

Chronic Pain, The Invisible Epidemic

How patients with chronic pain are mistreated and misdiagnosed

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Introduction

Chronic pain has become a major invisible epidemic in the United States; “More people live with chronic pain than heart disease, diabetes, and cancer combined” (Wahrman, Akers), reported by Healthline. According to The New York Times, it is estimated that 116 million Americans live with chronic to severe pain; that’s 30% of all Americans. Chronic pain severity can range from several underlying causes, as “It occurs after around a seventh of surgeries, a seventh of accidents, and even without injury, as is often the case in fibromyalgia.” (Tatum, 2856). Chronic pain has the capability of affecting a person's life from 3 months to indefinitely, often leading to opioid addiction and even suicide. In many cases the cause may remain unknown, and chronic pain becomes its own condition. Depending on the severity and underlying cause of chronic pain, the time between diagnoses and proper treatment is crucial, as a condition can permanently become worse. Patients who suffer from invisible illnesses are often accused of hysteria, seeking opioids, and exaggerating their symptoms, as the description of pain is simply not enough for most physicians. According to Healthline, most medical schools in the United states only require nine hours of training in chronic pain. The medical field is not giving chronic pain the attention and research it deserves, compared to more visible illnesses. A large quantity of people who struggle with chronic pain are unable to receive the proper treatment and diagnosis due to several reasons; the lack of training and education a physician receives in chronic pain, women being excluded from clinical trials, sexism, and opioid addiction.

As a chronic pain survivor myself, I felt that this topic was quite relative to me, as I have experienced and lived through the mistreatment and misdiagnoses from several medical professionals. For the purpose of educating the public and spreading awareness, I decided to take a qualitative approach by interviewing two women who suffer from chronic invisible illnesses.

Women especially tend to be mistreated and misdiagnosed by their physicians due to the lack of research on women's anatomy, the exclusion of women in clinical trials, and stigmas like hysteria. Due to the constant patterns of sexism and the lack of education in the female body, I chose to specifically interview two women who suffer with chronic pain. Both Chrissi and Arianne share their personal experiences on how they were treated by medical professionals and how long it took for them to receive proper diagnoses. In this paper, I share a few of Chrissi and Arianne's experiences in relation to my main arguments, in hopes to spread awareness on what is continuously happening behind the scenes to victims of chronic pain.

Discussion

There are several factors that contribute to the mistreatment and misdiagnosis in patients with chronic pain. One of the most crucial factors is that medical schools do not apply the focus on chronic pain as they would any other visible medical condition. The hours of education a medical student receives in chronic pain is not nearly enough for a doctor to diagnose a condition correctly or treat it properly. The large burden of chronic pain compared to the medical attention that chronic pain receives is disastrous and unacceptable. The neglect of chronic pain education in the United States is so severe, that even veterinarians are more educated in chronic pain in animals than physicians are in humans (Medpagetoday). Unfortunately, the United States displays less effort in chronic pain than Europe or Canada does, as "A 2011 study in *The Journal of Pain* found that U.S. medical schools allot a median of 9 teaching hours on pain and its management, compared to a median of 19.5 hours in Canada. In the U.S., that's approximately 0.3% of the total curriculum hours" (Medpagetoday). In fact, it has even been reported that some medical schools in the United States neglect chronic pain completely; "In their 2011, study, Mezei and Murinson found that a number of American medical schools did not report any

teaching of pain whatsoever, with many requiring 5 or fewer hours of such education. Elective courses were available in 16% of schools; 80% of American medical schools had no formal pain education” (John D. Loeser & Michael E. Schatman, page 333). Although the United States has proven to place chronic pain as a last priority, it is even reported that even in other developed countries “... the amount of time currently allocated to pain management is generally inadequate; in the UK, for example, the median time spent on pain management by a medical student is 13 hours, and sometimes as little as 6 hours” (The Development of Chronic Pain). Chronic pain is being neglected worldwide. In further studies, it was also stated that medical students, themselves, are uncomfortable with the idea of treating patients with chronic pain, as they feel they should be receiving more hours of training (John D. Loeser & Michael E. Schatman). Medical students must also learn to detect the difference between chronic pain; pain lasting 3 months or more, and acute pain; pain lasting 3 months or less, as acute pain has the potential of becoming chronic if it goes untreated. The description of pain alone gives physicians the opportunities to brush their patients off or give them false diagnoses, especially if they do not know the right answers. Physicians will even sometimes blame their patients and tell them that it’s “all in their head”. Invisible illnesses are more difficult to diagnose, as physicians have a harder time with determining the correct tests to run on a patient with an invisible illness; “Chronic pain cannot be measured independently like blood pressure or temperature either, relying instead on subjective reports from sufferers” (Tatum, 2857), as “Many are dismissed as moaners, malingerers, or told it is all in their heads” (Tatum, 2857), especially women.

Women are continuously neglected and brushed aside the most by their physicians when it comes to seeking treatment and a medical diagnosis. A major leading cause as to why women are so neglected medically, is due to the fact that there’s still not enough women in clinical trials.

Due to women being excluded in medical trials, physicians are often completely unaware of how a woman's body will react to certain illnesses, medications, and procedures, compared to a man. Since women are so underrepresented in clinical trials, this can lead to women experiencing more side effects from medications due to incorrect doses as well as biological differences (Healthline). Women are also profoundly misdiagnosed in comparison to men, thus leaving medical conditions to go untreated for years, or even decades, as “Some women spend years shuttling between doctors searching for answers only to find that the disorders other doctors missed or misdiagnosed were potentially life-threatening” (BC&G Law Firm). For centuries, physicians have been trained to treat women's health similarly to men's, which is wrong considering the major differences between a female and males anatomy. Sadly, “It takes approximately five years for autoimmune diseases to be correctly identified and diagnosed in women” and “Female-specific conditions (endometriosis, adenomyosis, fibroids, etc.) often take 10 years or more for accurate identification and diagnosis” (BC&G Law Firm). Chrissi, one of the women I chose to interview, is a prime example of someone who was misdiagnosed for decades of her life. At just 16 years old, Chrissi was falsely diagnosed with Crohn's disease, which defined her life for 18 years. In actuality, Chrissi's gastrointestinal health complications were being caused by other more severe chronic illnesses; Ehlers Danlos Syndrome (EDS) and Postural Orthostatic Tachycardia Syndrome (POTS). Chrissi spent most of her life in pain, quietly struggling with the symptoms that come with EDS and POTS. It wasn't until Chrissi was 34 years old that she finally was able to be diagnosed correctly, a diagnosis she had found herself, but was later confirmed by a doctor. Chrissi's physicians also blamed a majority of her symptoms on anxiety and stress, which ultimately unmotivated her from seeking additional treatment for her pain for years; *“I was convinced I had about fifteen different conditions that*

nobody could diagnose because I'm just some sort of weird medical mystery," said Chrissi.

Gender norms and gender biases have also had a negative impact on women's health, as women have been labeled "emotional" and accused of hysteria; a term created to describe women as being too emotional and dramatic. In some cases, women are even mistrusted if they look good, and will receive comments like "you don't look sick". Our healthcare system prioritizes men's health, thus causing women's health to become invisible; "The concept of andronormativity implies that men and masculinity dominate health care to such an extent that women and femininity become invisible" (Samulowitz, 9).

Physicians often confuse the difference between chronically ill patients and patients with addiction, as a result of their lack of education in chronic pain. The fear of addiction often leaves patients with chronic pain neglected and in the absence of medications they desperately need. Due to the current ongoing opioid crisis, physicians have a tendency of creating assumptions towards patients with chronic pain, ultimately accusing them of coming in for opioids and not pain; "Everyday pain patients are the ones being put on trial and criminalized because of the opioid crisis. I sign a paper every year now because I am prescribed a painkiller. I have to sign a contract just to pick up my prescriptions that says I agree to submit to random drug tests," (Healthline). Although the opioid crisis is a major and dire issue that must be addressed, chronic pain patients tend to be highly burdened and are continuously left in the dark. On account of some physicians' attitudes towards addiction and opioids, patients who complain of chronic pain are frequently questioned, looked at with skepticism, and judged (Healthline). Arianne, one of the women I interviewed, shares an interesting experience she had at an urgent care, where she was accused and questioned repeatedly. A week prior to Arianne's urgent care visit, one of the nurses had a difficult time drawing her blood, resulting in bruises on her arm. Later that week,

when Arianne was getting a heart monitor removed at urgent care, her doctor noticed the bruises on her arm, and repeatedly questioned her as to whether or not she has done drugs. At the time of her visit, she was confused as to why she was being questioned, as she didn't notice the bruises on her arm until after. The doctor proceeded to ask "are you sure" several times after Arianne confirmed that she has never done heroin. Instead of the urgent care physician helping her, he focused more on accusing Arianne of doing drugs and judging her. From a physician's perspective, "There's very little to no training in chronic pain treatment, but doctors are taught to look for signs of addiction. People who ask for pain medication are assumed guilty until they're proven innocent," (Healthline). Physicians need more education in chronic pain to be able to determine the differences between addiction and dependence, as some patients with chronic pain depend on opioids in order to live a life without pain. Educating physicians on the difference between dependence and addiction is crucial, as "Only 8 to 12 percent of chronic pain patients are at risk of addiction, but about 1 in 4 chronic pain patients experience dependence, in particular psychological dependence" (Healthline). Due to the constant medical neglect and rejection of pain medications, patients with chronic pain are left to suffer, often leading to suicide in some cases.

Conclusion

Chronic pain has become a huge burden to millions of people worldwide. A large quantity of people who struggle with chronic pain are unable to receive the proper treatment and diagnosis due to several reasons; the lack of training and education a physician receives in chronic pain, women being excluded from clinical trials, sexism, and opioid addiction. It is alarming that patients spend years, or even decades of their life, seeking relief or a diagnosis. Patients who are left misdiagnosed and not treated properly often turn to suicide, as the pain has

become too severe for them to continue living. Education in medical schools in regards to chronic pain must be changed, as 9 hours is clearly not enough. Women tend to be misdiagnosed the most due to the exclusion from clinical trials. We must advocate for more women to be included in clinical trials for education, and we must encourage young girls to look toward medicine as a chosen career path. The more women who enter the field, the more we can really begin to help eliminate stigmas like hysteria. In order for doctors to fully understand patients with chronic pain “It will be up to medical schools to begin better education of doctors in the treatment of pain, and the National Institutes of Health to decide whether to promote research into chronic pain” (Parker-Pope, 2011). Education in the differentiation between patients with chronic pain and addiction must also be considered more in medical schools, rather than focusing solely on signs of addiction. Until our healthcare system recognizes and focuses on the need for more education in chronic pain, people with chronic pain will unfortunately continue to suffer.

Works Cited

Anderson, Tatum. "Doctors Lobby for Better Chronic Pain Management." *The Lancet (British edition)* 388.10062 (2016): 2856–2858. Web.

Caudle, Robert. "What Is Chronic Pain and Why Is It Hard to Treat?" *The Conversation*, 13 Sept. 2018,
theconversation.com/what-is-chronic-pain-and-why-is-it-hard-to-treat-57943#:~:text=Unfortunately%2C%20patients%20rapidly%20develop%20tolerance,agents%20for%20treating%20chronic%20pain.

Firth, Shannon. "Medical Schools Boost Pain Management Education." *Medical News*, MedpageToday, 4 Feb. 2016,
www.medpagetoday.com/publichealthpolicy/medicaleducation/56025.

"Is Misdiagnosis an Epidemic Among Women?" *National Medical Malpractice Law Firm*, 31 July 2019,
www.medmalfirm.com/news-and-updates/misdiagnosis-epidemic-among-women/#:~:text=Misdiagnosis%20Occurs%20Far%20More%20in%20Women,-Research%20done%20in&text=In%20specific%20areas%20of%20healthcare,overlooked%20entirely%2C%20following%20a%20stroke.

Loeser, John D, and Michael E Schatman. "Chronic Pain Management in Medical Education: a Disastrous Omission." *Taylor & Francis*, 6 Mar. 2017,
www.tandfonline.com/doi/full/10.1080/00325481.2017.1297668.

O'Donnell, Jayne, and Josephine Chu. "Chronic Pain Patients, Overlooked in Opioid Crisis, Getting New Attention from Top at FDA." *USA Today*, Gannett Satellite Information Network, 3 July 2018, www.usatoday.com/story/news/politics/2018/07/02/chronic-pain-patients-needs-ignored-opioid-epidemic/727015002/.

Parker-pope, Tara. "Giving Chronic Pain a Medical Platform of Its Own." *The New York Times*, The New York Times, 18 July 2011, well.blogs.nytimes.com/2011/07/18/giving-chronic-pain-a-medical-platform-of-its-own/.

Pergolizzi, Joseph et al. "The Development of Chronic Pain: Physiological CHANGE Necessitates a Multidisciplinary Approach to Treatment." *Current medical research and opinion* 29.9 (2013): 1127–1135. Web.

Pratt, Elizabeth. "We Don't Have Enough Women in Clinical Trials- Why That's a Problem." *Healthline*, 25 Oct. 2021, www.healthline.com/health-news/we-dont-have-enough-women-in-clinical-trials-why-thats-a-problem#:~:text=We%20Don%27t%20Have%20Enough,Trials%20%E2%80%94%20Why%20That%27s%20a%20Problem&text=Experts%20say%20women%20are%20underrepresented,incorrect%20dosages%20or%20biological%20differences.

Samulowitz, Anke et al. "'Brave Men' and 'Emotional Women': A Theory-Guided Literature Review on Gender Bias in Health Care and Gendered Norms Towards Patients with Chronic Pain." *Pain research & management* 2018 (2018): 1–14. Web.

Wahrman, Anna, and Whitney Akers. "America Is Losing the War on Chronic Pain."

Healthline, 24 Sept. 2018,

www.healthline.com/health-news/america-is-losing-the-war-on-chronic-pain.

"What Is Chronic Pain Management? Symptoms and Reasons to Control Chronic Pain."

WebMD, WebMD,

www.webmd.com/pain-management/guide/understanding-pain-management-chronic-pain#1.