

Self-Advocacy for Female Patients with Chronic Pain

by
McGwire Smith

A THESIS

submitted to
Oregon State University
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degree of

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(Honor Associate)

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A significant proportion of the population of the United States suffers from chronic pain, a category of disease that is not yet well understood by healthcare professionals. A majority of this group is made up of women; individuals who often have to convince healthcare professionals that their symptoms are real even when they come from well understood diseases. The reasons for this predicament are the lack of research on differing physiologies and anatomy between men and women, historically established stereotypes about female patients that mean they're considered unreliable in reporting their own symptoms, and the interaction of these two problems for chronic pain. This interaction is a result of a disease that boasts few research findings and many stereotypes of patients (mostly female) that are particularly unreliable in a medical setting.

Key Words: chronic pain, female patients

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I understand that my project will become part of the permanent collection of Oregon State University, Honors College. My signature below authorizes release of my project to any reader upon request.

McGwire Smith, Author

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Prologue

One day in the summer of 2018, I was alone in my apartment doing the dishes. I was listening to a podcast I often listened to over the sound of the rushing water and the traffic outside the open window in front of me. The episode I was listening to was titled “Why Isn’t the Medical Community Taking Women’s Pain Seriously?” I listened as the two women discussed various health disparities women faced such as race disparities in childbirth outcomes and the mistreatment of women during cardiac events. Then my own chest tightened as I listened to the conversation about a topic new to me: pain. I was angry when I heard how often women are not believed by doctors and have to endure a mysterious, painful disease alone. I wanted (and still do want) to become a doctor in the future. For me that means learning about the shortcomings of modern medicine and how I can help make up for them. What was this mysterious affliction that mostly affected women? Why didn’t anyone seem to believe they were actually suffering? I hope to explore these questions along with possible solutions in this paper.

Introduction

In the U.S., nearly 30% of people have chronic pain conditions (Ballweg, 2010). This occurrence is twice as likely in women as in men (IOM, 2011). Often time the immediate question after this statistic is “Why? Are women really so different from men?” The answer is: yes, in part because women are *biologically* different from men. Recent studies suggest that the physiology of men and women is so different that women consistently show lower pain thresholds and tolerances (Clark and Robinson, 2019). This is discussed in the first section of this paper which explores the potential physiological processes behind common chronic pain diseases like fibromyalgia, irritable bowel syndrome, temporomandibular joint pain, rheumatoid arthritis, and lupus. The potential processes will be summarized through the analysis of various research projects from the past four years. These recent experimental findings contribute to a growing body of information regarding disease in the female body.

The second section of this thesis describes the struggles female patients have with medical institutions built on years of false generalizations about them. Women seeking medical help must overcome the assumptions that they are 1) Too likely to complain needlessly about their symptoms and 2) Too emotional to accurately relay details about their symptoms. These stereotypes lead to a lesser standard of care for women, particularly for women of color, girls, disabled women, sexual assault survivors, queer women, overweight women, and transgender women.

In the final section the focus is on female chronic pain patients and how the interaction between biological and sociological factors influences women’s medical

care and create a difficult territory that women must navigate. The recent developments in biological studies of women with chronic pain are heartening but there is much work to be done in medical education. When doctors don't trust their patients, patients learn to not trust their doctors. Patients must learn to advocate for themselves in order to receive the care they need. Systemic adjustments in medicine can ease the burden these women face and lead to more effective treatments for chronic pain.

Part 1: The Biology of Women's Pain

This topic of chronic pain is of the utmost importance to women's health because the majority of chronic pain sufferers are in fact women. The unfortunate truth is that women have historically received different, often lesser, quality medical care when compared to men. Chronic pain diseases that disproportionately affect women include fibromyalgia, irritable bowel syndrome (IBS), temporomandibular joint pain (TMJ), rheumatoid arthritis (RA), and lupus¹. It's not completely understood why women are more susceptible to pain and chronic pain conditions, but various potential reasons are currently being studied. The presence and concentration of female sex hormones have been determined to have an influence on fibromyalgia, IBS, and TMJ.

A common feature of fibromyalgia, RA, and lupus is the presence of inflammation. Some correlations between inflammation and female sex hormones have helped explain why these conditions tend to be predominant in women, but the evidence is not yet strong enough for solid conclusions. Another possibility could be recently discovered differences in neuroanatomy between men and women that contribute to different pain responses.

Within the nervous system, signals are transported through electrochemical means. One study observed the communication between Nociceptin/Orphanin (NOP) pain receptors and the chemical Nociceptin/Orphanin FQ (N/OFQ) formed in the body that it binds to relieve pain (Wright, Small, Nag, & Mokha, 2019). The purpose

¹ The last two being autoimmune disorders, which women are also more likely to have than men, but are not the focus of this paper apart from their pain component

of this experiment was to confirm a relationship between the presence of estrogen and a specific kind of pain (Wright, Small, Nag, & Mokha, 2019). The target category of pain was a generalized surface sensitivity to even light touch, this is referred to as allodynia (Straub, 2007). The researchers were able to support their original claim because test subjects treated with estrogen (in a manner where it outcompeted the chemical N/OFQ for NOP binding) were quicker to withdraw their limbs as a result of the heightened discomfort from a certain level pain stimulus (Wright, Small, Nag, & Mokha, 2019). In a system where estrogen can out compete the pain-reducing chemical, for example the female body as opposed to the male body, pain can become a much more common experience. Another case of women commonly experiencing pain, not necessarily due to estrogen levels, would be fibromyalgia.

Fibromyalgia, a chronic pain condition, is a consistent, dysfunctional (meaning neural and without cause) pain felt deep in the muscles (Woolf, 2010). The symptoms of this disease were recreated in an experiment (using rat subjects) to test the interaction of two other female sex hormones- estradiol and progesterone- in the fibromyalgia pain response (Chang, et al., 2019). This was done by creating a similar pain response through acid injection into the muscle and then injection of estradiol or progesterone near the spine (Chang, et al., 2019). A similar limb withdrawal as the last study was recorded and it was found that the presence of either of the hormones created a faster withdrawal time in response to a standardized painful stimulus (Chang, et al., 2019). This change was noticeable because pain-reducing mechanisms already exist in the body and the controlled presence of either of these hormones led to lower pain thresholds in the subjects (Chang, et al., 2019).

This is not to suggest that the cause of fibromyalgia is due to female sex hormones (the nature and potential cause of the disease will be discussed later on). However, the reason this condition is so often experienced by women could be, as suggested by this study, that already present symptoms may be exacerbated by the presence of these hormones. The occurrence of chronic pain can also become the start to a never-ending cycle as it starts to feed into chronic stress as is the case with irritable bowel syndrome.

Irritable bowel syndrome (IBS) is a chronic pain disease related to the gastrointestinal tract that includes digestive problems as well as abdominal pain. The presence of this condition is correlated with higher levels of stress. This is not the only potential cause of IBS, but given the common coexistence of chronic stress and pain it's important to acknowledge the relationship. In a study, examining the interactions of stress and sex hormones, the stress response was produced through the use of a "forced swim test" and IBS was imitated by manipulating the conditions of the subjects' viscera to promote "hypersensitivity" (Ji, Hu, Li, & Traub, 2018). Once the conditions of the experiment were in place, both estradiol and testosterone were injected into rats of the opposite sex (Ji, Hu, Li, & Traub, 2018). Male rats without estradiol injections were recorded as registering pain later and for not as long as female rats without injections (Ji, Hu, Li, & Traub, 2018). Male rats with estradiol injection experienced more pain sooner and longer than female rats with testosterone injections (Ji, Hu, Li, & Traub, 2018).

While previous studies aimed only to confirm that female sex hormones play a role in promoting pain, this study also included male sex hormone and concluded that

male hormones may play a role in inhibiting pain (Ji, Hu, Li, & Traub, 2018). Pain was measured by the level of electroactivity in the abdominal muscles in response to varying levels of IBS pain conditions (Ji, Hu, Li, & Traub, 2018). The increase in pain after the stress of the forced swim test, for female subjects was significant, which seems to be true for human women as well (Ji, Hu, Li, & Traub, 2018). Stress can have a major, negative impact on the human body, especially when paired with ceaseless pain. This is the manner by which visceral pain (IBS) is expressed and can also be the case for facial pain, like with Temporomandibular Joint Pain (TMJ).

Temporomandibular Joint Pain is another chronic pain disease. It is named for the pain that accompanies movement between the mandible and temporal bones. These movements occur often during normal actions like talking and chewing. Sensation in this region is supplied by the trigeminal cranial nerve, the activity of which was the focus of a study by Nag and Mokha. Adrenoceptors are receptors that bind adrenaline and influence nerve activity, in this case, to reduce the effect of noxious pain stimuli (Nag and Mokha, 2016). An experiment was conducted which tested the influence of sex hormones on the level of pain reduction caused by adrenaline binding to adrenoceptors in proximity of the trigeminal cranial nerve (Nag and Mokha, 2016). It was found that the effect of the adrenaline was countered by the presence of estrogen in the subjects (Nag and Mokha, 2016). Tolerance was measured by whether or not a rat was willing to pursue a “reward” if it meant enduring more pain, but tolerance was low for female rats and a majority of the time the reward wasn’t pursued (Nag and Mokha, 2016). This depressing example can be directly translated to the experience of human women: what is the “reward” that can no longer

be pursued because the chronic pain is too great? One type of pain evaluated in this study was inflammation (Nag and Mokha, 2016). It has already been demonstrated that nociceptive (injury related) and dysfunctional pain have a pretty strong correlation with female sex hormones, and inflammation plays a role as well.

Different female sex hormones have been found to correlate with inflammation, depending on circumstances like the state of the immune system, type of tissue targeted, and concentration of the hormone (Straub, 2007). This is to say that certain triggers do reliably cause an immune response (inflammation), but the depth and duration of that inflammation may depend on these hormones. The type of female sex hormone (which in this case included estrogen and estradiol) and the section of the nervous system it's administered, whether it be the central (brain and spinal cord) or peripheral (everything but the brain and spinal cord), positively influenced inflammation (Straub, 2007). For example, in the peripheral nervous system, the presence of female sex hormones, like estradiol, were linked to inflammatory conditions commonly found in women like fibromyalgia, rheumatoid arthritis, and lupus (Straub, 2007). Neuroanatomy plays a larger role when the central nervous system is involved.

There's an area in the brainstem called the Periaqueductal Gray (PAG). The PAG holds an important pathway for pain processing up and down the body (Tonsfeldt, et al., 2016). This final experiment focused on the difference in the PAG between males and females experiencing inflammation. It was found that female rats had a higher number of GABA_A receptors in their PAG (Tonsfeldt, et al., 2016). When GABA_A receptors are activated, they inhibit the ability of the PAG to reduce

pain (Tonsfeldt, et al., 2016). So a higher number of these receptors would mean it wouldn't take as much chemical to activate them and, therefore, deactivate the analgesic properties of the PAG, leading to more pain in females. During the artificial inflammation, an attempt to reduce pain with opioid was more effective in male rats than female rats because of their lower number of GABA_A receptors (Tonsfeldt, et al., 2016). The author suggests that GABA_A inhibitory chemicals might prove an effective treatment for women with chronic pain (Tonsfeldt, et al., 2016).

In conclusion, research suggests that women are more predisposed to chronic pain conditions because of common characteristics of their bodies. This can mean female sex hormones out competing pain inhibiting chemicals, prolonged inflammatory responses, or more neural structures that deactivate pain inhibiting pathways. In contrast, it was found that male sex hormones can have pain reducing properties. While these discoveries represent steps to finding better ways to treat women's pain, incorporating them into medicine can be a long and arduous process. A more immediate way to help women with chronic pain would be to attack the problem from a sociological standpoint.

Part 2: The Sociology of Women's Pain

Let's move on from the topic of anatomical and hormonal causes of pain, to actual patient experiences and doctor-patient interactions. If a woman were to experience the symptoms of some of the diseases previously mentioned, for example an autoimmune disease or fibromyalgia, she might explore available resources before calling a doctor. This might include visiting an accredited website such as the autoimmune diseases page for [womenshealth.gov](https://www.womenshealth.gov). In this case, our hypothetical patient would find phrases like "Getting a diagnosis can be a long and stressful process" (OWH, 2019). This is not totally discouraging, mostly just a warning of what's to come. It's the last bullet of the *How do I find out I have an autoimmune disease?* section that is most concerning: "Get a second, third, or fourth opinion if need be. If your doctor doesn't take your symptoms seriously or tells you they are stress-related or in your head, see another doctor" (OWH, 2019). This is just one indication of how common it is for women to experience this type of treatment. This section will focus on the adversity women face in the pursuit of competent medical treatment in all specialties, not just pain. The reason for this focus is to take an in depth look at the contributing factors that turn women into second-class patients.

This is not just a modern-day problem, it's a phenomenon built upon centuries of reinforcing old ideas that women and their symptoms are not to be trusted. For example, in the 1970's (well within the second wave of feminism) an account given by a female medical student describes a male instructor teaching her that women complaining of stomach pain are "unreliable historian[s]" (Campbell, 1973). So why are women and their symptoms dismissed? What is it about women that makes them

so unbelievable? This paper posits two primary reasons: 1. Women are more likely than men to report their symptoms and 2. Women are believed to be more emotional than men. To address the first: some studies show that women do tend to report their symptoms more often (Fillingim, et al., 2009). This is not actually a valid reason to refuse female patients the care they need and doesn't indicate whether or not the reports are accurate. The second is definitely a stereotype: women are not necessarily more emotional than men when receiving medical treatment on all occasions (Bernstein and Kane, 1981). The consequence of doctors believing this stereotype is assuming there's nothing actually wrong with emotionless women because they should be emotional, but also not believing emotional women because they're just more emotional than men. Both of these stereotypes hold complicated, yet inextricable places in medical history.

Part of the stereotypes around overreporting is the false notion that women exaggerate their symptoms or completely make them up. This concept is summarized by the term *somatoform disorder*, what used to be known as hysteria (Lipowski, 1988). A somatoform disorder is a result of somatization which means to transform mental problems into physical problems (Lipowski, 1988). This diagnosis suggests that the patient never had any legitimate medical issues at all. Somatoform disorder and somatization go hand in hand with a medical category called Medically Unexplained Symptoms (MUS). This category is a dangerous invention used as a catch all for afflictions that medicine hasn't defined quite yet (Goldstein Jutel, 2011). This is a problem because dismissing these patients is neglectful regardless of underlying conditions, and sometimes the results can be deadly. According to a 2013

trial study, 15% of cancer, 15% of heart disease, 26% of IBS, and 26% of fibromyalgia patients could be given this diagnosis... as well as 7% of healthy people (Frances, 2013). A diagnosis (if it should even be called that) of MUS is much more common for women than men, about 70% of patients diagnosed with MUS at surveyed pain clinics were women (Huang and McCarron, 2011). This is demonstrated by the mnemonic that medical students used to be encouraged to study to remember the symptoms for somatoform disorder “Somatization Disorder Beset Ladies and Vexes Physicians (Shortness of breath, Dysmenorrhea, Burning in gonads, Lump in throat, Amnesia, Vomiting, and Painful extremities)” (AJP, 1985).

These results suggest that the MUS category only exists because the fear physicians have of being wrong or without answers is greater than the prioritization of the patient’s physical and emotional wellbeing (O’Leary, 2013). Perhaps these physicians believe that the existence of a diagnosis is better than its absence. This would explain why, when confronted with medically unexplained symptoms, physicians will reassure patients that nothing is actually wrong with them because no test turned up an organic cause for their symptoms (Hartman, et al., 2009). In all likelihood, patients do not find this news reassuring, instead they end up feeling hopeless and scared (Salmon, et al., 1999). Circumstances like these lead to the scenario like the one mentioned at the beginning of this section: a necessary warning by a reputable source of health information, targeted toward women, that states the fact that you have to fight to be believed.

Part of the stereotype that women are more emotional than men is the suggestion that this is linked to higher incidence of mental health issues. This is a

harmful stereotype for men, too, because the expectation that they don't have mental health issues means they may not get the psychological help they need. Regardless of whether or not this is an accurate representation of the population, women are more likely to be diagnosed with anxiety and/or depression than men (NIMH, 2015). This is in addition to the fact that often times, some symptoms of the physical disorders these female patients are suffering are psychological, too (Klonoff and Landrine, 1997). Once psychological symptoms are in the mix it becomes incredibly likely that doctors will dismiss the possibility that these women are also experiencing physical symptoms (Croskerry, 2003). This is especially true with chronic pain conditions because of the lack of research there has been done on them, and this will be discussed further next section.

When the assumption among medical professionals is that female patients report symptoms needlessly and are overly emotional, it becomes exceedingly difficult to get a diagnosis or treatment. This is in addition to the obstacle of a physical predisposition for exaggerated and chronic pain responses in female bodies. Women are at a distinct disadvantage in medicine both biologically and sociologically. This is especially the case when these two factors interact within chronic pain cases.

Part 3: The Interaction between Biology and Sociology

A 2008 emergency room study on acute abdominal pain found that women waited, on average, 16 minutes longer than men to be seen and were about 18% less likely to get opioids when treated for this pain (Chen, et al., 2008). This exemplifies the overall disadvantage of the female patient when it comes to the pursuit of pain treatment. However, the likelihood was that a majority of those patients (men and women) could have undergone basic screening tests to determine the source of their pain. This luxury is not often afforded to those with chronic pain conditions.

Each interaction between doctors and patients is made up of two major components: diagnostic tests and symptoms (Malterud, 1999). In terms of chronic pain, diagnostic tests rarely help with an actual diagnosis unless the patient is unlucky enough to receive the label of Medically Unexplained Symptoms (MUS). This is because past medical research has not effectively included female subjects and thus doesn't reflect majority female afflictions (like chronic pain). We established earlier in this paper that symptoms (as described by the female patient) aren't always taken seriously by the physician. The same stereotypes for women pursuing medical treatment, as discussed before, apply again to chronic pain patients, but in different ways. This will be the first time we dive into the topic of blind spots in medical research.

Medical research in the 1970's was subject to an FDA policy that restricted female subjects who were of "childbearing potential" (DHHS, 1977). This meant women who weren't pregnant weren't studied and therefore lost some of the benefits of the research. This action was justified by two contrary reasons: 1. Men were

similar enough to women that they didn't need to be represented and 2. Women were so complicated with their fluctuating hormones that they would unnecessarily complicate the study (Merton, 1993). Apparently these cyclical changes in women (which include the effects of sex hormones mentioned previously) were too challenging to risk the prioritization of women's health. It wasn't until the Revitalization Act of 1993 that NIH funded studies required there be a sufficient number of female participants to analyze differences between the sexes (NIH, 1993). And it wasn't until 2014 that the same standard was applied to animal subjects, tissues, and cells in NIH research (Clayton and Collins, 2014).

As if the lack of an existing body of research on women's health wasn't bad enough, present contributions are still being hindered. By 2014, only 30% of NIH funded researchers were women (Rockey, 2014). This is to say it would be unlikely that a female researcher with a chronic pain condition would get an opportunity to research her own disease, based on her gender. This serves as a detriment to medical students, as well. As of 2008, they would have been unlikely to see whatever research was available unless they went to a medical school that was a part of the 33% of schools that had an office overseeing women's health curricula. When these students graduate and become doctors this impacts their ability to properly diagnose patients with chronic pain diseases.

Finding a diagnosis to a chronic pain disease can be a long journey for women. Often studies on the subject of gender disparity in chronic pain treatment rely on comparison of women's experiences to those of men (Samulowitz, et al., 2018). The focus was on how to break the cycle of toxic masculinity that led to silently

suffering men with overly emotional women as an afterthought. While it's important to examine the negative effects on all those afflicted, this research focus perpetuates the stereotype that women are inaccurately describing their symptoms. If the standard is stoicism, and women are feeling pain more often and more intensely, then many female patients are going to slip through the cracks for daring to be openly expressive. This wouldn't necessarily be the case given a different diagnosis with a firmly established organic cause because a follow up test could be ordered to confirm or deny it. This study supports the argument that men and women are treated differently in a medical setting. However, in this scenario both parties lose because the denial of chronic pain symptoms in men and disbelief of women means the denial of chronic pain as a legitimate disease.

So this is the scenario: a woman already battling through the pain of everyday life has to put in effort to convince a physician that her pain is real because tests don't exist yet to prove it. As if it weren't complicated enough, qualitative studies find that there's a certain *way* one should report their symptoms for the best results. "Their efforts reflect a subtle balance not to appear too strong or too weak, too healthy or too sick, or too smart or too disarranged" (Malterud and Werner, 2003). Just as in most areas of life, women have to monitor their outward appearance to navigate a generally inhospitable territory. In medicine this is a cross-discipline tight rope walk as well. Most female patients have to be wary of how doctors perceive them in order to get an accurate diagnosis. However, women with chronic pain face the additional obstacle of being considered *particularly* hysterical. This has earned them the moniker of "heartsink patients", which means to disappoint doctors by the improbability of

finding a diagnosis or the general “difficulty” of the patient (O’Dowd, 1988). All of this creates an impossible situation in which healthcare professionals aren’t on your side and even science isn’t on your side. There are some potential solutions to improve the odds for these “heartsink patients”, however.

The disbelief and misdiagnosis of women with chronic pain is a systemic problem that requires a systemic solution. This paper offers three potential solutions: bias training for physicians, more female doctors, and a new accountability process. One experimental study recorded a group of physician’s pain assessments (and recommended treatments) for virtual patient profiles displaying various combinations of race, sex, pain (as assessed by posture), and observable anxiety (Clark and Robinson, 2019). Trials with this technology uncovered bias from participants based on treatment of these demographics (Clark and Robinson, 2019). An adapted version of the test could be used for physicians to learn about and combat their own implicit bias. These biases are often what lead to a lack of diagnoses or treatment in chronic pain patients.

Another experimental study analyzed the empathy level of a transcribed conversation between a doctor and patient, depending on the doctor’s gender (Nicolai and Demmel, 2007). Gender blind survey results showed that participants perceived female doctors to be more empathetic even without the stereotypical expectation that they would be (Nicolai and Demmel, 2007). The suggestion here isn’t only that the number of female doctors needs to increase, but also that all doctors should attempt to follow this example of more empathetic conversations. If this were the case, women with chronic pain wouldn’t have to focus so much on the performative element of the

patient-doctor interaction and could instead relate the details of their condition to their physician without fear of judgement.

Finally, when a chronic pain patient goes to one doctor and doesn't receive a diagnosis, she might move on to another opinion. If she eventually gets a diagnosis, there currently isn't a system in place to notify the first doctor (Dusenbery). So doctors aren't necessarily learning from their mistakes because they aren't being held accountable for them. This could be remedied by the implementation of a process that notifies doctors when patients they couldn't diagnose do get a diagnosis down the road (Dusenbery). With this process in place, the number of doctors unable to diagnose chronic pain will go down and chronic pain patients will begin to receive the treatment they need.

Conclusion

If you, reader, are a woman suffering from chronic pain who feels you should memorize this information to better advocate for yourself, STOP! While it's not a bad idea to learn more about your condition, it would be ridiculous to ask you to memorize the results of studies that indicate female sex hormones and anatomy biologically predispose women to lower pain tolerances and thresholds. It would be unfair to make you learn women face stereotypes of being too alarmist and hysterical to be taken seriously. And it would definitely be unjust to ask you to recite all of these things and add that the lack of research on chronic pain and female subjects in general lead to moments where you have to try to prove the existence of a disease causing you very real pain. While you, dear reader, wait for the addition of bias training for physicians, more female doctors (or more empathy training for all doctors), and a new accountability process to the medical field, consider two things: 1. Your disease is real and there are healthcare professionals willing to listen and help. 2. Something that can make this battle a little easier for you is, even though a medical system that requires you to be an expert in your own disease is an unrealistic one, you can help by bringing a printed copy of relevant information from a reliable source to a doctor's appointment (Dusenbery).

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