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Missing from Research: Exposing the Deficit in Knowledge and Research of Endometriosis and Women's Health

“Self-knowledge is no guarantee of happiness, but it is on the side of happiness and can supply the courage to fight for it.”

(Simone de Beauvoir, *The Second Sex*, 1949)

I remember placing my foot outside of the shower and immediately collapsing to the tile of my bathroom floor. I remember lying there, curling my body into a fetal position, bringing my knees to my chest to stop or relieve any amount of the pain that I was experiencing. I remember screaming, as much as I could, for my family members who were outside enjoying the muggy summer day. I remember when someone was finally able to hear me, my mother rushing into the bathroom and panicking to call an ambulance. I remember her frantically attempting to clothe my suffering body before the ambulance arrived. I remember the paramedics arriving and having to carry me down a set of stairs into the ambulance that was waiting for me. I remember every rut in the road that we hit on the way to the hospital as I felt it all in my body. I remember the IV, the

morphine I was given, the sonogram, the CT scan, and so on, but most of all, I remember all the hours that I have writhed in pain in emergency rooms.

This is one, just one, of my experiences living with Endometriosis and Polycystic Ovary Syndrome. This was not the start of my symptoms or when I realized that something was seriously wrong with my body, but the start to truly beginning to advocate for myself and my body. Prior to and following this experience, I endured many of the severe and unpleasant symptoms of these chronic pain disorders, commuting to the emergency room laid in the back of an ambulance or the back seat of my mother's SUV, countless times. I do not want to say that I had become accustomed to the symptoms and the constant trips to the doctors or emergency room, but it all had developed into an unfortunate routine.

Painful Teen Years

I was greeted by the lovely presence of Mother Nature when I was about 13 years old. Immediately, the whole thing was agonizing. I experienced the cramps that were disruptive to my everyday life, the intense back pain, the flux of having clear skin, the imbalance in being able to regulate my mood and emotions, the bloating, the fatigue, and so much more.

But little did I know, during my naïve middle school and high school years, that my wellbeing and health was about to diminish even more. I began to experience intense, sharp, and streaking pain in my lower abdomen, more consistently on my right side. This was the start to fluid-filled sacs and cysts growing on my ovaries and rupturing quite often.

I was very active in high school, at least to the best of my ability, considering my health. I was a competitive dancer, taught dance to younger students, had roles in musicals, and loved spending time with my family and friends. This all began to change the more I experienced excruciating and debilitating abdominal pain. Suddenly, I was told that I needed to stop dancing, stop teaching, not accept that role in the musical, and let my body rest as much as possible. All of these sacrifices were due to the size of cysts that had been continuously growing on my ovaries and the fear that my then level of activity could cause ovarian torsion. It was explained that cysts sometimes just grew like this, and that it would be something that I would maybe have to occasionally deal with. Occasionally turned into frequent, and I continued to go to the ER many times a year.

It was frustrating to visit the emergency room so much, however the most frustrating aspect to the visit was the care I received. It took me years of visits, years of cysts rupturing and having internal bleeding for an emergency nurse to suggest that I might have polycystic ovary syndrome. It always seemed to my mom and I that doctors never fully understood how to care for me when I did go to the hospital. One gynecologist visit after a trip to the hospital, I told my doctor that an ER nurse thought I might have polycystic ovary syndrome. My doctor looked at me and told me that it is very possible, but to be diagnosed, I have to fit a certain criteria. I ended up fitting the criteria and finally got an explanation for what had been causing me years of pain. But with this explanation, I didn't receive a magical solution, as there was not and still isn't one. My life became managing the daily pain and hormonal imbalances that I was experiencing. Not only was this already extremely difficult to deal with as a teenager, it got even worse from there.

Will College Really be the Best Years of my Life?

I decided to go away to college after I graduated from high school. This was when I started to encounter higher levels of pain than I had been feeling before.

The cramping pain in my abdomen and back matured into feeling like I was constantly being kicked in both areas. Extreme bloating made me look as if I was expecting a child. I was experiencing all-around chronic fatigue and very excessive bleeding, clearly suffering every day. My management plan included being on birth control, taking pain medications, and wrapping my back and abdomen in heating pads. I have changed birth control over ten times between the time my issues began and now. The trips to emergency rooms continued and so did the dismissive and shaming responses from nurses and doctors. I would essentially be told there was nothing they could do for me after they concluded it was not my appendix rupturing, but just my ovaries. Just my ovaries.

Between doctor's visits and trips to the hospital, I was trying to live the life of a college student. I was trying to attend my classes, engage in extracurricular activities, work in my Resident Assistant position that I was very lucky to have, and interact with my friends and boyfriend. Balancing my college student life and my distressed body was incredibly challenging. The pain and not knowing exactly what was wrong with me took a toll on my physical, mental, and emotional health -- really, every

aspect of my life. More and more, I struggled to get out of bed to attend my classes because of my physical and emotional troubles. Sometimes it became exhausting for me to interact with my residents and do simple tasks that were required within my position. My boyfriend unintentionally became my caretaker. He became the person who transported me to the emergency room, with my family being home, helped me deal with the after-effects of being dismissed and sometimes shamed at hospitals. Overall, he was my loving and caring source of stability and support throughout the whole experience.

One weekend at home, I was experiencing the most painful episode of cramping, bloating, and bleeding that I had ever experienced. This was followed with a very angry phone call by my mom to my OBGYN inquiring what were they finally going to do to help me. It was a Saturday. I was told to wait until Monday and come into the office. I spent the next day or so waiting, not able to move from my bed unless I absolutely had to use the bathroom. This doctor's visit contained the typical "Tell me what you're feeling" conversation, and I was greeted with two options. I could either have an explorative surgery, which is the only way to formally diagnose what they

thought was endometriosis, or I could be put in a 6-month temporary menopause, with all the side effects, to attempt to alleviate some level of the pain and problems. I chose surgery.

I scheduled my surgery for the first possible date. This date fell the Friday before midterm week. I expected to need at least one week of recovery, so I knew that I would be missing all of my tests and studying opportunities. I did not care. I cared, but I recognized that I needed to put an end to the miserable experience that I was encountering. So I, alongside my support system boyfriend, packed my bags to go home and get my surgery when it was time. I remember the overwhelming anxiety I had prior to surgery. I was thinking about what my doctor may find and remove, what if she doesn't find anything, what if it's extremely extensive, etc.

I woke up after my surgery, hysterically crying in the recovery room. I very briefly remember repeating, "I'm scared," over and over again to the nurse and her insisting that I needed to go back to sleep. I remember waking up again feeling nauseous. And then again, in a lot of pain. And then, lastly, waking up in a chair and seeing my family and boyfriend staring at me. My mom helped me eat the graham crackers and juice that I had insisted on not having. She told me my

doctor and surgeon said that the surgery went well, and they did find endometriosis lesions on some of my organs. I experienced a sense of relief, but also intense uneasiness. I finally got a diagnosis, but did I really want that diagnosis?

For the next week, I was basically couch bound. I needed assistance getting up and back down carefully, trying not to rip the stitches in my belly button and in two spots on each side of my abdomen. I followed up with my doctor a few days later and got a surprise that I was not expecting. I got pictures of my organs. My doctor circled and pointed out each place that she had found endometriosis invading my body. She said, “You can even make these pictures your Facebook profile picture if you want!”

This is a very condensed version of my experiences with symptoms, getting misdiagnosed, getting diagnosed, and living with endometriosis and polycystic ovary syndrome. I am one in ten women who exist with this quality of life due to the lack of knowledge and research surrounding women's health, but specifically, gynecological health.

What is Endometriosis?

Endometriosis, a chronic and painful gynecological disorder, is defined by the

presence of endometrial-like tissue covering the outside of the uterus and surrounding organs, in turn impacting female bodies in physical, mental, emotional, and social ways (Luciano & Luciano, 2006, p. 617). Endometriosis is not a rare disease, but harms approximately 10 percent of reproductive age females in extraordinarily negative ways due to symptoms, experiences of diagnosis delay, experiences with health care providers, a blatant lack of information, and the impacts it has on physical, psychological, and social realms of life (Gerlinger, Faustmann, Hassall, & Seitz, 2012).

There are many unfortunate and weakening symptoms indicating the presence of endometriosis. Endometriosis is commonly marked by various pains, painful sexual intercourse, heavy/irregular bleeding, and issues of fertility. Pain associated with endometriosis is described as “sharp, stabbing, horrendous, tearing, debilitating, and breath catching” (Moradi, Parker, Sneddon, Lopez, & Ellwood, 2014, p. 4). These descriptions of pain can occur in different areas such as one's abdomen, bowel, bladder, lower back, and lower body. Endometriosis related pain impacts female bodies in different frequencies fluctuating

between every day, weekly, or a year to years marked with pain (Moradi et al., 2014, p. 4). Severe and progressive pain during menstrual and non-menstrual phases tied with other symptoms of fatigue, bloating, bladder urgency and symptoms, bowel symptoms, and sleep disturbance essentially epitomizes endometriosis.

Physical pain typically brands endometriosis, but most experience a psychological impact as well with feelings of low self-esteem, self-confidence, and feelings of powerlessness (Moradi et al., 2014). Women with endometriosis often carry varying anxieties, some regarding future fertility, “recurrence of the disease, disease prognosis, worsening symptoms, interference in their education, employment, sexual/marital life and motherhood responsibilities, financial concern because of losing their job and high treatment costs, finding a new partner” (Moradi et al., 2014, p. 7). Endometriosis’ disruption of the social realm of life is typically the cause for many of these anxieties that are not as much of a concern for health care providers as the physical aspects of the disease (Riazi, Tehranian, Ziaei, Mohammadi, Hajizadeh, & Montazeri, 2014).

Though these symptoms, both physical and psychological, are often excruciating and very frequent, there is trouble in connecting them to a diagnosis of endometriosis. A woman’s experience getting diagnosed with endometriosis varies and is often marked with unpleasantness. This unpleasantness typically includes a delay in diagnosis, misdiagnosis, dismissive attitudes from doctors and others, ineffective treatment options, and an overall lack of knowledge and research surrounding endometriosis.

Delay between first experience of symptoms and diagnosis is typically many years, with an average of 8.1 years before diagnosis (Moradi et al., 2014, p. 3). During this time, those reporting symptoms are undergoing varying tests, often misdiagnosed and mistreated. Some misdiagnoses include “appendicitis, ovarian cyst, ectopic pregnancy, pelvic inflammatory disease, and ovarian cancer” (Moradi et al., 2014, p. 4). While being poked and prodded, these patients are interacting with health care providers who do not seem to listen to their concerns or dismiss their symptoms as normal or not pervasive enough to act on. Those impacted by endometriosis have reported both positive and negative experiences with health care providers. Most striking are

the negative experiences of providers not listening to their concerns, not having time to answer their questions, and dismissing their symptoms (Moradi et al., 2014, Results section, para. 6).

Another large issue of receiving an endometriosis diagnosis is the necessity for laparoscopic surgery. Laparoscopic surgery allows the surgeon to see the degree to which the disease has invaded organs. A laparoscopic excision sometimes provides relief for those who endure it, but “is not always an ultimate cure for patients as recurrence rates after the operation can be as high as 40-50% after approximately two years” (Simsa, Mihalyi, Kyama, Mwenda, Fulop, & D’Hooghe, 2007, p. 649). Laparoscopic surgery is necessary to receive a diagnosis. However, it is “expensive and puts an extra burden on both the operation room and the patient” (Simsa et al., 2007, p. 649) and can be replaced with further knowledge and research.

Stemming from the lack of knowledge and research of endometriosis comes a lack of treatment options. Currently there is no cure for endometriosis. Medical professionals seek to manage symptomatic endometriosis by attempting to relieve symptoms and prevent recurrence and progression (Luciano & Luciano, 2006). Because endometriosis is chronic and predicted

to reoccur, repetitive cycles of medical and surgical therapy are necessary unless one elects to remove their ovaries and uterus, which doesn’t specifically promise relief of symptoms (Luciano & Luciano, 2006). Initial medical therapy for symptomatic endometriosis includes hormonal contraceptives with estrogen and progestin (Luciano & Luciano, 2006). Alternative therapies and changes of lifestyle are often recommended, such as change in sleep, exercise, and dietary habits.

In the United States, endometriosis and its extensions cost society an estimated \$70 billion dollars in 2009 (Brüggmann, Elizabeth-Martinez, Klingelhofer, Quarcoo, Jaque, & Groneberg, 2016, p.1)., Endometriosis poses a threat to female health globally, just as in the United States, In in a multitude of countries, there is a large disparity in research even though millions of female bodies are impacted. In their research, Hickey, Ballard, and Farquhar (2014) note a European study of 1,000 women indicating the average annual cost of endometriosis, per woman, was \$1,380, with two thirds of the cost from loss of productivity (p.1). In low resource countries, disparities of knowledge and research are even greater. In a data analysis of endometriosis related publications between the years

1990 and 2009, 11,056 publications were identified across 88 nations (Brüggman et al., 2016, p.3). The United States lead with 3,705 publications, followed by the United Kingdom (Brüggman et al., 2016, p.3). Brüggman et al. state that taking “a closer look into the global research exemplifies that a large gap of research activity exists in a multitude of countries in which -- under conservative estimations -- tens of millions of affected women live” (p. 9). With this known, research efforts not only need to be increased, but also expanded towards disease prevention rather than disease management.

Recognizing the Inadequacy

Many issues and groups of health problems need to be addressed. One that is specifically, and could be considered intentionally, excluded is the absence of scientific knowledge and research in women’s health. There are many reasons for the lack of research, knowledge, and care surrounding women's health. Auerbach and Figert (1995) point out a few basic issues as to why the current field of medicine is lacking research, knowledge, and care for women's health. These are, “... the lack of inclusion of women in major clinical studies, inadequate attention to gender differences and gender analysis in

medical research, and inadequate attention to diseases and conditions specific to, more prevalent among, or more serious in women” (Auerbach & Figert, 1995, p. 118). There are other factors, beginning at defining women’s health and who it is doing that.

A Sex Missing from Research

Medical knowledge is typically derived from and created by men. It is then enforced on women, carrying the notion that the results can be functional for both sexes, even though there are stark differences in health risks between the sexes (Auerbach & Figert, 1995). This difference is exposed in morbidity and mortality rates, treatment options and outcomes among men and women (Auerbach & Figert, 1995). Research studies need to include both men and women in order to comprehensively grasp those specifically at risk for specific diseases or conditions.

In 1986, the National Institutes of Health (NIH) issued a policy encouraging the inclusion of women in clinical scientific trials, due to the prior lack of women admittance. This policy issue came from the Public Health Service Task Force on Women's Health Issues’ publication addressing the “lack of scientific data on women's health as a barrier to understanding women’s

physical, mental and social health care needs” (Auerbach & Figert, 1995, p. 117). The report emphasized the general lack of research regarding women's health and, particularly, health issues surrounding the menstrual cycle. In 1990, it was found that the NIH was not adhering to its own policies, and there was no formal way of monitoring the policy. Large NIH research studies blatantly “involved no female subjects”; the report questioned whether research findings “could legitimately be applied to women” (Auerbach & Figert, 1995, p. 118). These studies included the effects of aspirin on reducing the risk of cardiovascular disease, a study of coronary heart disease, and longitudinal studies of aging. It was found that, “among studies of non-gender specific diseases, women were underrepresented (either excluded from or less than one-third of subjects) in nearly three times as many studies as were men” (Auerbach & Figert, 1995, p. 118). Clinical studies, both past and some present, have specifically excluded women from studies. This causes underrepresentation in medical knowledge, resulting in unfavorable care for women who need it.

There are many supposed reasons why women are excluded from research studies. For example, biological

variabilities, such as the menstrual cycle, pregnancy, and menopause, could alter a study in the researcher's eyes (Auerbach & Figert, 1995). There is also a fear of an increase in the cost of research if one chooses to use women as subjects. Another reason for this exclusion is the budget restraints that have required focus on “high risk” populations, “such as... white men with heart disease” (Auerbach & Figert, 1995, p. 119). Most of all, there is a general acceptance and belief that the differences between sexes is not compelling enough to cause a researcher to not only research women, but also medically treat them different from men. There is one recognized difference between sexes: the female body's reproductive abilities and hormonal cycles. This recognition is used as a rationale for exclusion, and stamps female bodies with only the importance of reproduction. This is extremely counterproductive and continues the ideal of those in patriarchal control defining what should be important about female bodies.

Defining Women's Health

Women are often not included in the identification of what encompasses women's health, and the field is typically defined by others. The authors of *Our Bodies, Our Selves* declare:

Policy Makers, usually male, have designed the system primarily for the convenience and financial gain of physicians, hospitals, administrators, and the medical industries. We believe that women, as the majority of consumers and workers, paid and unpaid, should have the major voice in the health and medical care policy-making in this country (Boston Women's Health Book Collective, 1998, p. 653).

Not only are women not included in the declaration of what women's health is, but many factors of women's lives such as the "sociocultural matrix in which women's ills develop, including in the context of poverty, patriarchy, and other life stresses" are not being considered when creating an agenda of women's health priorities (Inhorn, 2006, p. 349). Temmerman (2015) argues that it is critical to place "the human rights and health of women and adolescent girls, particularly sexual and reproductive health and rights" (p. 3) at the center of mending the gaps within the past women's health agendas that have been made. Endometriosis, being extremely relevant to reproductive health, desperately needs to be included in the agenda of women's health priorities as it impacts all realms of life for those who are diagnosed.

Tuana (2006) discusses a "Speculum of Ignorance" within the women's

health movement, and speaks of feminist health activists and their goals of being

"committed to uncovering the ways women's bodies had been ignored, to examining knowledge that had been withheld from women and certain groups of men, to reclaiming knowledge's that had been denied or suppressed, and to developing new knowledge freed from the confines of traditional frameworks" (2006, p. 2).

There is importance in recognizing that ignorance exists within those who control the medical community and those who advocate for women's health. Even more important is the recognition of why such ignorance exists. In "They Do Not Want Us to Know" (2006), Tuana states it is key to "remove the veil of ignorance around topics where our ignorance has been systemically cultivated" (p. 10). Such ignorance has been created by the current systems and social standards society has placed value upon. By "remove the veil" (p. 10), I argue that a feminist approach to health care is necessary.

Feminist Approach to Health Care

Integrating a feminist approach and critique to current standards of medicine is crucial to making a fundamental and long-standing reconstruction of

women's health care. *The Boston Women's Health Book Collective* (1998) states that the feminist approach to health care should be "focused on wellness and health rather than disease and treatment" (p. 653). Reasoning for this derives from the thought that "health [as in ideal] does not generate as much profit as illness" (Cavalcanti de Aguiar, 1998, p. 27). When there is a focus on illness, the healthcare industry can sometimes specifically be focused on rare conditions. This is what Cavalcanti de Aguiar (1998) considers "a waste of time and energy" (p. 29). Endometriosis is a disease known to have considerable prevalence within communities, and it is by no means a rare condition. By shifting the focus to health and prevention, endometriosis could be included within a new women's health care agenda and would be granted the opportunity to increase knowledge surrounding the disease.

A feminist approach to health care means the inclusion of gender, feminism, and women's studies in medical education. Such a modification would provide those who are entering the medical field to become more conscious of gender, race, class, power systems, social constructions of identity, politics, intersectionality, and how they all cohere to health care, and patients.

Cavalcanti de Aguiar (1998) states that working with an interdisciplinary approach would "enhance the awareness about the risks that affect women and other 'minorities,' as well as prepare professionals to develop a meaningful dialogue with the clients, starting from the clients' previous knowledge and beliefs" (p. 33).

At the heart of some doctors' ideological perspectives are misogyny and sexism in professional training and health care (Cavalcanti de Aguiar, 1998, p. 10). This is often magnified throughout their professional training and extended into their practice. These ideologies often include assumptions about women's identities, bodies, sexualities, and social roles. Auerbach and Figert (1995) note that exploring gender within the medical field was not a focus until there was a shift in coverage. When this shift in focus began, it was found, in Western society, that men die at an earlier age, but women experience more sickness and illnesses, thus filling women's lives with chronic disease and misfortune (Auerbach & Figert, 1995, p. 121). Including gender within the medical field creates recognition specifically towards health concerns that are unique to women, or that disproportionately affect women. (Auerbach & Figert, 1995, p. 122).

Endometriosis, being specific to female bodies, would benefit from a health care system that explores how gender is intertwined not only within medical care, but in all realms of life.

To start modifying current practices, it is important for those who are entering the field, and those within the field, to understand that women's health and illness is not only biologically determined, but socially as well. Medical curriculum does not include social factors of illnesses, but specifically scientific or biological approaches (Cavalcanti de Aguiar, 1998). By ignoring these social factors, medical professionals are ignoring the fact that "inequalities of gender, race and class lead to poor health" (Cavalcanti de Aguiar, 1998, p. 36) and lessens of the possibility of empowering not just patients, but people in general. Exploring these forms of oppression as intersectionality is key to understanding that there are more health consequences

to particular groups of people, such as poor, women of color.

The Future of Women's Health

Mending the discrepancies in women's health entails interdisciplinary thought and endeavors. These endeavors need to include women in research, women's voices, and always carry the thought of intersectionality and oppression, thus encapsulating a feminist approach to the field of health.

Endometriosis, one of the many reproductive health related diseases that specifically impact female bodies, could be either less prevalent, or less excruciating in a society that integrates a feminist approach to health care. As one of the many women impacted by the disease, I could be living a less painful and distressing life. I would not be the one in the "one of ten women" who exist with an inferior quality of life due to the lack of knowledge and research surrounding women's health.

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