risk of exposing this woman to more estrogen/progesterone. But we also need to consider that there aren’t many good options for birth control that don’t involve a synthetic hormone (which is a totally different topic of our awful drug market and nonexistent incentives for drug discovery in birth control). In short, it comes down to patient comfort with a synthetic hormone product and the alternatives that exist if that patient is not comfortable. I fully believe in patient education and letting women make informed decisions about their birth control after weighing the potential risks that we can definitively rule out.”

What is lacking is a consistent balance between physician recommendations and physician disclosures of all the strings attached to those recommendations. Many patients trust their doctors to understand concepts beyond patient expertise and to notify them of any dangers and implications of taking medications or agreeing to treatments.

“The reason I chose the form of birth control that my doctor recommended was mainly to stop the painful periods,” 21-year-old Amanda Hirschfeld said. “He explained the different brands I could use and that if this one wasn’t working for me, we would switch me to another. I trusted his opinion as I had no other knowledge of the subject, just the overwhelming pain every month that I desperately wanted to get rid of. Honestly I don’t remember him telling me the side effects. I remember he said it should improve my periods and I was sold.”

Angel Conlon is a 24-year-old marketing director for Donohue Real Estate in Palm Beach, Florida. She currently takes two different antidepressants in conjunction with Blisovi Fe, a hormonal birth control pill.

“I went into the antidepressant medications trusting that genetics would step up because my mom takes the same ones,” she said. “There are so many possible side effects so even changing any dosage can totally mess with your system, and that terrifies me. I guess I did a little research after getting them, but not a ton, and I haven’t thought much about researching them until now!”

Conlon was prescribed birth control for complications with her periods and for hormonal acne and waited almost a year before starting it after reading negative reviews online.

“I was scared of how my body would change and if it would make me so depressed that I would then have to reevaluate my antidepressants, but eventually I decided to give it a try after hearing of other friends who took the same birth control pill and were fine. I waited almost a year after being prescribed the birth control before I ended up starting it, and I wish I had started sooner, but researching it definitely held it off for a bit!”

Her waiting period allowed her to make an informed, calculated decision, one that she

could feel comfortable with in the future.

If patients are not receiving the answers they need, Godlewsky says to not underestimate what a pharmacy can do in terms of providing extensive information and peace of mind.

“I think pharmacy has just become an underrated field that not many people think to turn to when they’re looking for treatment information and medication options,” Godlewsky said.

“You’d be so shocked at the people that call me or come back to the pharmacy to ask if something they picked up that week interacted with their other medications because they didn’t know that our job is to make sure the medication they’re going home with doesn’t interact with other medications!”

I had one year from the first scan of my ovarian cyst to the day of my surgery to contemplate what might be wrong with my body. I had one year to ask questions, do my research, see how my body responded to natural remedies, gather other medical opinions, and look for studies in case it was endometriosis. In retrospect, I saved myself multiple times from undesirable outcomes including unnecessary medications (depo-provera) and a more invasive surgery with increased scarring (robotic-arm).

I did not want to feel like I was on the outside looking in to what happened to my body. And when it was all said and done, I did not want any woman to feel the same.

CHAPTER VIII

POST-OPERATION APPOINTMENT, FOURTEEN DAYS AFTER SURGERY

I carry in my purse the orange and yellow box.

I sit down on the cold metal chair.

The electronic waves crash above my head and I have time to look at the ugly red and yellow walls and think about the conversation I had with a close friend the weekend before.

Kathy Micciantuono is my mother's age. Her daughter, Maria, grew up with me from preschool and was my best childhood friend. Years ago, Kathy had mentioned that she had this disease called endometriosis when she was younger, and that she had a total hysterectomy to rid her of the symptoms. When I had healed enough from surgery to be willing to discuss my diagnosis, she called me.

Her voice was soft and fluid, the voice of someone who understood.

I told her of what my doctor was recommending.

"I stayed on birth control pills for only a month or two when I was 23," she said. "They gave me major pounding headaches that could have ended in stroke and major depression. This was before I knew I had endometriosis so after the second month I quit using them. When I was trying to get pregnant, they tried an estrogen-based birth control again and same results so they took me off immediately. To control the endometriosis at 28, they had to put me on a

progesterone-based birth control, which I used six months to a year. I still couldn't get pregnant. The endometriosis had only gotten worse, so I had to have a hysterectomy with double oophorectomy."

The words hung on the line between us for a while.

"If I don't do this, I might not be able to have kids," I said.

In that same velvety voice, she told me, "You know what? I wouldn't change my endometriosis for anything. Without it, I would never have adopted Maria."

I hear two knocks and Dr. Barnes enters the room.

He smiles, "So it's two weeks after surgery! Did everything go alright with starting the birth control pack I gave you? The first day of your cycle was two days ago, yes?"

"Dr. Barnes," I say, "Thank you for everything." I offer him a hug, and I mean it. "You did so much, you left me with two tiny scars barely an inch across that sit below what could be visible over a bathing suit anyway. You spent three hours on me, for a procedure meant to take one. You have been hopeful and warm. But I have made a decision. I will not be using hormonal birth control."

He looks almost panicked.

I tell him I read studies that the effectiveness of hormonal birth control usage in women after laparoscopic surgery for endometriosis is as low as 50 percent. I tell him that if I do nothing, if I let my body figure out my hormonal imbalance on its own with the help of nutrition and routine exercise, my chances of recurrence are about the same. I ask if that is true.

"Well, yes, some women after surgery simply never see endometriosis again. And yes, birth control is not a guarantee it will not return."

I nod and say, “If this disease can come back either way, I’ve chosen the route that leaves me with no side effects.”

He protests and I acknowledge that his medical opinion *is* valid. Without any type of protection against the disease, I am left vulnerable to it returning, but I tell him I have too many years between now and menopause, when endometriosis is finally quieted once and for all, to pump my body with synthetic hormones and wait for cancer, or pelvic inflammatory disease, or depression.

I ask one final question, “What are my chances of infertility after prolonged use of birth control?”

He pauses. “Well, there are documented cases of subsequent infertility.”

“And I’d go on birth control to save my fertility, correct?”

He looks cornered.

“I’ll take my chances,” I say, and I leave the orange and yellow box on the cold metal chair.

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VITA

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She graduated with her master's in journalism in 2019. Throughout her graduate studies, she served as Public Relations Coordinator for Ole Miss Bands, NewsLab.org Contributing Writer, Vice President of Sigma Phi Lambda, and the communications graduate assistant in the Division of Diversity and Community Engagement.