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The Real Dickheads: Investigating the Source of Patient-Physician Conflict in the United States

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SCIENCE, MEDICINE & PUBLIC HEALTH

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In October 2018, the Twitter hashtag #DoctorsAreDickheads began trending after YouTube blogger Stevie Boebi released a video discussing her years of experiencing medical gaslighting and dismissal, as well as her eventual diagnosis of Ehlers-Danlos Syndrome. The hashtag was started by Wren Frey, formerly known as K. Sauder, in response and solidarity with Boebi’s experiences to foster a wider conversation about these issues.[1] Other social media denizens (predominantly women, people of color, and people with psychiatric conditions) used the hashtag to express their own frustrated histories of medical neglect and abuse. The hashtag has been part of a larger discussion of implicit and explicit bias[2] amongst physicians that prevents them from providing adequate medical care to patients with marginalized identities.[3] The discourse empowered by #DoctorsAreDickheads exposes the ways that our cultural rhetoric of normative health has material consequences for those most vulnerable to (cis)sexism, fatphobia, and stigma against mental illness.

Unsurprising to most people with chronic conditions, physicians reacted to this social media trend … dickishly. The reactionary hashtag #PatientsAreDickheads began appearing in posts on physicians and healthcare workers’ personal social media accounts, particularly on Twitter and Reddit. While abuse of healthcare workers, particularly nurses, is a recognized problem,[4] these reactionary posts by providers mocked and humiliated patients for their weight, hygiene, class, and symptoms of psychological distress—the very same harmful attitudes patients using #DoctorsAreDickheads were testifying about in the first place.

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The tensions between the narratives exposed by the #DoctorsAreDickheads and the #PatientsAreDickheads hashtags illustrated a pervasive problem in medical care that spans continents, governments, and policy models. All over the world, patients do not trust their doctors, and doctors do not respect their most vulnerable patients. At the CoLiberation Lab at Purdue University, we are investigating the social, societal, administrative, and policy-based causes of this deadly adversarial trend in patient-physician relationships.

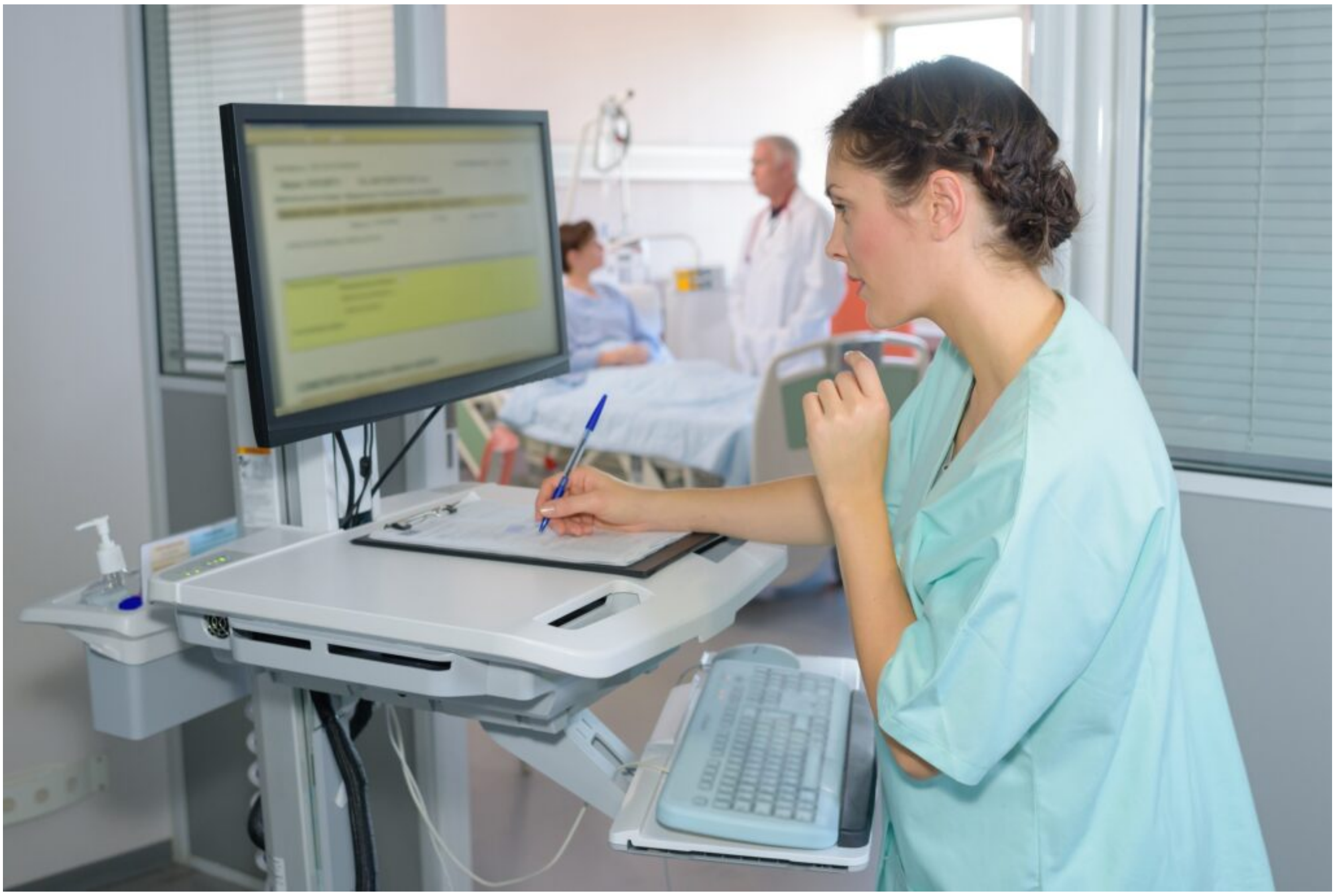
Testimony of a Dickhead Doctor

Medical records have been a core part of medical practice since ancient times. These are the documents physicians use to record trends and notice the patterns necessary for accurate diagnosis, prognosis, and treatment plans. Electronic Health Records (EHR)—or the digitization and central storage of clinical notes, test results, and other patient health information—have been an essential tool administrators and insurance providers use to standardize care, communicate across specialties, and provide accountability. However, the roll-out of EHR initiatives have had mixed success, with these database systems rarely achieving their aims without significant system-wide idiosyncrasies, bugs, and errors, not to mention the increased risks of cyberattacks and data security breaches.

Just before the #DoctorsAreDickheads social media clash, *JAMA Pediatrics* published an opinion piece by Dr. Peter Louis Loper Jr. titled “The Electronic Health Record and Acquired Physician Autism.”[5] In this editorial, Loper blames the deterioration of physician-patient interactions on an autistic-like state caused by administrative priorities that place procedural conformity and maintenance labor for the EHR over engaging with patients with the attention they deserve.

His editorial went viral on Twitter. When challenged on his article via letters to the editor, Loper doubled down, using the full text of the *DSM-5* criteria for autism to justify his metaphor.[6] Public perceptions of autism as a problem, in general, and as a deficit of empathy and compassion, in specific, are at the heart of the pervasive stigma and discrimination Autistic people face on a daily basis. This stigma and pathologization underlies many, if not all, of our experiences with bullying, trauma, abuse, and our risk for falling victim to filicide.[7]

Loper’s editorial illustrates a conspicuous irony: Patients with chronic conditions are exactly those who stand to benefit the most from well-maintained EHRs; yet Autistic patients are those who are often vulnerable to patient-physician miscommunication. Many Autistic people are both autistic and have one or more chronic condition to manage.[8] In fact, due to disproportionate unemployment,[9] histories of trauma, and experiences of invalidation by medical staff, many Autistic people struggle to even access adequate healthcare.[10]



The situation that Loper describes is quite fascinating. As a disabled person, I am regularly obligated to devote hours of my week to tracking and tracing symptoms, appointments, medications, and referrals. To do this, I rely on information technology. Yet Loper, and many other physicians, seem to take enormous exception to EHR as a concept. Would physicians prefer returning to bound A5 pads? Physicians need patient notes. Physicians cannot be expected to remember and track the progression of their patients' conditions any more than the record (electronic or otherwise) should ever be expected to autonomously "decipher the exponentially complex, individually autonomous, nuanced human characteristics and experiences that perpetuate the diseases that ail us as a society."[11]

If the task demand of attending to patients with compassion while simultaneously maintaining the EHR to administrative policy standard is too high, and causes (as Loper describes) both the physician and the patient to suffer, then any disabled person could tell you that it is the task that is flawed. The necessary supports and accommodations are not in place. The callous and inattentive doctor that Loper has become in his vignette is not an autistic one; it is one debilitated by the draconian requirements enforced by profit-motivated administrators and insurance policy lobbyists.

Understanding and Learning from the Patient-Physician Relational Rift

The CoLiberation Lab has been interviewing patients and physicians about their experiences with seeking care, giving care, and the circumstances that bring about Dickhead behavior. In our research, we are finding patterns in contemporary healthcare policy that disempower, disillusion, and obstruct physicians, leading to cycles of patient deferral, dismissal, and abandonment.

For example, multiple participants have described a maddening “specialist runaround”: A general practitioner refers a patient for specialty evaluation and, after months of waiting, that specialist declares a lack of expertise in the specific details of the patient’s concerns, sending the patient back to the GP with either a totally different kind of specialist or merely a shrug. Patients report that even some of their better experiences with GPs eventually devolve into dismissal after multiple rounds of specialist hot potato.

The best experiences with physicians, whether general or specialist, were characterized by the physician’s openness, humility, curiosity, and willingness to take an investigatory approach to symptom analysis and problem solving. What supports an investigative approach to clinical practice, and why do so many physicians seem to lack the capacity for it?

Our interviews with physicians have proven to be even more harrowing than those with patients. So far, our physician participants have not been obvious dickheads. Yet their testimonies make it possible to recognize how easy it is to slip into a dickhead position. Some physicians report spending many hours of extra time playing the most enraging game of telephone with insurance providers. Physicians must say the right words, in the right order, and enter the right words and the right details into the EHR, in order to satisfy the incredibly specific and willfully obtuse criteria to get the insurance company to authorize the right treatment and pay the appropriate amount. Physicians describe conversations with insurance representatives where they are certain that the person on the other line is looking at a flow chart and can only give them the required information if they guess the magic word.

Often, physicians communicate with so-called peer reviewers—specialists and physicians hired by insurance providers to validate the treatment decisions made by a practitioner. In our interviews, physicians reported that these peer reviews are often with physicians from the wrong specialty! These peer reviewers are *also* following flow charts and are often unable to argue in support of the request. Some physicians report that their offices have learned the magic words for certain procedures for certain providers, but that these magic words change often, and they have to build up their secret knowledge all over again. Meanwhile, patient care is delayed, treatment plans are substandard, and patients pay the price with their wallets and lives.

Though implicit bias in healthcare, which disadvantages people by weight, race, gender, and disability, is a pressing problem, my research indicates that there is more to dickhead behavior than implicit bias and bigotry. When a physician knows that they can't fight the system to get their patients the care they need, when they know they need to spend an hour with you, but they're only allowed 15 minutes, when their administrators view patients as a commodity rather than an obligation, it becomes easier to dismiss a patient's concerns than suffer with them in an impossible struggle for adequate care.

A Call to Forge New Patient-Physician Coalitions

For decades, advocates have been communicating that our healthcare system is broken. It absolutely is. My prior scholarship describes how insurance denials, sometimes tenaciously resisted by physicians, have directly led to the deaths of even our most resourced and experienced healthcare advocates.[12] So, what can we do to fix it? Many people believe that a single-payer or universal healthcare model will solve the problem. Though I personally dream of universal healthcare, I don't think this dickhead phenomenon will go away with public insurance. For example, the #DoctorsAreDickheads hashtag was started by a Canadian and embraced by people in the United Kingdom and Australia, countries that have at least provisionally public healthcare systems.

> *Patients and physicians need a coalition with which to revolt—to destroy the embezzlement scheme enabled by contemporary insurance policy.*

Any system that denies a patient's right to choose the details and conditions of their care, any system that denies a physician's expertise and prioritizes their clerical work over their clinical efficacy, is inherently obstructive to care and productive of death. Patients and physicians need a coalition with which to revolt—to destroy the embezzlement scheme enabled by contemporary insurance policy. Right now, patients can't trust physicians, because physicians treat patients as part of the administrative burden that has broken their profession.

To identify social and policy mechanisms for new patient-physician coalitions, we need to better understand the #Dickhead experience as a complex social, political, and fiscally derived phenomenon. We are collecting qualitative data on physician attitudes toward the EHR, and how their working conditions under medical industrialism may be exacerbating bias against patients as "unreliable witnesses" to their own embodied experiences. Through triangulating testimony between patients, physicians, administrators, and insurance staff insiders, we hope to build recommendations for physician-patient collective resistance against a neoliberal medical industry that extracts value from human life. By forming authentic connections, physicians and patients can form powerful disruptions and transformations to our nation's ethics of care.

If you identify as a patient, physician, healthcare worker, administrator, or insurance staff and wish to participate in our study, please visit https://www.tinyurl.com/dickheadsurvey.

Footnotes

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