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Suffering In Silence: Demystifying Endometriosis

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SUFFERING IN SILENCE: DEMYSTIFYING ENDOMETRIOSIS

by

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B.A., Southern Illinois University Carbondale, 2008

A Research Paper

Submitted in Partial Fulfillment of the Requirements for the
Master of Science Degree

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RESEARCH PAPER APPROVAL

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Master of Science

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Approved by:

Jan Thompson, Chair

Graduate School
Southern Illinois University Carbondale
November 10th, 2015

AN ABSTRACT OF THE RESEARCH PAPER OF

CANDACE TALLEUR, for the Master of Science degree in MASS COMMUNICATION AND MEDIA ARTS, presented on NOVEMBER 9th, 2015, at Southern Illinois University Carbondale.

TITLE: SUFFERING IN SILENCE: DEMYSTIFYING ENDOMETRIOSIS

MAJOR PROFESSOR: Jan Thompson

“Suffering In Silence: Demystifying Endometriosis,” explores endometriosis, a disease that affects 176 million women worldwide during their reproductive ages. Endometriosis, which is referred to by many as “endo”, is classified as an autoimmune disease that does not have a definitive cause or cure. Endo is hard to diagnose, because it is an “invisible” disease, meaning there are no external indicators, and the pain symptoms are largely associated with menstrual symptoms. This conundrum causes a lengthy time for diagnosis and treatment for many women, and they end up suffering in silence for many years. “Suffering in Silence: Demystifying Endometriosis,” tells the stories of four women who have dealt with the disease in different ways. I am one of the women included in the documentary dealing with the disease, and I also interview experts in the endometriosis field, who give their opinions on the controversial theories of possible causes and appropriate treatments, and the prospect of a cure.

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CHAPTER ONE

What is Endometriosis?

Unless you have endometriosis, or know someone who is afflicted with it, chances are, you've never heard of the disease. The name, endometriosis, is derived from the word endometrium, which is the tissue that lines the inside of the uterus and builds up and sheds each month in the menstrual cycle. In women with endometriosis...tissue like the endometrium is found outside the uterus, in other areas of the body (Ballweg, Olive, Doczman & Nezhat, 2003 p. 2). Reproductive Endocrinologist, Grace Janik, describes the various places it may implant, "It can be anywhere on the body, but typically it's on the ovaries, or the area behind the uterus, over the bowel, called the cul-de-sac. It can be on the appendix, even up by the diaphragm" (G. Janik, personal communication, August 17, 2011).

Endometriosis, or endo for short, can come in many different forms. Obstetrician and gynecologist, Dr. Afriye-Gray, explains the various forms, "You can have tiny little clear implants, or bluish implants, or red ones, some people call them powder burn implants...sometimes you don't see anything, and that's because there are clear lesions that maybe are deeper in the tissue and are not on the surface" (A. Gray, personal communication, October 15, 2010). Another form of endo is endometriomas, according to C. Martin (2015) of wiseGEEK.com, "In medicine, endometriomas are a type of ovarian cyst. Ovarian cysts are sacs of fluid within the ovary of a woman...these cysts are called endometrial cysts, or sometimes chocolate cysts, due to the brown appearance that occurs when these cysts have grown inside the ovary for a long period of time" (Martin, wiseGEEK).

Regardless of the type of endometriosis a woman may have, scarring of the tissue (adhesions) in the pelvic anatomy is very likely to occur, as William Pfeffer (1982) explains in *Contemporary Ob/Gyn*, “Inflammation occurs around the misplaced endometrial tissue, internal bleeding occurs as active growths cause cyclical bleeding, and the misplaced tissue may cause a foreign-body reaction” (pg. 19). In a nutshell, the body is trying to “heal” itself from the misplaced endometriosis, but the adhesions can actually cause tissue and organs to stick together. “Another way to think of adhesions is to compare them to taffy, that sticky, stringy candy that, the more you pull it, the longer it gets and the more it adheres itself to your fingers” (Zimlicki, 1995 p.145). Whether a woman develops adhesions, or her endometriosis comes in the form of a powder burn lesion or an endometrioma, the results are detrimental to her health, as discussed in the proceeding chapters.

History

Although doctors throughout the centuries have known about and dealt with pelvic pain in women, it is Dr. John A. Sampson, of Albany, New York, who is responsible for giving endometriosis its name. Speert (1980) reports that,

While endometriotic cysts had been described before- so by W.W. Russell in 1898-, it was Sampson who studied the disease systematically, described the clinical manifestations, and contributed to our understanding by proposing, in 1921, that endometriosis-a term he coined- is a process produced by escape of menstrual debris including endometrial tissue that escapes retrograde through the fallopian tubes into the pelvis” (Wikipedia, 2015).

According to Mary Lou Ballweg, President and founder of the Endometriosis Association, “At that time, endometriosis had only been identified in something like 21 women in the world, it was considered very rare, and in fact, even after I started the associated, into the

1980s, it was still considered rare. Now I don't think by the 1980s it was rare anymore. I think, just as now, most had not been diagnosed" (M. Ballweg, Personal communication, March 10, 2011).

John Lucas, Assistant Professor for the University of Vanderbilt's women reproductive health research facility, estimates that a one in ten woman in their reproductive age group has endometriosis (J. Lucas, personal communication, April 25, 2011). One in ten women seems like a high occurrence rate for the disease, yet many women weren't even aware of the disease until the 1980's. For that matter, many doctors and gynecologists weren't specialized in diagnosing or treating the disease. The lack of knowledge and information on endo is what prompted Mary Lou Ballweg, a woman diagnosed with endometriosis, to create the Endometriosis Foundation in 1980. Ballweg describes how astonished she was with how little the medical community knew about the disease when she was first diagnosed, "I couldn't find any help. I was used to researching anything and everything, and I had read all the medical literature within maybe a week at most. There just was very little available" (M. Ballweg, personal communication, March 10, 2011).

Ballweg went to on to find other women with the disease, but no one wanted to talk about it. Apparently there were stigmas and myths attached to the disease. Ballweg et al. (2003) recalls, "One of these assumptions was that nonwhite women did not generally get endo. This has now been shown to be untrue. Often nonwhite women were not getting the kind of medical care to have endo diagnosed" (p.4). Adding on to that misconception, black women with endometriosis were being misdiagnosed with PID (pelvic inflammatory disease) because they were thought to be promiscuous. Ballweg goes on to detail another misconstrued notion,

Another myth about endo is that very young women do not get it- an idea that probably arose because formerly teenagers and younger women endured menstrual pain (often on of the early symptoms) in silence and did not get diagnosed until the disease progressed to unbearable proportions. It was also believed that endo more often affected well-educated women. Now we know that this notion developed because well-educated women were those getting the best care and were more often persistent enough to obtain explanations for their symptoms” (Ballweg et al., 2003 p. 5).

In my interview with Mary Lou Ballweg, she explained that through the Endometriosis Association’s first market research, only 13% of women with endometriosis were being diagnosed. So this mean 87% of women with endo were suffering in silence, and those that were diagnosed had little to no information on what it was or how to be treated for it. Desperate for answers, a group of women from the Endometriosis Association got together for one of their first meetings and had someone from the medical field come in to offer some insight to their inquiries, “So we arranged for the then director of planned parenthood, a lovely doctor, who answered our questions as best he could. But most of the answers were, we don’t know, we don’t know, we don’t know. He was honest, bless him for that” (M. Ballweg, 2011, personal communication, March 10, 2011).

Once the Endometriosis Association got up and running in January of 1980, they began their first survey with an extensive questionnaire and brochure for women with endometriosis, and they distributed it in the United States and Canada. Any woman that would send in a dollar would receive the survey. According to Ballweg, “By fall of that year, we had more data than had ever been gathered on endometriosis,” (M. Ballweg, personal communication, March 3, 2011). For women at that time, it was exciting that they were finally getting some answers. But it

was also frustrating to discover that it was a much more complex disease than just a purely “gynecological” issue, as discussed in the next chapter.

CHAPTER TWO

What Causes Endometriosis

Retrograde Menstruation

Although there are a handful of theories as to what causes endometriosis, there really is no definitive “origin” for what causes endo to grow. However, the longest standing and most widely accepted theory amongst the OBGYN community is “Sampson’s theory”, or more commonly called retrograde menstruation. Ballweg et al. (2003) explains, “During menstruation, some of the menstrual tissue backs up through the fallopian tubes, implants in the abdomen, and grows” (p.11). Dr. Afriye-Gray expounds on the process,

Probably the most popular theory is that the cells that are on the inside of the uterus, the endometrium, actually go out through the tubes and into your pelvis, and they land on your ovaries, they land on your tubes, they may land on your colon, your bowel. And as a result, every month when you get your period, you have significant pain (A. Gray, personal communication, October 15, 2011).

Many women’s health practitioners believe that the cause for retrograde menstruation and the implantation of endometriosis is an overproduction of estrogen. However, not everybody subscribes to this theory, “Endometriosis occurs on more than one etiology, it’s not retrograde menstruation” (R. Albee, personal communication, March 20, 2011). Much of the Endometriosis Association’s research in the early 1980s leaned towards this being a much more complex disease than just one that perpetuated by out-of-whack hormones.

Immune Dysfunction

The immune system's role is to protect the body from harmful intruders. It should be able to identify "self" from "non-self" and extinguish the "non-self". Author of *The Thorn in the Starfish*, Desowitz (1988), describes a healthy immune system as, "the body's doctor, or personal physician that cures and protects us from a panoply of disease" (p. 14). In women with endometriosis, this is not the case, and researchers are not sure why these women have a malfunctioning immune system. Dr. Osteen, Professor and Director at the University of Vanderbilt's women reproductive health research facility reports, "The biggest mystery to those who study endometriosis is, what is the relationship between the endocrine system (responsible for hormones) and the immune system" (K. Osteen, personal communication, April 25, 2011).

Grace Migaki, M.D. (2003), describes an additional responsibility of the immune system, "Another important duty performed by your immune system is that of "cleanup". Your immune system includes cells that are specialized for such duties and, in normal situations, recognize when a tissue or cell-even though it is your own- is out of place. Does this remind you of endometriosis?" (Ballweg et al., p. 160)

The two basic components that are responsible this clean up are monocytes and natural killers (NK). The monocyte is responsible for recognizing the endometriosis implant or "intruder" in the abdomen, and the NK is responsible for the destroying the implant, the "cleanup". Dr. Lucas expounds on the malfunction of this process in certain women,

In most cases, those endometrial cells don't implant. But in 10% of women in their reproductive age group will have endometriosis. So clearly there's an immune system that allows, instead of going with normal surveillance and a clean up of these cells, it allows those cells to attach (J. Lucas, personal communication, April 25, 2011).

Another point worth mentioning is that many women with endometriosis also have other autoimmune disease, as reported in *Human Reproduction*, a survey analysis,

We already know that endo is a disease of the immune and endocrine (hormonal) systems. Now an important study shows that the prevalence of other hormonal or immune disorders is higher in women with endo than in the general female population. These diseases include hyperthyroidism, fibromyalgia, chronic fatigue immune dysfunction syndrome (CFIDS), rheumatoid arthritis, lupus, Sjogren's syndrome, and multiple sclerosis. (Sinaii, Cleary & Ballweg, 2002, p. 2,715).

Dr. Arthur Shattuck, certified acupuncturist and Chinese herbalist, further verifies the ideology that endometriosis is an autoimmune disease,

When I look at a whole patient population of women with autoimmune illnesses, it's not unusual that I might see a woman who comes in with lupus, an autoimmune illness, and along the way with her doctor's visits she comes back, it's not unusual that I hear, "oh by the way, I have endometriosis (A. Shattuck, personal communication, August 11, 2011).

Environmental Factors (Toxins)

One theory that is gaining momentum for researchers studying endometriosis is that toxins in our environment (air, water, food, household products, etc.) could be a major cause for the development of endometriosis. Ballweg et al. (2003) states, "Research super headed by the Endometriosis Association since 1992 has shown that environmental toxins such as dioxin and PCBs, which act like hormones in the body and damage the immune system, cause endometriosis in animals" (p. 2). Essentially these toxins are endocrine disruptors, and their job is to mimic the hormones in our bodies, telling our system to overproduce or under produce various hormones, and our immune system is confused and lethargic, therefore unable to assist in combating the

toxins in our bodies. During a 1998 speech to the United Nations Commission on the status of women, J. P. Myers reported that,

Using state-of-the-art blood testing, researchers find that all of us, no matter where or how we live, have a minimum of 200 detectable manufactured chemicals in our blood. And although some are worse for our health than others, we really do not know which ones interact with each other to cause potentially larger effects than they do individually. Human beings, at present, lack the scientific ability and resources to test them together to uncover their synergistic chemical reactions. Yet these chemicals continue to intermingle in our bodies (speech).

Alain Audebert, M.D (2001), in his article “How to Prevent Endometriosis?” implores his audience, “Indeed, every effort should be engaged in order to reduce pollution and to avoid exposure to pollutants carrying a potential risk of favorising endometriosis. As readers may know, the pollutants “favorising” endo include the notorious dioxin family, made up of the dioxins themselves, PCBs and furans” (p.375).

Mary Lou Ballweg explains, “We’re dealing with serious stuff here, and what people don’t understand is that these chemicals are not very much regulated...and it’s terrifying” (M. Ballweg, personal communication, March 10, 2011).

CHAPTER THREE

Symptoms of Endometriosis

Pain

Endometriosis presents itself in various ways for each woman living with the disease. But one of the most prevalent symptoms is pain. Ballweg et al. (2003) states,

The most common symptoms of endo are pain before and during periods (usually worse than “normal” menstrual cramps), pain during or after sexual activity, and heavy bleeding. Other symptoms may include fatigue, painful bowel movements with periods, lower-back pain with periods, and diarrhea and/or constipation and other intestinal upset with periods (pg. 2).

Figure 1 are the findings from two separate registry surveys conducted by the Endometriosis Association, showing the percentages of women experiencing the endometriosis symptoms described above.

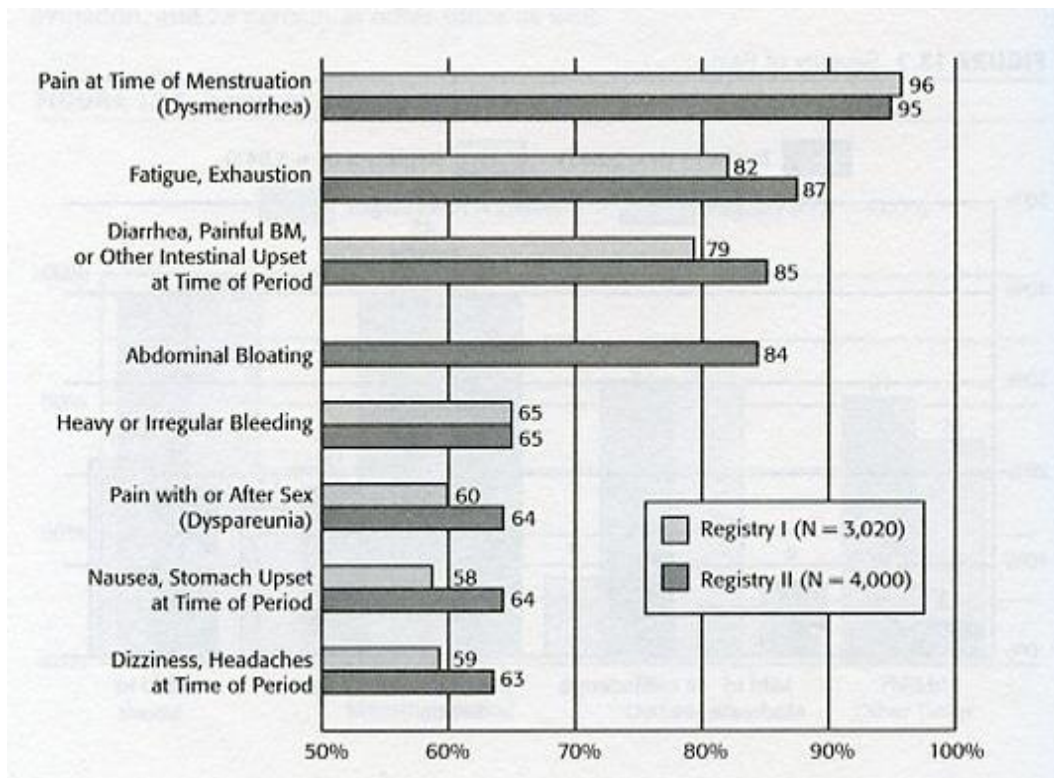


Figure 1 Endo Symptoms reported

Figure 2 is result responses from 864 women with surgically confirmed endometriosis, describing the areas where they feel pain on their bodies:

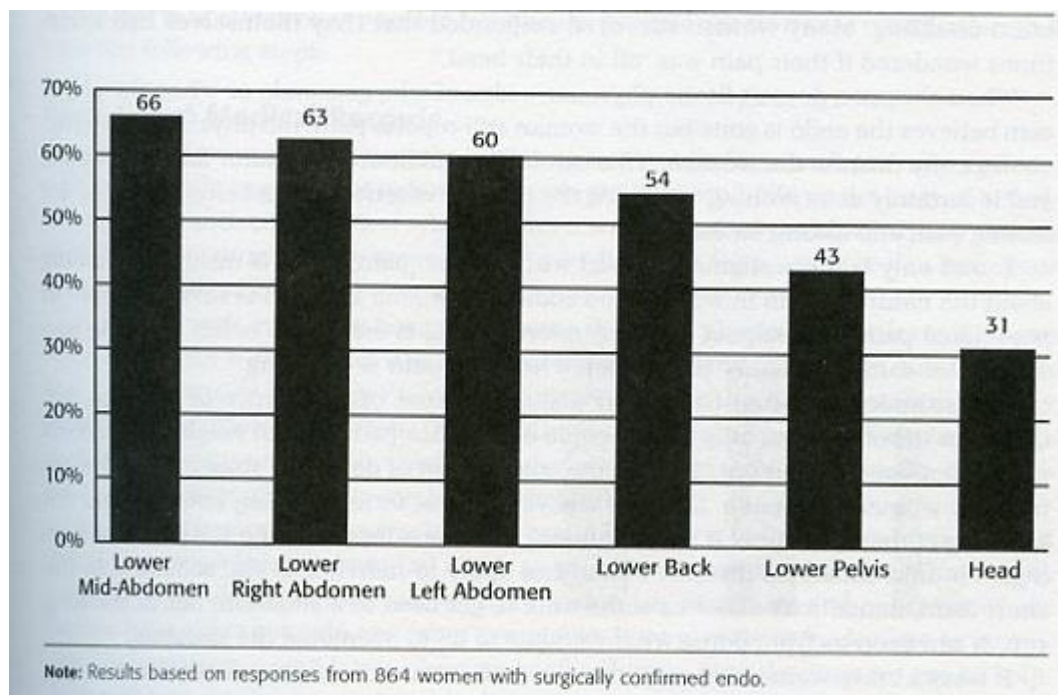


Figure 2: Where Do You Feel Pain?

With regards to the pain experienced, the cause could be for a number of reasons. Inflammation to the endometrial tissue can cause pain, along with the pressure or stretching of the tissue due to bowel or bladder functions. The nerves surrounding areas of endometriosis may be damaged after progression of the disease. Lastly, muscle contractions are a major cause of pain. The severity of the pain can vary in each patient, from mild to severe, as listed in Figure 3, from the same Endometriosis Association registries I and II.

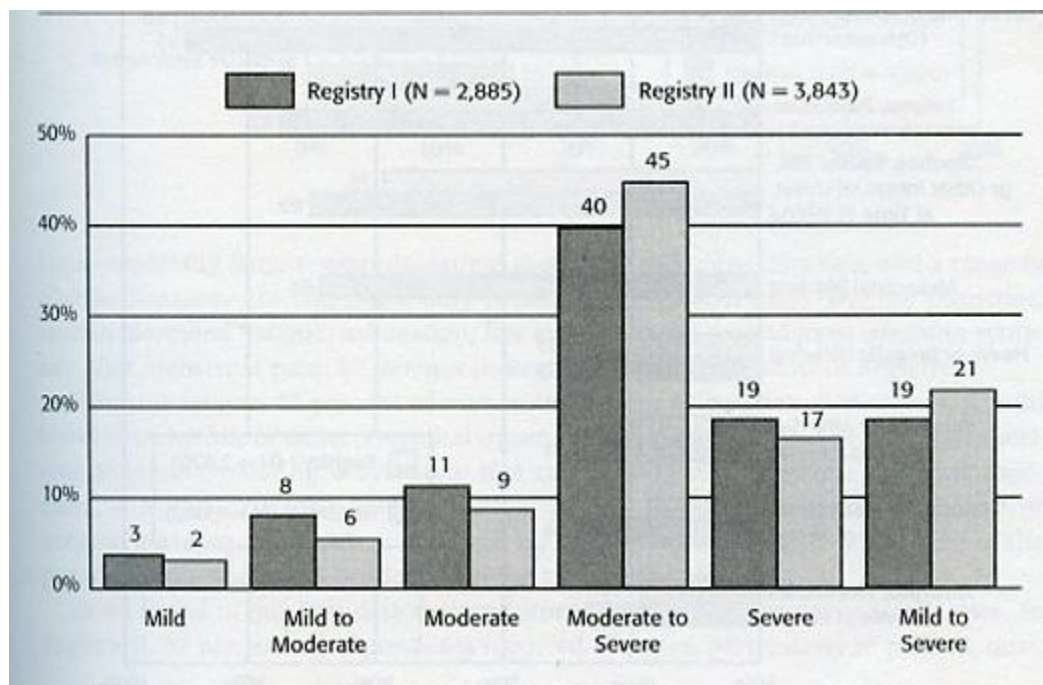


Figure 3: Severity Of Pain

Despite there being clear evidence that women are experiencing pain that isn't the normal "menstrual cramping", it seems that pelvic pain isn't being taken seriously. A report in the *Journal of Law, Medicine and Ethics* states that, "Medical Professionals take women's reports of pain less seriously than men's and that women receive less aggressive treatment" (Avery, 1995). Research presented at a U.S National Institutes of Health meeting suggests that, "hormones likely play a role in how pain is perceived. Women are more sensitized to some pain during the premenstrual period than in the postmenstrual period, and higher estrogen levels were associated with heightened sensitivity to temperature" (Armitage, 1979 p. 187).

Prevalence of other Chronic Pain Disorders

An estimated 50 million American women suffer from at least one chronic pain disorder. The 2010 campaign to end chronic pain in women reported that these conditions frequently coexist or "overlap". In the film *Through the Maze: Women and Pain* (2010), Christin Veasley, Associate Director of the National Vulvodynia Association states that, "We have very little

knowledge or epidemiology research that's taken place on chronic pain in general, and even less on the chronic overlapping conditions such as vulvodynia, temporomandibular disorders, interstitial cystitis, fibromyalgia, headache, chronic fatigue syndrome, irritable bowel syndrome and endometriosis." Women suffer from fibromyalgia nine times more frequently than men, and experience migraine more than twice as often. According to Ballweg (2003), "In fact, of the leading causes of chronic pain, only back pain reportedly affects men as often as it does women" (p.12).

Dealing with these disorders can often become so debilitating that it affects a woman's ability to function normally and accomplish daily activities. Based on the Endometriosis Association's registry I and II survey, 79 percent of women reported that they were unable to carry on normal work, as shown in figure 4:

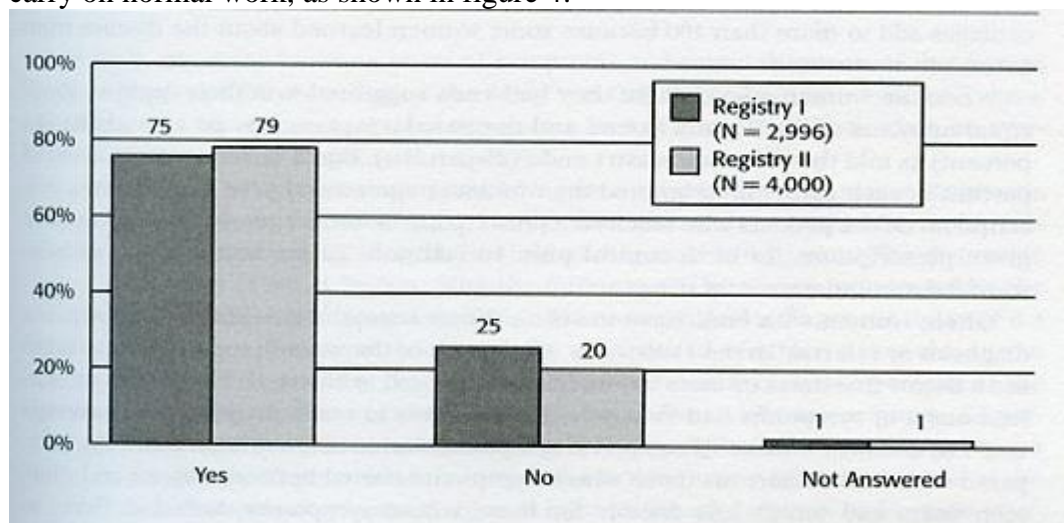


Figure 4: Are You Sometimes Unable to Carry on Normal Work?

Despite these findings, women are often told it's all in their head, as Veasley (2010) confirms, "We've heard from many women at the organization that they've been told nothing is wrong with you" (Alliance, 2010). Barbara J. Berg, PH.D, and author of *Sexism in America: Alive, Well and Ruining our Future*, "The doctor's are frustrated, they can't find the disease so

the quickest thing is go see the shrink about it” (Alliance, 2010). Additionally, *The Journal for Women’s Health* (2009) reports, “Health care professionals are more likely to dismiss women’s pain reports as emotional, psychogenic, hysterical or oversensitive, and therefore not real, leading to more frequent mental health diagnoses” (Alliance, 2010). Sherill Rose-Hill recalls being frustrated when she first started bringing her daughter, Kristi Ann, to the doctors after having worse than normal period pain, “I began taking her to the doctors here in Kokomo, and I think they even suggested a psychiatrist, which we went. And one of the phrases I believe was, ‘oh she’s just trying to get attention’, and if you knew Kristi, she wasn’t anything like that” (S. Hill, Personal Communication, May 18, 2011).

The bottom line is that doctors need to take women’s complaints of pain more seriously, as the *Through the Maze: Women In Pain* film addresses, “Despite the clear need competency in pain assessment and management skills, there is ample evidence that this competency is lacking at all levels of medical training” (Alliance, 2010). Because at the end of the day, as Veasley puts it, “Chronic pain diseases don’t kill you, but in many cases, as women have told me, they make you want to die” (Alliance, 2010).

Infertility

Although most women that have endometriosis report having varying levels of pain, some don’t experience any form of pelvic pain associated with their period or otherwise. In fact, they don’t know anything is wrong until they try to become pregnant, and can’t. Elizabeth Dougherty (2003) reports that, “About a third of women with endometriosis experience infertility, and about a third of women with infertility have endometriosis. Infertility typically is defined as failing to become pregnant after one year of unprotected intercourse or two or more

spontaneous pregnancy losses” (Ballweg et al. p.133). Reproductive endocrinologist, Grace Janik, describes some of the ways that endometriosis can cause infertility,

Endometriosis can cause fertility in two ways; one is that it can cause adhesions that can cause scarring and physical distortion of the anatomy. And the other is just its presence (endometriosis) can release chemicals that can inhibit fertilization. But if the endometriosis has a lot of involvement, especially of the ovary, with an endometrioma, that causes scarring of the ovary. And in order for an egg to be released and picked up, it has to come out of the ovary and the tube has to scoop down and pick up the egg. So if either of those elements are incumbent in adhesions, that process is not going to happen (G. Janik, Personal Communication, August 17, 2011).

My own personal issues with fertility came about after my gynecologist, Dr. Afriye-Gray, told me that I shouldn't attempt to become pregnant naturally for fear of an ectopic pregnancy due to endometriosis. So she referred me to Dr. Janik, and she describes my potential issues with fertility because of the damage done to my ovaries,

From a fertility perspective, you're looking at the percentage of your ovary that's free and the status of the tube. This is the most reflective of what the outcome will be for fertility. If greater than 50 percent of the ovary is free, the fertility rates are reasonable, provided that your tube is open (G. Janik, personal communication, August 17, 2011).

As of now, I'm not trying to become pregnant, but as most women with endometriosis are warned, the longer you wait, and the disease continues to progress, the less likely you'll be able to conceive in the future. Only time will tell.

CHAPTER FOUR

Treatment Options

Birth Control

There is no known cure for endometriosis. However, there are a handful of treatment options available to aid women, depending on whether the goal is to alleviate pain, or assist in improving fertility. According to Meresman, Auge, and Baranom in *Fertility and Sterility* (2001),

Today, oral contraceptives are the most commonly prescribed treatment for endo. Despite this, there are little data regarding the mechanism of action. One recent investigation suggests that oral contraceptives suppress proliferation and enhance programmed cell death in endometrial tissue, perhaps providing a clue for the action of these drugs (pp. S47-S48).

According to Dan Olive, M.D. (1989), “Numerous uncontrolled trials have evaluated pain relief, generally demonstrating improvement in 75 to 89 percent of women treated with this medication” (pp. 189). The birth control pill is usually the first step a gynecologist will take to try and treat a woman who might present with endometriosis. But it isn’t always effective. Courtney Feinman describes her experience with being pressured into going on the pill, “He said, you need to go on birth control, I said no. He didn’t like my answer. Three months later he said, okay let’s put you on birth control, and then three months later the pain actually got worse while I was on birth control” (C. Feinman, Personal Communication, March 20, 2011). While Kate Griggs had a very different experience, “He put me on Yazmin, and Yazmin really helped me a lot. But a side effect is that it puts tumors on your liver. So years down the road after I was experiencing pain, I found out I had six adenomas on my liver” (K. Griggs, personal

communication, May 18, 2011). Clearly, in some cases, women are trading one health issue for another.

Pain Medication

When it comes to treating endo-associated pain, NSAIDS (nonsteroidal anti-inflammatory) are the most commonly prescribed medication by physicians and gynecologists. However, a lot of the time, over-the-counter pain medications won't even put a dent in the pain. Some doctors will offer relief with narcotics, while others refuse because they don't want their patient to become dependent on the medications. Dr. Robert Albee puts it in these terms,

Obviously we want to be compassionate and use as much medication as is safe to use and will work. But my opinion is you don't want to take any individual and encourage them to revolve their life around cyclical change and the use of medication. Interestingly, painkillers don't help patients with endometriosis very much, they may help a little. But once a patient starts rolling on the floor and they take codeine or Percocet, they'll tell you it doesn't help that much (R. Albee, Personal Communication, March 20, 2011).

Courtney Feinman was one of those women that revolved her life around cyclical changes and needing medication, "The third doctor gave me pain medication, and I was on that for a year and a half, up to two years. And I would take it two weeks before my period and during my period. And so I was on pain medication for three weeks out of the month" (C. Feinman, Personal Communication, March 20 2011). Kate Griggs also experienced a lack of relief from NSAIDS or narcotics, "Naproxen seemed to help, but a lot of times it didn't and I would end up in the emergency room to get some stronger medicine" (K. Griggs, Personal Communication, May 18, 2011).

Laparoscopy

Doctors can try to “quiet” the pain and symptoms endometriosis with birth control and pain medication, but the only way to diagnose and remove endometriosis is through surgical laparoscopy. Mary Lou Ballweg (2003) describes laparoscopy as,

A surgical procedure done under anesthesia in which the patient’s abdomen is distended with carbon monoxide gas to make the organs easier to see and laparoscope (a tube with a light in it) is inserted into a tiny incision in the abdomen. By moving the laparoscope around the abdomen, the surgeon can check the condition of the abdominal organs and see the endometrial implants, if the surgeon is careful and thorough (p. 3).

Prior to laparoscopy, laparotomies (major open abdominal surgery) were the common course of treatment, which involved months of recovery for women, and often still a recurrence of endometriosis. Mary Lou describes how surgical procedures have changed through the decades,

In the 80’s, it was still very common for our women to have five, six, seven, eight laparotomies. And then a few pioneer surgeons minimally invasive surgery, laparoscopy. They were not welcomed, as an understatement, by the OBGYN establishment, who said until it’s proven better than laparotomies; we need to keep doing laparotomies. And our position was even if it’s not as good but just about, it’s certainly better for the woman. Now even more is happening in that field with robotics (M. Ballweg, personal communication, March 10, 2011).

As Ballweg stated, laparoscopy was not pioneered or practiced in medical schools, but by top endometriosis surgeons. To this day, laparoscopy is still not a very well developed training program in the medical field. Because of this, gynecologists are still resorting to laparotomies, or are poorly performing laparoscopies. And women aren’t aware that their gynecologist doesn’t

have the necessary credentials to perform minimally invasive surgery. This is because it seems every health organization has different guidelines. According to Alan Johns, M.D. (2003), “The various organizations have established recommendations for credentialing that are essentially meaningless. The guidelines are designed to be broad enough so that the vast majority or an organization’s members will qualify. There is no objective assessment of expertise” (p. 62). What this ultimately means is that it’s the patient’s responsibility for doing her research on which doctor she wants performing her surgery. Camran Nezhat, M.D. (2003), renowned pioneer laparoscopic surgeon and Endometriosis Association Advisor, adds these tips,

As knowledge is power, and educated patient would benefit significantly by doing proper due diligence on the surgeon who is going to operate on her. Endometriosis is a specialty of its own. Not all gynecologists are specialists or inter interested in endometriosis surgery. The patient must ask the doctor many questions, and should find a surgeon who has done a lot of surgery for endometriosis and knows the disease very well, and only then have the operation. It is your body, and you only have one (p. 65).

Mary Lou Ballweg adds, “If that doctor hasn’t seen at least 200 patients with endometriosis, they haven’t gotten far enough on the learning curve” (M. Ballweg, personal communication, March 10, 2011).

Hysterectomy

What’s even more disturbing than gynecologists still performing laparotomies to treat endometriosis, or gynecologists not being well trained in laparoscopy, are doctors still convincing women that having a hysterectomy will cure them of endometriosis. Dr. Janik discusses this issue during my interview with her,

The concept of ‘we should do pelvic clean out and take out your uterus and ovaries and tubes and then you’ll be pain free’, that’s a huge misconception, and it’s still prevalent, very very prevalent, unfortunately, in that, that most common place for endometriosis is in the cul-de-sac, involving the bowel, bladder, ureter, places most gynecologists are not comfortable operating. So if you go in and remove the uterus but leave all the endometriosis in those places, people are not better (G. Janik, personal communication, August 17, 2011).

Dr. Albee agrees that hysterectomy is not the answer to treating endometriosis, adding, Have I operated on women who have had a hysterectomy that have endometriosis still? Absolutely, lots of them. And that’s because, unfortunately, their doctor’s were trained to think that if the uterus and maybe the tubes and ovaries were removed, that any other endometriosis would die off, but it doesn’t (R. Albee, personal communication March 20, 2011).

Figure 5 shows treatment results of 3,711 women who participated in the Endometriosis Association’s registry II. The results were based on the effectiveness of surgeries involving the removal of ovaries or a hysterectomy.

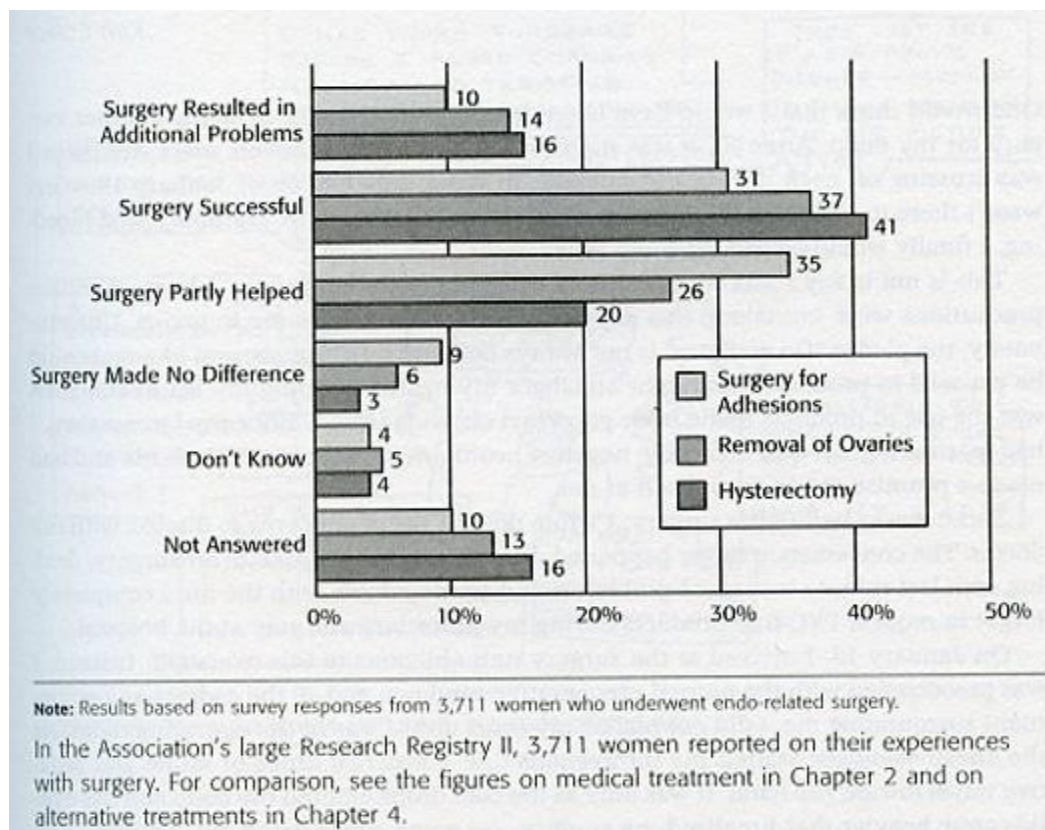


Figure 5: Treatment Results: Other Surgeries

The results show that 41 percent of women had a successful hysterectomy, with 16 percent saying that they had additional problems, and three percent reporting it made no difference. Kate Griggs is a woman with a success story involving hysterectomy. She describes her experience,

I had another surgery, and another and another and my doctor tried to convince me for years to have a hysterectomy. My hysterectomy was the best thing that I've done in my whole life. I wish I would've done it 10, 15 years ago, after I had my son, I wish I would've just done it because I haven't had any pain. No side effects, no hot flashes, no mood swings, absolutely nothing (K. Griggs, personal communication, May 18, 2011).

Medical Menopause

Medical menopause occurs when Gonadotropin-releasing hormone agonists (GnRH agonists), that are drugs similar to the hormone GnRH, are used to shut down a woman's cycle completely. The most commonly used form is called Lupron. Dr. Afriye-Gray describes its usage and side effects,

Lupron works from your brain to actually stop your hormones from continuing you on your normal monthly cycle. Lupron is a once every three-month shot, so it's really quite convenient for you. Side effects, however, can be an issue, so you can have some of the same symptoms you would have if you went into natural menopause, like hot flashes and vaginal dryness and after awhile actually an increased risk of developing osteoporosis (A. Gray, personal communication, October 15, 2011).

Shortly after I had my laparotomy surgery done with Dr. Gray, she put me on two rounds of Lupron to stop the growth of a new endometrioma I had forming inside my ovary. She reported after a vaginal ultrasound, "the cyst that you had in your ovary before has shrunk down significantly, not completely gone, but it's less than before, and I think it's because of the Lupron" (A. Gray, personal communication, October 15, 2011). Lupron, and drugs like it, can only be taken for short amounts of time, due to its harmful and lasting effects. Kate Griggs was one of the women that experienced harmful effects from the drug,

It was the worst thing ever, after the second shot I started getting really depressed and I didn't care about anyone or anything. And after the fourth one, my husband at the time, called my doctor and told him I couldn't take another shot cause I was suicidal, it just, it wasn't worth it (K. Griggs, personal communication, May 18, 2011).

Some doctors will put their patient on Lupron before they decide whether or not to do minimally invasive surgery, while others will put them on it after laparoscopy, as Dr. Janik explains,

A common general approach is to do laparoscopy, remove what disease you can, and then add Lupron on to suppress, but that suppression doesn't dissolve any of the endometriosis that's present. It only, just like menopause, makes you not cycle. You take Lupron away and you go back to where you were in a very amount of time. So Lupron doesn't seem to add much because you can't be on it long term... and it doesn't dissolve disease (G. Janik, personal communication, August 17, 2011).

Traditional Chinese Medicine

Many women have turned to traditional Chinese medicine after trying all the other "western" medical treatments available, with no resolve, in terms of pain and/or infertility. In traditional Chinese medicine, you use a holistic approach to treat the person as a whole, not just in one specific area of "dysfunction". According to Daoshing Ni, L.Ac., Ph.D., D.O.M. (1995),

Traditional Chinese medicine is a natural medical system developed by the ancient Chinese Taoist sages. Acupuncture and herbal therapies, which are known to many Westerners, are parts of this ancient medical system, which developed through the observation of nature. The ancient sages believed that the human body is like a miniature universe or microcosm that functions in a similar harmonious pattern on universal principles. Our bodies subscribe to the laws of nature, and when there is a disease or illness it is because our universe has a certain imbalance. To treat an imbalance, an introduction of traditional Chinese medicine therapy to the body can help bring the body back to balanced homeostasis (p. 267).

Traditional Chinese medicine has been tested, proved and accepted by the Chinese people for more than 5,000 years. In recent decades, westerners have turned to this type of therapy to cure their ailment when Western medicine has failed to do so. Dr. Shattuck describes the differences in how traditional Chinese medicine treats endometriosis, as opposed to how western medicine treats the disease,

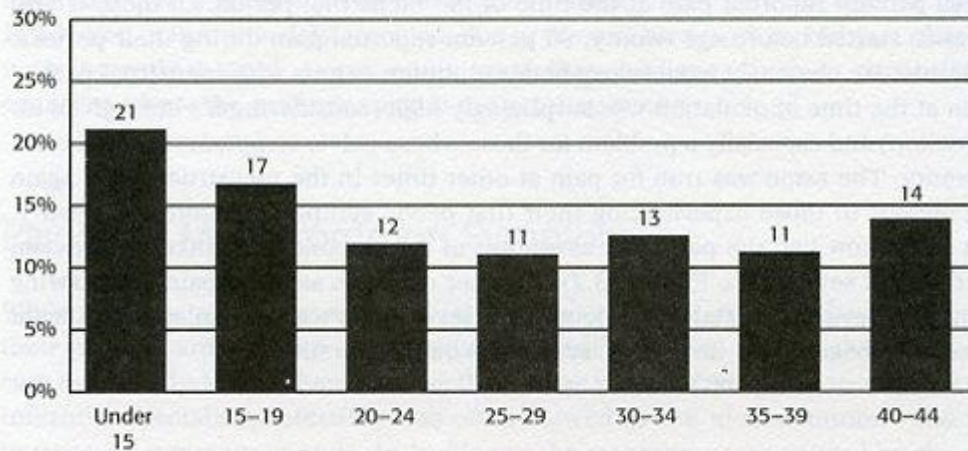
In traditional Chinese medicine, we always go back to this flow, everything is supposed to flow in an orderly pattern through all of your cycles your menstrual cycle, sleep cycle, emotional cycle, bowel movement cycle. And when it doesn't flow perfectly, we think that's attributed to how the Chinese understand the flow of energy (Chi) out of the liver. We think of it as liver stagnation. So rather than further shutting down the flow of Chi, which Lupron is stopping your cycle, we think that's a prescription for more pain in the next ten years. Nothing is being treated; it's just being shut down. It's telling nature to not do nature's job. With traditional Chinese medicine, we wouldn't shut down the flow of Chi, we would increase the flow significantly.... through herbs, acupuncture and food, and you could probably expect a 60-65% success rate in pain relief (A. Shattuck, personal communication, August 11, 2011).

With regards to improving fertility rates using traditional Chinese medicine, Dr. Shattuck treats both the woman and the male with herbs, acupuncture and food. When the interview was conducted in August of 2011, he had seven women with endometriosis and infertility issues become pregnant.

CHAPTER FIVE

Conclusion

So now what? What are women with this disease supposed to do with all this information? Trying to figure out which treatment option will work best seems impossible, as there is no rhyme or reason for why one treatment works for one woman but doesn't for the next. It's a stressful and frustrating situation to be in, however, there is no choice but to walk through the complicated maze that is this disease. Every woman has to be her own advocate for her health. Don't listen to doctors when they tell you that the pain you're experiencing is normal and that every woman does through it, or that it's all in your head. Research every avenue and decide for yourself what you think is the best option for you. Early diagnosis is the key with this disease. Parents need to listen to their teens when they tell them that they're in pain. According to Fallon (1946) in the *Journal of the American Medical Association*, "The first research to focus on the incidence of endo among teenagers was that of Fallon's 1946 study suggesting that endo likely begins soon after the first period and should be treated early to avoid infertility and incapacitating pain" (p. 1,405). Figure 6 is a survey of 4,000 women with endometriosis that reports 38% under the age of 15 experienced pelvic symptoms.

FIGURE 13.3 Age of First Symptoms for Women Reporting Severe Pain

Note: Percentages based on survey responses from 4,000 women with endo.

Figure 6: Age of First Symptoms for Women Reporting Severe Pain

Figure 7 shows that, in the same survey, women were seen by an average of 4.2 doctors before they were diagnosed with endometriosis, with the delay in diagnosis being 9.1 years.

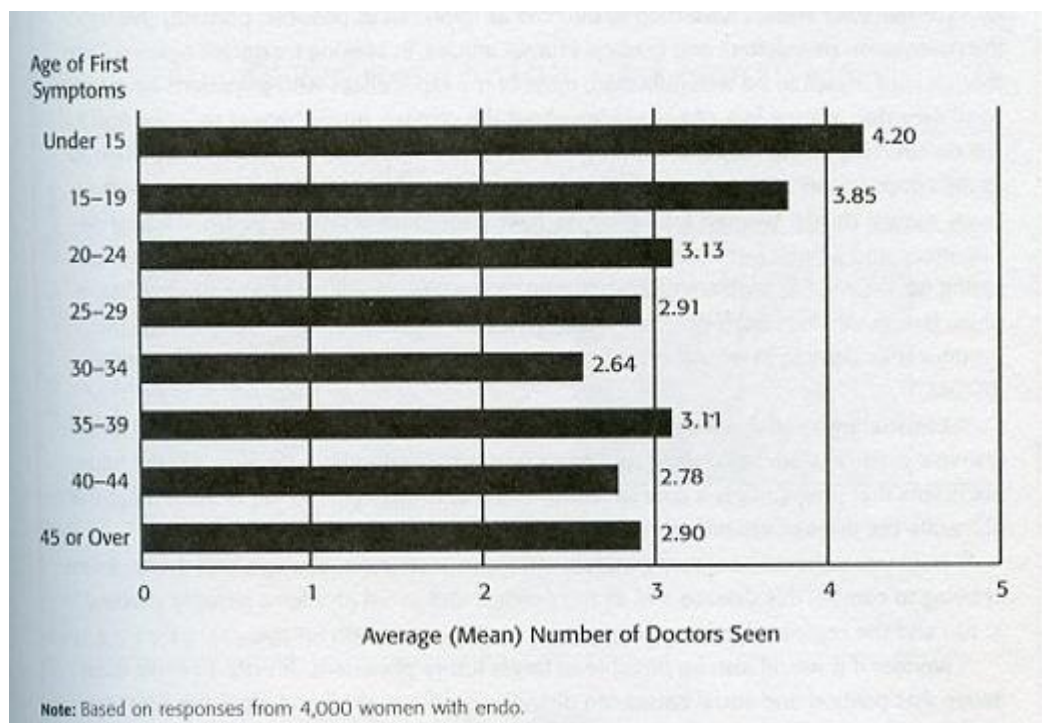


Figure 7: Younger Patients See More Doctors Before Endo Is Diagnosed

Keep up to date on the research being done on new information regarding causes and treatments for the disease. Anybody can join the Endometriosis Association or the Endometriosis Research Center and receive monthly newsletters. As Ballweg puts it, “Endometriosis is a tip-of-the-iceberg disease. And until we women, mothers, physicians start taking menstrual pain, which may be the first sign, seriously, we’re not going to be in a good position to slow down this whole process” (M. Ballweg, personal communication, March 10, 2011).

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