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Religion, Violence, and Peace
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Final Paper

In 2016 the Center for Disease Control (CDC) released non-mandatory guidelines to primary care physicians to act as recommendations for the prescribing of opioids to patients with chronic pain in an attempt to control the amount of opioids entering the market through legal prescriptions, and to combat the opioid crisis.[1] What resulted was massive misapplication of the guidelines with physicians from other disciplines misinterpreting the guidelines for their own practice, insurance companies making policies based off the guidelines, all while forcing thousands of patients to dramatically taper, stop, or be denied access to their prescription medications.[2] In an article for the Los Angles Times, writer Kate M. Nicholson sums it up succinctly: "Because of well-intended efforts to address the overdose crisis, many doctors are severely limiting opioid prescriptions. Patients who rely on opioid analgesics are being forcibly weaned off the medication or seeing their prescriptions significantly reduced. Other patients are unable to find doctors willing to treat them at all."[3] In the most dire cases, suicides were reported when pain control was denied patients based on the interpretation of the guidelines.[4] The guidelines were meant to act as a tool or resource,

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[1] Dowell, Deborah, et al. "CDC Guideline for Prescribing Opioids for Chronic Pain - United States, 2016 | MMWR." Centers for Disease Control and Prevention, Centers for Disease Control and Prevention, 18 Mar. 2016.

[2] Szalavitz, Maia. "The CDC Admitted It Messed Up on Painkillers and Left Thousands In Agony." Vice, VICE, 25 Apr. 2019.

[3] Nicholson, Kate M. â€œThe Clampdown on Opioid Prescriptions Is Hurting Pain Patients.â€Â *Los Angeles Times*, Los Angeles Times, 18 Jan. 2019.

[4] Szalavitz, Maia. "The Sad Cases of Pain Patients Getting Their Doses Cut and Taking Their Own Lives." Vice, VICE, 6 Nov. 2017

not a static measure to wield with fear. They were not to interfere with a doctor's judgement acting in a patient-by-patient basis with their individual knowledge of the patient's needs like function, metabolism, mental health, medical history, tolerances, and changing needs.

Opioids are no longer being treated like the magic pill of the late 1990s, and the CDC is right in encouraging judicious and thoughtful prescribing. What outwardly is stated as an effort to combat the creation of addicts and to curb the "opioid crisis" seems to contradict the CDC's own data that "show[s] that fatal overdoses are driven largely by illegally produced fentanyl, its analogs and heroin — not by medically prescribed opioids."[5] While overdoses are a serious and real problem, they are not occurring as a result of chronic pain patients seeking the care they need and doctors in the relevant discipline providing it. In their attempt to solve another problem, the CDC has unwittingly or unashamedly punished a population of vulnerable people.

After three years of reports of rising disability, plunging quality of life, reports of completed suicide, the FDA released an urgent warning urging physicians not to abruptly taper patients with a opioid pain regimen.[6] Included in their warning was the acknowledgement of psychological and suicide risks, as well as physical risks associated with drastic tapering. Following their suit, CDC released revisions to their

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[5] ibid.

[6] Center for Drug Evaluation and Research. "FDA Identifies Sudden Discontinuation of Opioid Pain Medicines.

guidelines to ameliorate how they were misused since their original publishing.[7] While some patients are optimistic that the revisions will lead to positive changes, some are saying that it is too little too late.[8] The CDC clearly needs to do more than release revisions to the guidelines to make amends with the disability community after what has occurred since the original guidelines were published in 2016. Before reconciliation efforts can be examined, one must first look at the experiences of patients getting pain management care in the first place, how the guidelines have affected their care, and then peacemaking efforts can be examined from the disability perspective. Since this is such a broad group of people with many experiences, I will examine the female perspective.

Undergirding almost all female patient's experience of chronic illness is the pervasive notion of hysteria, whether conscious or internalized by their provider. It becomes especially present when dealing with symptoms of chronic and/or idiopathic pain. Hysteria is a term derived from the Greek word for uterus, *hystera.*[9] In ancient Greek medical practice, any complaint of a malady from a woman was assumed to derive from her uterus roaming throughout her body, and treatments were focused on restoring it to its proper place in the pelvis.[10] Hysteria became a catch-all term for any

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[7] Dowell, Deborah, et al. "No Shortcuts to Safer Opioid Prescribing | NEJM." New England Journal of Medicine, New England Journal of Medicine, 24 Apr. 2019.

[8] Szalavitz, Maia. "The CDC Admitted It Messed Up on Painkillers and Left Thousands In Agony." Vice, VICE, 25 Apr. 2019.

[9] Dusenbery, 63.

[10] ibid.

illness or unpleasant symptoms a woman experienced or was perceived as having. With the arrival of the medieval period, a roaming uterus was no longer the trending theory as the culprit for hysteria- demons were. Women were treated with prayer, incantations, and exorcism, while some of their "hysterical" counterparts were tortured and executed as witches.[11] Demon possession gave way to "nervous disorders", which were diagnosed fairly equitably between men and women. Women called the "fairer" and "weaker" sex, were believed to have a poorer constitution that contributed to hysteria, whereas hysteria in men was believed to emanate from the spleen.

In the 19th century the new specialty of gynecology was introduced, and treatments localized to the female reproductive organs were used to combat any untoward symptoms, reinvigorating the uterine theory, this time including the other reproductive organs. Many women had their perfectly healthy uterus, ovaries, and fallopian tubes removed. The trend only came to an end "mainly because doctors became uncomfortable sterilizing women- or, as one physician put it, being 'the destroyer of everything that makes a woman's life worth living.'"[12] As the 19th century continued to unfold, women were less likely to be sterilized, but were increasingly accused of making themselves sick by not accepting their gender roles- doctors were saying ladies were getting sick because they were choosing to conduct themselves in an unfeminine manner.[13]

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[11] ibid, 64.

[12] Dusenbery, 65.

[13] ibid, 68.

This theory became further defined as doctors claimed hysteria was caused by being female. Symptoms could not simply be an underlying illness because women were "unreliable historians" who were not knowledgable about their own bodily experiences.[14] Thanks to Sigmund Freud and his contemporaries, "Women's illnesses are assumed to be psychosomatic until proven otherwise."[15] Put succinctly:

> Hysteria was something of a catch-all diagnosis in its day. Symptoms ranged from the frustratingly vague to the impressively grotesque, and the uterus was almost always blamed for a hysteric woman's suffering. It was all supposedly explained by something called 'reflex theory,' which meant, essentially, that physical symptoms resulted from mental overexertion, excessive emotions, and the like.[16]

Today, hysteria often masquerades by the moniker of "stress" until medically unexplained symptoms *can* be explained. Maya Dusenbery gives some examples: "Many…experience long delays and see multiple health care providers before getting correctly diagnosed: four years, on average, for patients with autoimmune diseases. Seven for patients with rare diseases. As many as ten for those with endometriosis."[17] While medically unexplained symptoms can make proper diagnosis difficult for any patient, it predominantly affects women with hysteria still pervasive in the hidden micro-aggressions of sexism in medical care. Whether overt or covert, "women are considered

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[14] ibid, 75.

[15] ibid.

[16] Norman, Abby. Ask Me About My Uterus: A Quest to Make Doctors Believe in Women's Pain (Kindle Locations 426-429). PublicAffairs. Kindle Edition.

[17] ibid, 79.

to be unreliable…Female sufferers of chronic conditions frequently find that the level of pain they must experience before they are taken seriously is significantly higher than that of men with the same condition."[18] It is important to note, however, that male practitioners are not solely at fault for this type of sexism- "Male physicians were not the only ones carrying this narrative. The patriarchal structure of medicine informed how female physicians practiced, too—as much, if not more than, it did their male colleagues. At the expense, yet again, of female patients."[19] It is the ghost of hysteria that often leaves women misdiagnosed, dismissed, and untreated.

If a female patient manages to make it past disbelief, she must make it through a muddy system of "indications". This is often where the guidelines were put into place and pain patients were lost amongst procedure. If a female patient had idiopathic pain or was in the process of being diagnosed, or had a condition that no longer met the indications (or what conditions qualified for treatments with opioid pain medications) a patient could be cut off from pain medication they once received, or be left in a position with inadequate pain control. This is what happened to me.

One morning I woke up in unbearable pain- I felt like both of my ovaries had burst. I got an appointment with an ob-gyn that day and she said a couple of important things- that she thought I had endometriosis, because this wasn't the first time something like this had happened, that the pain would stop once my period was over

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[18] Bula, 153.

[19] Norman, Kindle Location 481.

that weekend, and that eventually we'd set up surgery to look for it. Only the pain never stopped.

I was passed around from doctor to doctor trying to find a solution for the pain. Almost immediately I had to begin doing all my class work from home because the pain was so excruciating. I found myself in the ER after throwing up at home from intense pain and was given a weekend's worth of opioids until I could get back to see my ob-gyn. She agreed to refill them (a thirty pill supply) with the agreement that I was only supposed to use them when my pain spiked above an 8/10 on the pain scale. This happened regularly, so I hoarded the pills for the moments when I felt like my appendix was exploding, like I was on the verge of throwing up, like I would pass out, like I wouldn't be able to sleep otherwise- because I never knew if I would have access to more. I lived in constant fear that there would never be relief.

I was sent to physical therapy. Given medicine so I wouldn't throw up from the amount of pain I was in, and after pushing for it, got the exploratory surgery scheduled to remove the suspected endometriosis six months after I woke up in pain. Then when I woke up from surgery the nurses told me "they didn't find anything." It was not only a devastating blow in that I did not have answers for the pain that I was suffering, but my doctor changed my working diagnosis. She changed it from endometriosis to Myofacial Pelvic Pain Syndrome- one in which opioids "were not indicated". I was in the same amount of pain, only now without any pain control.

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After recovering from my first surgery, I was shipped off to a pelvic pain specialist in San Francisco. She was brusk and terce, and when I told her about my unbearable pain spikes, describing the first one that happened where I thought my appendix had burst and I almost called an ambulance, she told me the next time it happened to “take a tylenol and meditate”. For one in the profession of pain management, she was fairly skeptical about pain. Nonetheless, she scheduled me for surgery six weeks from that appointment where she would inject my pelvic floor hundreds of times with botox to paralyze the muscles in hopes that it would cause pain relief. The only thing the surgery provided me was stress incontinence and no pain relief or answers. Despite promising more options beyond surgery, she released me as a patient with a referral to pain management saying, “you just have chronic pain.” It had been eight months of constant pain with no answers. I was beginning to think tylenol was a conspiracy, just capsules full of empty promises. I had almost dropped out of school. I had gone into debt from going to psychotherapy, and I was back to the beginning again.

What felt like doctors passing me off at the time ended up being the relief and belief I sorely needed. The nice thing about pain management is you don’t have to prove your pain to anyone. You’ve become part of an elite club of sufferers. This was the first doctor I had encountered who looked me in the eye, not at the computer, and had a conversation with me about my quality of life. He didn’t suggest that there was something I hadn’t tried, that my anxiety was to blame, or that I was drug seeking. He explained the multiple facets of pain we were going to treat- nerve, muscle, and flare.

He treated me with dignity. He willingly prescribed me opioids for my pain spikes, but that didn't mean there weren't procedural hoops. We had a very clear "flare plan" that we discussed for its use, which felt smart and judicious, then I had to sign a contract. The contract stated that I agreed to take the medication like my doctor and I discussed together, and then I had to agree not to get pregnant. If they found that I was not adhering to this contract, I would no longer receive my pain medication.

It was not the first time that I had heard of contracts like this. I ran a support group for the disabled and chronically ill, and had heard of even more stringent contracts. One story sticks out in my mind. A member had accidentally become pregnant, and as a result had mistakenly violated her pain contract. As a result she was stripped of all her medication, was kicked out of the chronic pain program entirely, and was faced with a decision where she had to choose between her pregnancy and her quality of life. She was given no leniency, no understanding, no guidance. These are just some examples of chronic pain physicians- doctors that are *exempt* from the guidelines and are not even addressed in them, being influenced by them in their procedure, and affecting patients lives in the most intimate of ways.

I had one more fight to wage. I met with my primary care doctor and asked to be referred to a rheumatologist who deals with autoimmune disorders and some pain disorders. She wasn't convinced that this was called for even after all I'd been through, (the hysteria was still whispering in her ear), but said that if my inflammation levels in the bloodwork she was going to run came back abnormal she would agree to the referral. My intuition was correct however, as they came back astronomically high, and I found myself in the waiting room of my new rheumatologist with folks three times my age.

When all her bloodwork came back yielding no definitive answers, my intuition pushed again. “Scan my pelvis.” I knew they had just opened me up on the operating table, but there was something in me that inherently knew *they missed something.* So they scanned. And they found it. Swelling at the base of the spine where it meets the pelvis, that the radiologist report said “cannot be ruled out as an inflammatory arthritis”. My rheumatologist or “rheumy” as she is called for short, conjectured that this swelling caused referred pain to the pelvis. As the arthritis progressed into other joints we began a biologic trial that confirmed the diagnosis: Undifferentiated Spondyloarthritis.

UsPA would be joined by friends fibromyalgia and Postural Orthostatic Tachycardia (POTS) which both were reached with similar persistence and intuition on my part, and which I give myself primary credit for their diagnosis. Despite having formal answers or a label for the pain I live with everyday, I still have the rarest arthritis type and will never be pain free. I now am out of the diagnostic process and am in a position where I have syndromes, diseases, and conditions that “indicate” the use of opioids when spiking pain levels call for it (and they increasingly do). Having a diagnosis does not mean that there is any consistency amongst providers, medical centers, insurers, cities, states, or policies among any of them, however.

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The CDC guidelines are influencing current legislation for folks and places that felt the guidelines weren't stringent enough. Presidential hopeful Kristen Gillibrand is co-sponsoring a bill that would limit all prescription opioids to a seven day supply for acute pain. Gillibrand received immense criticism from disability rights activists for her utter lack of disability inclusion on the bill, and attempting to legislate an experience that ultimately should be happening between doctor and patient.[20] While a seven day supply may keep the market from becoming saturated with illegal drugs, it does little to consider the lives of actual patients. What diagnostic criteria will be used? What about the chronically ill who are in the diagnostic process for years with idiopathic pain? What about conditions that have chronic pain as a symptom but aren't chronic pain conditions themselves? How is a patient who just had surgery seven days ago supposed to drive to the pharmacy for a refill? What about the financial burden of all these additional co-pay costs? And these were just some of the questions my fellow activists and I raised to Ms. Gillibrand.

After receiving criticism on her proposed legislation, Ms. Gillibrand said she was "open to improving the bill"[21], yet it remains to be seen if she will hire disabled staffers to aid in crafting new and effective legislation. Disabled people account for 25% of the

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[20] Nicholson, Kate M., and Laura Mills. The Problems with One-Size-Fits-All Laws on Opioid Prescriptions.*The Washington Post*, WP Company, 4 Apr. 2019.

[21] ibid.

United States population[22], therefore a policy affecting them should be written by them. If four people are working on fixing Ms. Gillibrand's bill, at least one of them needs to be disabled.

In order for positive relationships to move forward between the disability community, the CDC, and the community at large to move forward, reconciliation needs to happen in light of the 2016 guidelines beyond the revisions that were released in 2019. The CDC must take the lead as the medical and scientific entity so that legislative and judicial bodies can follow their lead. As in the example of Gillibrand's bill, it must be *nothing about us without us,* and must be informed by the disability community first, as the primary community affected and traumatized.

Firstly, the CDC must take responsibility and apologize for the lives lost to suicide. Chronic pain carries high suicide risk and that must be assessed and highly considered in the prescribing process. The CDC needs to provide and/or create resources for physicians to prevent future suicide attempts, help doctors assess risks, and properly refer patients for the mental healthcare they need. The CDC should reach out to families who have lost loved ones to suicide because of the 2016 recommendations and apologize individually.

Secondly, there needs to be chronic pain and disability advisors on staff for recommendation revisions, and in proportion to U.S. disability ratios on staff overall at the CDC to ensure proper representation overall. Able-bodied people cannot be

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[22] *Centers for Disease Control and Prevention*, Centers for Disease Control and Prevention, www.cdc.gov/media/releases/2015/p0730-us-disability.html.

making policies and laws and recommendations about the lives and bodies of disabled people without them being able to work side-by-side with them.

Lastly, the guidelines need to be further clarified so that nothing can be misconstrued and another patient does not suffer in agony or dies. The clearer they are the less inconsistency there can be amongst patient experiences, and amongst policies. This must be done centering the patient experience, and this must be done centering the disabled experience.

Nothing about us without us.

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