

RESEARCH BRIEF

Living with Endometriosis in the Philippines

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What is it like to live with endometriosis in the Philippines? In the course of my decades-long search for a permanent treatment for endometriosis, I have collected a significant number of experiences of the many ways issues of gender, class, and access to quality health care have intersected among, and within, each other. This essay seeks to share my story of endometriosis, a debilitating condition that I have been living with for the most part of my reproductive years. Although it would seem that endometriosis is just a simple gynecological condition that affects women only, the disease requires multiple approaches, interventions, and attention from all members of the community. The realities of Philippine society and the state of health care in the country make for a compelling case to elevate awareness about a disease that targets women in their reproductive and productive years. The impact of endometriosis is evident in the marital/sexual relationships, social spirit, and on physical and psychological aspects of women's lives (Moradi, Parker, Sneddon, Lopez, & Ellwood, 2014).

What is Endometriosis?

Endometriosis mainly affects women in their reproductive age (90%–99% of patients are aged 20–50

years), regardless of their ethnicity or socioeconomic status (Dobrokhotova et al., 2017). An estimated 89 million women worldwide suffer from the condition, according to the Endometriosis Association (2015), an advocacy group, which provides vast support via information and sharing of resources about endometriosis to the world.

According to Endometriosis World (n.d.), which is a website for endometriosis related concerns, endometriosis is a condition in which cells that are normally found inside the uterus (endometrial cells) are found growing outside of the uterus. That is, the liner of the inside of the uterus is found outside of it. The uterine cavity is lined with endometrial cells, which are under the influence of female hormones. Endometrial cells are the cells that shed every month during menstruation, and so endometriosis is most likely to affect women during their childbearing years. Endometrial cells that grow outside of the uterus are called implants. These implants are found normally on the ovaries, fallopian tubes, the outer wall of the uterus or intestines, and on the surface lining of the pelvic cavity. They can as well be found in the vagina, cervix, and bladder, although less commonly than other locations in the pelvis. However, these implants follow the same pattern as the endometrial lining the

uterus of getting thicker, breaking down, and bleeding. Problems occur because these growths are outside of the uterus, and the blood cannot flow out of the body. This can lead to the formation of scar tissue and cysts as well as difficulties getting pregnant.

There is no cure for endometriosis (Nasir & Bope, 2004; Schindler, 2011). The best hope for millions of sufferers out there is long-term pain management, which ranges from the use of NSAIDs or painkillers (Mefenamic acid, aspirin, paracetamol, and ibuprofen), hormone therapy, and surgery to remove adhesions and endometrial cysts. The treatment is expected to be enduring (Schindler, 2011).

The “Normalization” of Symptoms

Menstruation is a biological fact fraught with cultural implications (Lee, 1994). In the recent television advertisement of a local brand of sanitary napkins, adolescent girls liken the experience of having menstruation to gross and repugnant incidents such as sitting on a plate of spaghetti and the like. The ad declares, “Periods are yucky.” Meanwhile, ads of other brands practically erase symptoms commonly associated with menstruation, such as abdominal and pelvic pain, headache, fatigue and bloating, and gastrointestinal discomfort, by using popular female celebrities who run about their normal activities (supposedly) even while having their period.

These ads capture the cultural ambivalence with respect to menstruation in Philippine society. To regard menstruation, and everything connected with it, as “yucky,” advertisements reinforce the received notion that a woman’s bodily experiences underpin her subordinate status in society. While, on the other hand, ads that dismiss the debilitating pain and other symptoms of a challenging menstrual period, bolsters the image of an independent, modern Filipino young woman who does not let anything gets in the path of her success, including (inconvenient) menstruation.

The cultural ambivalence has resulted in lack of public discussions on endometriosis in schools and media outlets in the Philippines. An internet search on social forums dedicated to “endometriosis,” “dysmenorrhea,” “painful menstruation,” yielded only two results: femalenet.com and pinoyexchange.com.

At PinoyExchange.com, the forum thread started in 2000 and ended in 2008, with only 10 entries. Femalenet.com forum thread on “Women’s Reproductive Rights,” holds a sub-thread on endometriosis. Other threads are on many gynecological issues such as Polycystic Ovaries Syndrome (PCOS), fertility and infertility, and contraceptives. The forum thread on endometriosis is called, “Endometriosis Thread 3: Place for EndoWarriors.” It was initiated in 2014 and is still active. In the conversation (or replies, as they are termed in the thread), participants shared their experiences with symptoms associated with endometriosis. In many of the stories they have shared, they initially dismissed their experiences of debilitating pain as “part of menstruation,” “ordinary,” and “other female member of the family go through the same thing.” Outside these online forums, I have yet to know of any other public venue in the country where conversations about endometriosis have been conducted and/or supported.

Even more thought-provoking is the absence of a scientific study on the prevalence of endometriosis in the Philippines in *PubMed Central*, which is an internet database of approximately 4 Million scientific papers, briefs, and proceedings related to medical and allied fields. A search engine examination of keywords, “Endometriosis in the Philippines” has generated 44 results, but not a single result referring directly to the keywords used. This observation is confirmed by a study on the qualitative impact of endometriosis on women’s lives that endometriosis is a chronic disease, which is under-diagnosed, under-reported, and under-researched (Moradi et al., 2014).

My Struggle With Endometriosis and My Health Seeking Behavior

For so long that I could recall, I have had always the most excruciatingly painful menstrual periods. Older female relatives and friends had told me that the pain was part of the whole process, and I just have to grin and bear it. And bore it, I did. Back in high school, during particularly heavy periods, I would often be teased by classmates because my skirt would be soaked wet with menstrual blood—the striking red color stood out vividly against my dark green uniform. Moreover, my family was struggling economically while I was

growing up so medicines to help me alleviate the pain and discomfort would come far and between.

It was only when I turned 22 years old that I resolved to consult a medical expert to help me find answers for my condition. The decision came about after a harrowingly painful episode where I could barely walk towards my room, and whereupon reaching it, I promptly fainted.

Then one day, while armed with a health insurance card that my employer had provided for me, I set out to see an Obstetrics and Gynecology (OB-GYN) doctor at the De La Salle University Medical Center in Dasmariñas, Cavite. The female physician listened to my complaints and recommended I undergo an abdominal ultrasound procedure. Days later, I found out I had several small cysts on both of my ovaries. The physician advised that I take contraceptive pills to make the cysts smaller.

It would be my first time to see actual contraceptive pills, and was unbelieving when I was advised to take them. My strict Catholic upbringing had led me to believe that these pills were meant to prevent reproduction, and was in fact abortifacient. I was afraid that my colleagues at the Religious Education Department of a university where I worked would start to regard me differently should they know about them. So then I told everyone I knew at work that I had painful periods, and for some reasons, contraceptive pills would regulate my estrogen production, and thus would relieve pain. That these pills could be used as medicine was news to me at that time, as it was as well to my colleagues.

I do not remember if my physician ever mentioned endometriosis to me. I would discover about the term three years later when my sister-in-law who was living in the USA told me she also struggled with menstrual pain and other symptoms, and that the disease was called endometriosis.

After 30 days of contraceptive pill therapy, I got back to see my doctor. After another ultrasound procedure, it was revealed that my ovarian cysts had shrunk. Buoyed by this happy news, I discontinued taking the contraceptive pills. I was also a hopeless delinquent pill-popper that I would forget to take them daily as I was supposed to do so, and would sometimes double-dosed. Interestingly, the timeline coincided

with episodes of reduced pain and a sensation of general well being. I thought at that time that I had this condition under control. I would ease the occasional menstrual pain and discomfort with over-the-counter pain medicines. In my late 20s, however, I had started to feel the rising intensity of pelvic pain during my monthly periods. This time, however, the pelvic pain would be accompanied by abdominal pain, fatigue, and gastrointestinal irritation such as vomiting and diarrhea. To help me with the pain, I doubled down on the pain pills, especially ibuprofen, which in turn worsened my gastrointestinal discomfort.

The pain worsened when I came into my 30s. Around this time, I was completing my PhD dissertation and was teaching full-time as well. I would also commute for two hours to get to work, and would spend another two hours to return home. Due to my extremely busy schedule, I did not find the time see a medical doctor. The last time I saw a gynecologist was when I was in my early 20s. At this phase of my journey, I started writing a body journal to help me sort through the complicated feelings I was having. I thought I needed this form of therapy as a countervailing force against an overwhelming wish to have said uterus ripped out so I did not have to endure the pain ever again. In other words, I have had a very conflicted relationship with my body. I have come to conclude that this conflict is manifested in painful menstrual periods.

When I turned 39, and exhausted by the monthly suffering that would incapacitate me for several days, I went to see another gynecologist, an older and more experienced female doctor than my first one, to help me deal with the pain once and for all. She advised that I undergo a Transvaginal Ultrasound (TVU) procedure. After a few hours, I came to see the results and the ultrasound scan revealed that I have a large cyst on my left ovary. The result also stated that the cyst was consistent with endometriosis. This would be the first time that I was able to see in black and white, that my condition had a name, and it was called endometriosis.

Even so it took me three years to report the findings to my gynecologist! When I arrived back to her clinic, I was deeply embarrassed, and was about to get over the edge because of desperation and helplessness. After briefly admonishing me for my lack of worry over my own affliction, she then ordered another round

of Transvaginal Ultrasound (TVU) procedure. This time I immediately shared the findings with her. The ultrasound scan revealed that I had endometriosis and had a cyst on my left ovary, which had since grown to the size of a tennis ball.

She recommended a radical procedure, a Total Abdominal Hysterectomy because I was not planning to get pregnant anyways, so a major surgery seemed the best for me. But I was not about to let go of my ovaries and uterus. Although I would often wish, while in the throes of pain, that I could rip them out, I was also extremely hesitant to undergo a major operation that would result in the loss of certain body parts that had come to define me. Moreover, after countless hours poring over authoritative articles in the internet, I have decided that estrogen was good for me health-wise, and the risks of hysterectomy for someone like me who is a decade away from menopause, far outweigh its benefits.

So then I asked for a more conservative option and she referred me to a young gynecologist and an endocrinologist whom she thought could help me. It turned out that this young physician had been prescribing a new drug to her patients with endometriosis. The hormone drug, *Visanne* immediately stopped my period and more importantly stopped the pain after just a month since I started taking it. *Visanne*, which is manufactured by Bayer, is a dienogest-based hormone therapy. The progestin dienogest (DNG) was developed for oral contraception, endometriosis treatment, and menopause management (Kim et al., 2016). In many clinical trials, *Visanne* has proven to be effective in long-term pain management for long-time sufferers from endometriosis (Dobrokhotova et al., 2017; Kim et al., 2016; Petraglia et al., 2012; Schindler, 2011).

However, I was experiencing some side effects of the drug in the first few months I was taking it. Such concerns are confirmed in a research study in 2016, which listed the following contraindications: weight gain, uterine bleeding, fatigue, and depression (Kim et al., 2016). Yet I persevered in taking *Visanne*, which I still am taking today, because the pain-free existence trumps my other concerns. Gradually, the side effects disappeared as I continued with my treatment.

Nevertheless, after almost a year of taking *Visanne* the cyst in my left ovary did not shrink in size. This caused me some concern. So I ran back to my gynecologist, who, upon seeing my newest ultrasound scan result, reiterated her original advice, which is that I seriously consider radical hysterectomy. I however put my foot down and ever so gently insisted back that I wished to save my ovaries and uterus. Resigned, she referred me to a laparoscopic surgeon per my demand. This would be the second time she had referred me to some other specialist.

My new physician specializes in gynecological laparoscopic surgery. He made me undergo another Transvaginal Ultrasound Procedure to determine that my ovarian cysts did not change in size as well as confirm that they are indeed consistent with endometriosis. After a few hours, the results were in, and we talked about the laparoscopy option and everything that it would entail. He also prepared me to be ready for when my left ovary, which was stretched to grotesque shape by a very large cyst, would be removed or excised. We then decided to hold the procedure as early as possible. I turned 43 years old on a day before my operation.

Since laparoscopy involves minimally invasive surgical procedure, it is often recommended for endometriosis, either mild or severe. Laparoscopy provides the only possibility of ascertaining the expected diagnosis of endometriosis (Mettler, Ruprai, & Alkatout, 2014).

Not Just a Woman's Problem: Health Care and Social Security Benefits

As a tenured faculty member in one of the country's most prestigious universities, I have access to health care insurance. I can say I am one of the lucky ones to have a card from a Health Maintenance Organization (HMO) in addition to my Philhealth coverage. Philhealth is the country's attempt to provide universal health care coverage to all Filipinos. While there are clearly important benefits in having Philhealth access, Philhealth offers limited coverage. I underwent Ovarian Cystectomy, unilateral, and Philhealth covered only PHP29,810.00 (560 USD), which was about 19% of my total hospitalization cost. My HMO provider covered the other 81% of the cost.

Neither my HMO provider nor PhilHealth covers the expenses incurred for various medicines an endometriosis sufferer needs to live well and work productively. *Visanne* has helped me with managing pain by inhibiting my monthly periods. However, it is also rather expensive. A box of *Visanne* costs about PHP 2,400.00 (48 USD). Since it is intended to be taken for long term, the cost is too prohibitive for Filipino women who do not have the financial means to buy it for an extended period of time.

The Social Security System (SSS) offers several ways to help women who need support when they are undergoing some gynecological concerns. As stipulated in Republic Act. 9710, also known the Philippine Magna Carta for Women, specifically in the implementing rules and regulations (2010), Filipino women can apply for special leave up to 60 days. SSS also allows female members to file disability claim after they have undergone gynecological-related surgery that involves loss of reproductive parts provided that they are 44 years old and below on the day of the surgery (Philippine Commission on Women, 2010).

As put forward earlier in the paper, the management of symptoms associated with endometriosis is expected to be enduring. I started my journey towards a fuller quality of life, even while living with endometriosis, when I was 22 years old. I was 43 years old when I had a laparoscopic surgery wherein my left ovary and left fallopian tube were excised. My doctor told me they were inflamed with cysts and multiple adhesions and thus he decided to excise them. All in all, it took me 21 years to resolve, once and for all, to undergo surgical procedures for endometriosis. I am not yet free of endometriosis. Since my other remaining ovary still produces estrogen, I will have to continue to take *Visanne* in order for the symptoms to not come back sooner than expected. During my pre-*Visanne* days, when I would be screaming from unbearable menstrual pain, my husband would graciously and lovingly massaged my back, legs, and feet until I would fall asleep. Without this support, my agony would have been too much for me to function normally.

In the 22 years of health-seeking activity on my part, I have had continuous access to quality health care, ranging from opportunities to consult specialists, undergo costly diagnostic tests, and admission to

private hospitals, without worrying about my ability to financially afford it. I know that such privileges are not accessible to many Filipino women. And if we factor in the prevalence of endometriosis in many women in the world, it is reasonable to assume that many Filipino women, at the peak of their productive and reproductive years, are constrained to suffer from endometriosis, which is a chronic and painful disease.

Conclusion

My experience of living with endometriosis in the Philippines has led me to speak and write from an awakened ability of being mindful of my own bodily processes in a positive way and not to always regard them as a nuisance and inconvenience. Surely, this is what it means by body-Praxis, when one gets to be acquainted with one's bodily processes. Body-Praxis simply means that we allow "embodied" accounts to illuminate and transform our knowledge of ourselves and of the world. My journey towards getting free of endometriosis is shared by many women and their loved ones who journey with them. If before, we had suffered in silence, now we understand that when we encounter other women, who are willing to listen because they went through the same experience, we can begin to trust the journey to name our experience. The truth does set us free. Our homecoming is characterized by our embodied experiences such as menstruation, however agonizing this could be; so that what is repugnant and painful becomes the locus of the journey towards a fuller quality of life. Indeed, women's bleeding becomes the demand of solidarity.

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