Chronic Pain and Social Reform

Luke Slipski

2023-09-25

Table of contents

Preface

I got to know the Public Health 101 professor while working on a smoking prevention project with her in India. I had been pre-pre-med since the 6th grade, and in my sophomore year of undergrad I chose the University of Rochester's "Health, Behavior, and Society" major primarily because I thought it would look good on a medical school application. And I wasn't the only one with this idea. The major was teeming with neurotic and preening pre-meds all angling for a spot in the best medical schools so that they could better angle for a spot in the best residencies.

"Notorious" is too strong a word, but it was known among the public health majors that Dr. Chin encouraged pre-medical students to think broadly about their career options beyond any hospital. As opportunist as we were, most of us also came with a commensurate dose of idealism. We wanted to *change the world*. With some of this in mind, we were sipping our chais and looking out at the foothills of the Himalayas when she finally dropped the question on me.

> **0.0.0.0.1 *** I don't get it. Why do all these smart, motivated young people who want to change the world go into *medicine*?

> **0.0.0.0.2 *** - Nancy Chin

I responded with some amalgamation of all the platitudes frequently used to inculcate young people into a paradigm of health and health-morality that spotlights doctors as heroes.

What she was really asking was, "What makes people healthy? Do you *really* think it's *medicine*?"

And then we moved on. Because Dr. Chin isn't in the business of telling students what to do. Apparently, her MO is patiently asking students perspicacious questions at indelible moments that will haunt them throughout an adulthood full of mistakes and corrections. The following essays are an attempt to synthesize my learnings from years down a rabbit hole of trying to address the chronic pain pandemic through a treatment-centered approach. They serve as a course correction to the intoxicating conceit that an ever deeper, more scientific, more data-driven understanding of chronic pain could singlehandedly solve the suffering seen around the world today. But it was this high-technologic worldview that *was* in the business of telling students what to do.

I was accepted into Rochester's Take 5 Program and given a tuition-free fifth year to take classes in a field I hadn't had time to study while completing my public health degree. I titled my application essay `Befriending Big Data and Nurturing the Human-Computer Relationship`, and I proposed taking a set of Math, Computer Science, and Brain & Cognitive Science courses. It was during my introduction to java programming course that I was formally introduced to the gospel of technology.

0.0.0.0.3 * If you want to change the world, learn how to code.

0.0.0.0.4 * - Ted Pawlicki

Pointing out the obvious impact apps like Facebook and Twitter had made on the world, Professor Pawlicki was arguing that computer programmers were the people making decisions that actually affect people day-to-day. Through the power of the internet, everyone can be affected by the code written on *your*

laptop. Hot off a degree in public health, I interpreted this in some vague way to mean I could create tech that made people healthy. In fact, one of my Take 5 advisors was Henry Kautz, whose research had recently made headlines like Your Tweets Can Predict When You'll Get the Flu. The obligatory comparison to John Snow was plenty to make me envisage my code as part of the impending Big Data revolution in epidemiology and health. This program equipped me with the holy trinity of the high-tech-health worldview:

1. A nebulous notion of how `more_technology == better`
2. The suggestion that anyone (including me!) could be the hero who writes the code that saves the lives
3. Some tangible coding skills to immediately start becoming the hero

With some java and python skills under my belt I went on to complete my MPH at the University of California Davis, spending most of my study time learning to connect public health databases with analytic programming languages. This paid off when I was accepted to the first cohort of Kaiser Permanente's "Programmer/Analyst Training Program." At Kaiser I learned SAS programming, some statistics, and how to carry out a digital cohort study – something I still do for a living today. My next job was at an electronic medical records (EMR) company called Practice Fusion. This was my proper introduction to a true societal scourge: the health tech sector.

Practice Fusion brought me a huge salary, catered lunches, beer and wine on tap, and huge parties. And we were working on a product that helped patients! Right? RIGHT?! I learned a lot of programming there. And our mission was ostensibly to make a free EMR to help bring small doctors' offices into the 21st century. To combine these records and do important epidemiology, which would, in turn, even further benefit patients!

It is exactly this sort of hard-to-argue-with symbolism of technology as progress that I hope to untangle in this writing. Because who doesn't want to appropriate the algorithms to help cure disease? Who doesn't want people to have "precision medicine," where doctors utilize capital-B capital D Big Data to help doctors make personalized medical decisions? It is hard

for anyone who doesn't spend all day rummaging around in this data to articulate why high-technology in healthcare might not be the best investment. Even those of us most entrenched in the industry's details fall for the same abstract promises CEOs continue to sell to investors. This technology is going to *Change. The. World.*

But after a few years at Practice Fusion (and just before we found out they had been pushing opioids on patients for chump change) I got tired of working with the EMR data. I knew it was never going to tell us anything meaningful. I decided that I needed to venture futher into the technical weeds if I was going to find quality enough data to…err…change the world(?). Or whatever Ted Pawlicki had sold me. It sounded so cool when he had said it.

So I quit my life and moved to Boulder, Colorado with the prospect of working as a research assistant in a famous neuroscience lab. By famous of course I mean famous in within the small fMRI science community. Having watched an entire Youtube series on fancy statistical analytic methods using functional magnetic resonance imaging data, I was convinced that this was the field I needed to dig into if I were to solve chronic pain.

The most important thing I learned (read: remembered) in my neuroscience PhD work was the centrality of organized labor in shaping health and wellbeing.

> Every budget is a *moral* document.

- Ted Brown

1 High Technology and the Chronic Pain Pandemic

A family of billionaires agreed to pay $6 billion last year in response to thousands of lawsuits inculpating their company, Purdue Pharma, for its role in creating a nation-wide opioid crisis. This money will do little to stem the current of these life-ruining prescriptions, while also failing to address the dilemma opioids were originally purported to solve: people across the globe are struggling with very real and persistent pain. In a world still ravaged by deadly infections like malaria and chronic killers like cancer, pain may appear an unfortunate, though relatively inconsequential, externality of our economic system. But our pain can amount to something much greater than that. Chronic pain is uniquely poised to be a lodestar for public health in this moment and a rallying point for the working class the world over.

Chronic pain today has three important features. First, it is ubiquitous. Across the globe pain is the most common reason people seek medical care and its subtypes comprise three of the four leading causes of years lived with disability – a common measure of quality of life. Second, people's pain is being endured in the context of the popular, ongoing and catastrophic failure of prescription opioids. This ensures that pain researchers today are more likely to line up behind alternatives to pill-popping. Finally, perhaps more than any other ailment, chronic pain can now be seen as a poignant reflection of the structure of capitalist society. Unstable housing, long hours, poverty wages, food insecurity, and a general lack of social security coalesce in the human brain to produce much of the hurt we feel day-to-day.

Together, these three features can give new direction. Big Pharma's and Big Medicine's overtly technocratic attempt to

address the pain pandemic trumpets a fresh reprise of a tale as old as time in public health: high-tech gadgets, without broad social mobilization, rarely create lasting positive change. And yet, funding for pain research is being pumped into brand new tech "solutions" while ignoring the dire need for social reorganization. The result has been a vast dearth of treatment options, sparsely littered with feeble non-pharmacological strategies. Costly brain scans here, inaccessible therapy there, with mindfulness apps scattered throughout. But it is in this vacuum the working class has an opportunity to act on old wisdom: good health is won through class struggle, and disease prevention is best fortified with social reform.

1.1 Pain, Class, and a BioPsychoSocietal Model

Best estimates show the incidence of chronic pain in the US now surpasses that of diabetes, depression, and high blood pressure. Globally, it is estimated that 3 in every 10 people are affected by chronic pain. If you aren't living with pain yourself, it is likely you're interacting with someone who routinely suffers from pain. However, rates of chronic pain are not uniform throughout society. Persistent pain is more likely to be found in adults currently unemployed, adults living in poverty, and older adults. In other words, as with diseases like malaria and cancer, the most economically vulnerable members of society suffer the most.

This link between chronic pain and the social order has implications for how pain should be studied, treated, and prevented. Today's psychologists and neuroscientists argue the need for a "biopsychosocial" approach. Published in 1977, George Engel's biopsychosocial model of disease emphasizes that a strict biological approach "leaves no room within its framework for the social, psychological, and behavioral dimensions of illness." While nominally embracing a biopsychosocial framework, today's clinicians and researchers have adopted an incomplete interpretation of the word "social". In modern pain studies, "social" implies various aspects of interpersonal social interactions such as handholding, clinician-patient relationships, and

information based on others' experiences. While these things may play a small role in influencing a person's pain, they fail to clarify the role of enormous pain-producing forces that come into view when "social" is interpreted as "societal".

George Engel actually specified a more expansive meaning of "biopsychosocial" 46 years ago:

> "This approach, by treating sets of related events collectively as systems manifesting functions and properties on the specific level of the whole, has made possible recognition of isomorphies across different levels of organization, as molecules, cells, organs, the organism, the person, the family, the society, or the biosphere."

This interpretation of "biopsychosocial" would subsume social policies and structures in its attempt to understand the origins of chronic pain pathology. So what is the impact on pain of a lack of social housing, quality food, basic income, and medical insurance? What effect would wealth and land redistribution programs have on the huge prevalence of chronic pain around the world? The truth is that we don't know. And we're not looking.

1.2 Policy Framing and Victim Blaming

Faced with nearly 300,000 deaths from prescription opioids in the last 20 years, the US has spent a significant amount of money trying to better understand pain. But research initiatives to find opioid replacements remain focused on the technocratic treatment of individuals while failing to embrace a population-focused biopsychosocial perspective. Without so much as considering possible societal origins of pain, the US continues to prioritize the discovery of complex biotech solutions to treat pain after it arises, one person at a time.

Amid a record-setting incidence of prescription opioid deaths in 2010, the Affordable Care Act provisioned the creation of a new committee to harmonize pain research efforts across federal agencies. To this end, the committee published an analysis

detailing a $430,000,000 annual budget for pain research. This money was distributed to over 1,200 research projects. Investigations of "neurobiological/glial mechanisms" and pain treatment received the lion's share with 35% of the budget. In comparison, pain prevention received a pitiful 1.4%.

Table 1.1: Percentage of the Pain Research Portfolio by Category

Allocation of Pain Research Money

Grouped by 29 IPRCC Pain Research Categories[1]

Research Category	**Percent of Budget**
Neurobiological/Glial Mechanisms	20.4
Pharm Mechanisms & Treatment	8.3
Non-Pharm Mechanisms & Treatment	7.3
Training in Pain Research	6.9
Biobehavioral & Psychosocial Mechanisms	5.9
Development of Animal and Human Pain Models	5.2
Outcomes & Health IT for Decision-Making	4.6
Genetics and Genomics	4.2
Unique Populations	4.2
Mechanisms of Transition Phases	4.1
Pain & Non-Pain Comorbidities	2.8
Analgesic Development	2.7
Device & Therapy Delivery Systems Development	2.3
Comparative Effectiveness Research	2.0
Diagnosis & Case definitions	1.9
Epidemiology	1.8
Pain Education	1.8
Substance Use and Abuse/Addiction	1.7
Medical Management	1.4
Pain Prevention	1.4
Other "Omics" of Pain	1.3
Women's & Minority's Health Research	1.3
Informatics, Databases & IT Development	1.2
Chronic Overlapping Conditions	1.2
Sex & Gender Differences	1.1
Analgesic Drug Safety	0.9
Pain and Trauma	0.9
Health Disparities & Access to Care	0.9
Health Care Utilization	0.3

[1]**I**nteragency **P**ain **R**esearch **C**oordinating **C**ommittee
Source: IPRCC Federal Pain Research Portfolio Analysis Report

Even more tragic, the focal point of the nominally preventive research was "pain prevention through various approaches including self-directed activity, diet, life style programs and education campaigns for many disorders." This up-by-your-bootstraps conceptualization of prevention despicably foists the burden on people who are relegated to the most pain-inducing environments. Those driving uber all morning and bussing tables all evening for low wages and no medical insurance are also expected to find time to meditate in order to relieve their chronic low back pain. A truly preventive approach would focus on creating analgesic societies for the working class to inhabit. And while we can't expect too much from "prevention's" 1.4% of the pain budget, we could hope that significant strides have been made in translating our well-funded understanding of the neurobiological and glial underpinnings of pain into successful treatment strategies.

Table 1.2: Funding of technologically-driven research to the neglect of prevention
Pain Mechanisms and Treatment vs. Prevention
Funding Comparison

	Percent of Budget
Neurobiological Mechanisms and Treatment	
Neurobiological/Glial Mechanisms	20.4
Pharm Mechanisms & Treatment	8.3
Non-Pharm Mechanisms & Treatment	7.3
Group Total	36.0
Prevention	
Pain Prevention	1.4
Group Total	1.4

No such luck. Most pain neuroscience involving human participants uses functional magnetic resonance imaging (fMRI) to measure activity in the brain while study participants lie in a small magnetic tube and perform simple tasks. This type of

research is still barely able to identify when a person is currently experiencing chronic pain, let alone reduce their pain in a meaningful way. It also primarily recruits young healthy college students and fails to include participants from diverse income levels, all but ensuring study findings will not generalize to the working class. In fact, some clinical guidelines recommend against using imaging in the clinical treatment of patients with chronic pain. The last 14 years of pain neuroscience have produced a lot of neat and high-tech studies but taught us very little about how to prevent or treat pain in the global proletariat. Unfortunately, this sort of fetishization of high technology is not new in the world of public health.

1.3 Technology on the Horizon

Public health practitioners in the first half of the nineteenth century had weaponized broad social reform strategies to combat disease and promote health. Such work aimed to clean the environment, improve housing and working conditions, and provide water and sewage systems throughout society. But in the latter half of the 1800s, public health shifted its gaze with the advent of bacteriological research methods. The late doyenne of public health history and health leftism, Elizabeth Fee, pointed out that

> "Public health practice required a diverse set of disciplines and skills: economics, sociology, psychology, politics, law, statistics and engineering, as well as the biological and clinical sciences. In the period immediately following the brilliant experimental work of Pasteur, Koch, and the German bacteriologists, however, the bacteriological laboratory became the primary symbol of a new, scientific public health."

Reverberations of this new technologic symbolism, and promise of "scientific public health", shaped the treatment of acute and then chronic conditions for the next century and a half. In recent years, first opioids and then the fMRI scanner became the primary symbols of a new approach to pain management.

At first blush, chronic pain might seem like an entirely new category of pathology. It is a subjective experience arising from complex information processing in the central nervous system. Scientists can't point to something like a parasite or a tumor cell as its origin. Therefore one approach to managing pain is to spend exorbitant resources trying to pin down an objective measure, or "biomarker", of its neurological provenance. Having dragged subjectivity into the objective realm, scientific public health could then deploy its usual methods. In this case that would include developing technology that specifically targets the pain biomarker and beating pain with experience. The only snag is that the history of public health demonstrates that addressing even more "simple" diseases solely through the development of high-technology rarely leads to lasting prevention or cure.

Most people today understand Malaria to be an acute, infectious disease caused by mosquitoes. These mosquitoes, living near the equator and carrying one of the malaria parasites, bite and infect people. UNICEF reports that malaria infections kill a child under 5 years of age every minute. To save these kids and many adults, we need to directly kill either the mosquitoes or the parasites, right?

This is the logic that came to prevail around the turn of the twentieth century following the discovery of the malaria parasite. Malariologists began to describe the disease's epidemiology in increasingly narrow biological terms because for the first time they could see with their own eyes the immediate cause of malaria in a person's blood. New medical discoveries like these were made using the achromatic microscope, the latest and greatest microbiological technology of the time. These discoveries undoubtedly played important roles in curing patients and saving lives. But over time they served to close the aperture of the public health lens. What could not be seen under the new microscopes were the more proximal social structures ("the causes of the causes") sustaining malaria transmission in the tropics.

Prior to the fanfare surrounding parasites and mosquitoes, a large body of evidence had accumulated showing that malaria epidemiology is heavily influenced by agricultural practices. For

example, a lack of decent housing often forces farm workers to sleep outside, exposing them to infected mosquito bites. Facing low wages, these same workers migrate elsewhere at the end of a harvest season in search of alternative income sources. When their new work lands them in an area with little or no malaria, a new epidemic can be triggered. Such epidemics are not confined to tropical regions and have flared up in places as far north as [city] Russia, [city] Italy, and the Chicago river basin.

The symbol of technology as a perpetually impending solution to disease is recapitulated in public health budgets throughout the world today. The magic bullet seems perpetually on tomorrow's horizon while people suffer today. Further, what we know about pain in the brain already supports broad societal improvement initiatives over additional technology see the following chapter. Basically, on its face pain seems different from cancer or malaria, but all diseases and well being probably get better through societal improvement.

2 Neuroscience and Chronic Pain

Ironically, at the acme of modern cognitive neuroscientific theory lies a refutation of the neurobiological approach to the pain pandemic. One of the most recent and promising frameworks for understanding what the brain does is called "predictive coding". Put simply, the PC framework asserts that our qualitative experiences arise when our brains create hypotheses about the state of the world around us and then test those predictions. But when scrutinized, even this technical neuroscientific approach to pain control seems to support socialist preventive strategies over expensive neuroscientific treatment.

Imagine for a second that you're a brain: a dense set of 86 billion neurons trapped inside of a dark, wet cavern. You cannot directly see or hear or touch. Instead, you receive noisy electrochemical signals that are related to what's going on around the skull you inhabit. The problem of figuring-out-what's-going-on-out-there requires combining these inputs to make an informed guess about the environment causing those signals in the first place. As you make informed guesses you receive immediate feedback as to whether or not they were correct via the next set of electro-chemical signals. Guess and check. Guess and check.

But you're smart. So you write down notes of specific guesses you made and how correct they turned out to be. Of course not all guesses get one line in your notebook. Things are crossed out, underlined, and bolded and circled in the margins. As you make and test your little guesses every second of every day for your entire life, you develop an extensive understanding of what various signals from your environment likely mean. Neuroscientists call this palimpsest of memories you have a "model" of

the environment. It is a detailed user manual for the world you inhabit. Your model is a powerful thing.

Predictive coding theory emphasizes that conscious experiences are not simply the result of signals arriving at the brain. Your brain's model of the world sits between the world and your experience of it. Imagine walking into a shed in the afternoon on a hot day. On the ground is a coiled up piece of rope. Upon entering the shed your brain leafs through its notebook to the page that says "hot day, 2pm, shed in low light, small coil on the ground" and follows the arrow it drew to the note "THIS WAS A SNAKE ONCE!" And for a moment, you literally perceive the rope to be a snake.

The rope snake is a silly example of the power your model holds over your experience. It is also an example of an illusion; the rope wasn't a snake, after all. But what happens when the scary, caps lock warning in your notebook indicates exactly the situation you're currently facing?

A lot of people believe their chronic pain is the rope snake – the pain is not actually there. But it's actually the second case – your body is in serious danger!

Some studies have shown that people who expect an upcoming stimulus to be painful experience stronger pain than those who expect a benign stimulus. And the more certain they are that pain is coming, the stronger they feel it. In fact, many chronic pain patients are now being diagnosed with "primary", "nonspecific", "nociplastic", or "centralized" pain. These are essentially synonyms for when clinicians find the volume knob for a patient's pain signals is inexplicably high. It is estimated that in 85% of chronic back pain cases, the most common type of persistent pain, no definitive source of bodily harm can be found.

So where is all this pain coming from? In the context of PC, the absence of bodily damage means there shouldn't be strong bottom-up pain signals. And yet, day in and day out, people are experiencing debilitating pain. If chronic pain isn't coming from the sensorium, a good guess as to where it originates is a person's model of the world. Faced with a lack of social safety nets, a compulsion to sell one's labor, and the ever looming

threats of joblessness, homelessness, and poverty, how could we expect the human brain to predict much other than "Pain! Pain! Pain!"? Our 86 billion neurons curate a sophisticated model of the expanse of an avaricious civilization, and the truth they discover hurts.

3 Social Physical Therapy

Argument for physical therapists treating chronic pain to organize politically and consider social structures in treatment.

Paper for The Journal of the APTA to introduce "Social Physical Therapy" (SPT) as a clinical perspective, a comparison to the Social Medicine movement, and a set of policy recommendations that SPT requires. Somehow using chronic pain as the focal example.

Rudolf Virchow Quote:

> "medicine is social science and politics nothing but medicine on a grand scale"

(In no set order) Outline:

1. Understanding the determinants of chronic pain
    1. Allostatic load
    2. Allostatic capacity
    3. Endogenous vs. Exogenous sources of allostatic load
    4. Current Treatment vs. a SPT appraoch
2. What is SPT?
3. History of Social Medicine
4. Social Physical Therapy Requires Socialist Policies

Rando Notes:

- Clinicians who treat patients with chronic pain like to emphasize the necessity of using a "biopsychosocial" approach. Most, however, seem to think the boundaries of this approach end at the level of interpersonal interactions, but most exogenous load is coming from the environment, as produced by social policy.
- Justin had 2 other PTs in mind who work in this type of space who we will want to look at this. Their names are…
- Social Medicine wiki
- Rudolf Virchow, "the father of modern pathology" and "the pope of medicine": ajpha bio and wiki and his famous Report on the Typhus Epidemic in Upper Silesia.
- Paul Farmer is a name a lot of people are familiar – but he was a doctor in Haiti. We were actual physical therapists in Haiti and have some data on pain we could use to support what we're saying here using Paul Farmer quotes. Probably a separate paper.
- Could also include a section basically like "why should people trust us?" Where we discuss Haiti work and prevalence of chronic pain we found there – again could use our own data that we collected.

What is Social Medicine:

- What is Social Medicine? – monthly review
- What is Social Medicine? A genetic analysis of the concept (george rosen)
- How did social medicine evolve, and where is it headed? – PLoS med

4 Chronic Pain in Haiti

Analysis of STAND data collected in Haiti over 5 years. Showing estimates of the incidence and prevalence of chronic pain and chronic pain subtypes through primary data collected in one of the poorest cities in one of the poorest countries on the planet.

References