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Authors

Hussain, Mustafa I

Bowker, Geoffrey C

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Phenotyping as disciplinary practice: data infrastructure and the interprofessional conflict over drug use in California

Mustafa I. Hussain, PhD¹, Geoffrey C. Bowker² [Professor Emeritus]

¹Department of Medical Informatics and Clinical Epidemiology (DMICE), Oregon Health & Science University (OHSU) School of Medicine, Mail Code: BICC. 3181 S.W. Sam Jackson Park Rd. Portland OR 97239

²Department of Informatics, University of California Irvine, Irvine CA 92697-3440

Abstract

The narrative of the digital phenotype as a transformative vector in healthcare is nearly identical to the concept of “data drivenness” in other fields such as law enforcement. We examine the role of a prescription drug monitoring program (PDMP) in California—a computerized law enforcement surveillance program enabled by a landmark Supreme Court case that upheld “broad police powers”—in the interprofessional conflict between physicians and law enforcement over the jurisdiction of drug use. We bring together interview passages, clinical artifacts, and academic and gray literature to investigate the power relations between police, physicians, and patients to show that prescribing data appear to the physician as evidence of problematic patient behavior by the patients, and to law enforcement as evidence of physician misconduct. In turn, physicians have adopted a disciplinary approach to patients, using quasi-legalistic documents to litigate patient behavior. We conclude that police powers have been used to pave data infrastructure through a contested jurisdiction, and law enforcement have used that infrastructure to enroll physicians into the work of disciplining patients.

Keywords

drug use; phenotyping; law enforcement; health informatics; professions

A compromised profession

In 2019, over 136 people died due to an opioid-related overdose in the United States every day; over the past decade, deaths implicating synthetic opioids, most often illicitly manufactured fentanyl, increased as those related to prescription opioids decreased (Christine L. Mattson et al., 2021). Centers for Disease Control (CDC) declared an opioid epidemic in 2015 (CDC, 2015), and law enforcement traced the crisis to Purdue Pharma’s OxyContin marketing (Donovan, 2019).

Pharmaceutical corporations have wielded immense power in U.S. healthcare; in the 1990s and naughts Purdue Pharma managed to change professional norms regarding opioid prescription based on flawed scientific and moral claims. Scientifically, they framed as fact a letter to the editor of the New England Journal of Medicine (Leung et al., 2017). That letter contained a preliminary analysis of clinical data that suggested the habit-forming potential of opioids was an order of magnitude smaller than previously believed. Morally, they claimed physicians were harming patients by depriving them of opioids (Donovan, 2019), which brought the most satisfying short-term pain relief of any available pharmaceutical class. Their efforts contributed to a “war on pain” in the 1990s (Fishman, 2005) leading to a deadly opioid use crisis (Van Zee, 2009).

Prescribing rates fell through the second decade of the 21st century, due in part to prescription drug monitoring programs (PDMPs)—data infrastructure that state departments of justice, often aided by boards of pharmacy have used to surveil controlled substance prescriptions. We focus on the role of PDMPs in law enforcement’s efforts to superficially counteract corporate influence while further eroding medical self-governance by extending law enforcement’s claim over the contested jurisdiction of drug use. This is a form of dispute familiar to readers of Abbott’s (1988) *System of Professions*, which explores the agonistic field of different professions vying for control over a given problem.

A brief history

First, we offer a brief history of PDMPs at the national level, focusing on periods of rapid change. The prototype to the contemporary PDMPs were paper-based triplicate prescription programs, most of which were established in the 1920s (Younger, 1978). Physicians used a special pad for prescribing dangerous drugs; like a checkbook, each page was numbered in series, and each page had two carbon copies. One copy would be kept by the physician, one by the pharmacist, and the third by the state.

In the 1970s, a heroin crisis had emerged (Hunt, 1974), and Percocet entered the market (FDA, 1976); against this backdrop, some states such as New York began to use tape storage and computers to detect overprescribing. Physicians and patients fought this practice in the Supreme Court, which ultimately upheld such practice as a “reasonable exercise of the State’s broad police powers” (Stevens, 1977).

In response to a rise in OxyContin overdoses during the naughts, PDMP databases were opened to physicians through Internet portals, allowing physicians to investigate patients—previously, data were only available to the state (e.g. Small, 2013). In the teens, as the crisis worsened, states increasingly required physicians to check these databases before prescribing opioids. On October 2, 2018, California mandated that prescribers consult their database prior to writing a patient’s first opioid prescription after a period of abstinence, and every four months thereafter (Becerra, 2018).

In physician-dominated medical informatics circles, papers were published on how unusable these systems were. Physicians had trouble locating login screens, logging in, searching databases, reading reports, and interpreting reports (Leichtling et al., 2016). Here, we focus

on interpretation; it was common for key information—“*why* was this patient receiving these prescriptions?”—to be unavailable (Hussain et al., 2019). In the present analysis, we move beyond universal notions of usability to ask, if these databases have inadequately served physicians’ purposes, then whose purposes have been served?

According to court documents, Purdue Pharma promoted the criminological view in order to avoid responsibility for harms caused by their drugs (Donovan, 2019). From a criminological perspective, addiction is a symptom of moral failure, requiring disciplinary treatment. From a medical view, addiction is a disease, requiring clinical regimentation when it affects patients’ ability to work. Police and physicians alike view drug use as a potential impediment to productivity. Because the policing establishment has demonstrated little interest in alleviating suffering, we were more sympathetic to the physicians’ positions. So, we viewed the dual purposes of the California PDMP—a law enforcement database, opened to physicians for secondary clinical use—as suspect.

One of us previously conducted interviews with 16 pain and emergency physicians, and published a paper on PDMP usability (Hussain et al., 2019). That work yielded interview passages that did not fit an ergonomic narrative. These surprising results served as the points of departure for our second, abductive analysis (Timmermans and Tavory, 2012), in which we formed hypothetical explanations for observed effects, then sought confirmation and disconfirmation in the interviews, the field site, and the academic and gray literature. When these searches yielded further surprises, we formed additional hypotheses. We continued this process until we had developed a coherent narrative.

Our findings follow the chain of discipline—first, physicians using a law enforcement database are faced with ambiguous data and amplified risks. This serves to enroll them in practices of patient discipline. Attempts have been underway to speed up patient judgment using a phenotypical metric.

Physicians faced with uncertainty and risk

PDMP databases have presented physicians with prescription records without explanations. Physicians have been able to see when, who, what, and how much was prescribed, but not why those drugs were prescribed—not even in the form of diagnostic codes. This informational lack has often led to incorrect assumptions about why patients have received prescriptions, as exemplified by the following quote from an emergency physician:

“You get a general sense of risk, but you can make some assumptions simply because you don’t know. You don’t have solid data.”

– Physician 11, Emergency Department

In addition to ambiguous data, physicians have contended with salient risks. A pain physician cued us into this thread of the narrative, when telling a story about a patient with subacute pain, to whom she denied opioids, due to his self-reported, long-past history of opioid addiction:

“What if he relapses and dies, or what if he has an adverse event? Then his family could say, ‘he told you he was an addict,’ and I could literally go to jail for murder. There was a case like this in the news.”

– Physician 2, Pain Specialist

We looked into the news and found a handful of related reports, in California and nationwide (e.g. Sullivan, 2018; Wootson, 2017). These reports appear to represent outlying cases, but this is an effective law enforcement tactic, in which newspaper editors have been complicit: making a spectacle of the disgraced professional, to cue other physicians to discipline themselves. This calls to mind Foucauldian self-discipline, wherein those who are knowingly subjected to surveillance tend to enact discipline upon themselves (Foucault, 1977), with the addition of mediated public spectacle, previously noted by Palmer (1998).

Disciplining patients

Law enforcement had established a salient presence in physicians’ jurisdiction, presenting the threat of discipline. Our results indicate that physicians have responded by extending this discipline to patients. These disciplinary practices are typically outlined in opioid exclusivity agreements, informally known as “contracts.” It is uncommon to see quasi-legalistic documents in medicine.

We take the American Academy of Family Physicians’s medication use agreement (AAFP, 2001) as an example. It has some severe stipulations. For example, it requires the patient to comply with urine drug testing at any time, and to file a police report anytime they misplace their medicine. Further, the patient may be discharged for non-compliance:

“Failure to abide by these agreements will result in the termination of medication prescriptions and possibly the termination of services from my doctor and his or her practice.”

– AAFP Medication Use Agreement (AAFP, 2001)

The document also stipulates that the physician may stop prescribing opioids if the physician believes there is risk of an adverse event. Because of the ambiguities mentioned earlier, patient risk assessment is an uncertain business. Automated metric systems are often promised to absorb uncertainties (Choo, 1991).

Phenotyping patients

Here we examine an instrument of metrification maintained by a corporation called Appriss, Inc., whose motto is “knowledge for good.” In addition to running PDMP databases for the majority of US states (Appriss, 2019), Appriss has offered surveillance of employees following a court appearance or incarceration (Brian Kelly, 2021). Appriss has portrayed their metric, NARxCHECK®, as a predictor of overdose risk (Huizenga et al., 2016). We view this metric as a digital phenotype—it repurposes patient behavioral data initially collected for law enforcement to produce a clinically useful risk assessment.

NARxCHECK's patent (Huizenga, 2014) describes multiple possible permutations of an algorithm, apparently a sum of weighted factors. It is not clear which permutations or weights have been used, and a whitepaper on the algorithm is light on mathematical explanation (Huizenga et al., 2016). Dataset(s) used to generate weights do not appear to be available, even in deidentified form. This lack of transparency may be to blame for the fact that a sampling error went unidentified for an unnamed period of time (Huizenga et al., 2016). The error may have resulted in specious evidence being brought to bear on patients' cases, resulting in unfair discipline. However, key details on the error—its nature, scope and consequences, for example—do not appear to have been provided. Further, we are at a loss as to how Appriss planned to identify and correct further possible errors in a timely fashion.

Key components of an apparatus meant to be used by professionals to assess patient risk have been kept secret by a private corporation. Despite its obscure, proprietary nature, the Office of the National Coordinator for Health Information Technology (ONC) promoted the use of NARxCHECK as a risk assessment tool, complete with specific thresholds for risk interpretation (Be Confident, Be Curious, Be Cautious) and a physician testimonial touting its helpfulness (ONC, 2013: 23, 26).

Physicians across the US have expressed concerns about the expansion of this phenotyping technology. True to the spirit of biomedicine, a key representation of these concerns has been published as an empirical research article in a medical journal (Leichtling et al., 2019). That article documents efforts by researchers who conducted brief interviews with 93 physicians at three national medical conferences about their perspectives on enhanced PDMP profiles, including risk scores. Key results included concerns about transparency and validation of risk metrics. More fundamentally, physicians were concerned that risk scores would gain dominance over clinical judgment. Taken together, physicians' perspectives appear to suggest that inserting a high risk score on-screen could prompt the prescriber to inappropriately deny opioids to a patient, or else accept a liability associated with going against the phenotyping algorithm's supposedly objective judgment (Leichtling et al., 2019).

In the non-metrified regime we previously studied, physicians made their judgments mainly on the basis of a simple list of past prescriptions (Hussain et al., 2019). In such a regime, if an overdose incident occurred and the physician was brought to the state's attention, a fellow practicing physician could be called to the court to provide an expert testimony on the patient's prescription history, and their testimony would aid or harm the prescribing physician's case—one pain management physician we interviewed, Physician 15, was called upon more than once to, in his words, "explain how to read the [PDMP] table in court." In a regime reliant on an opaque yet ubiquitous metric and threshold for "caution," the role of interpretation by expert practitioners is likely restricted even further.

Concluding remarks

Database design and disciplinary tactics have led to a dual approach to addiction among physicians: that addiction is a disease *and* a moral failure, which requires clinical treatment *and* discipline. In the context of ongoing austerity policies that preclude the long-term, state-

funded, evidence-based treatment for drug users, law enforcement has effectively enrolled California physicians into disciplining opioid users.

These tactics were effective at reducing opioid prescribing in California (Castillo-Carniglia et al., 2021). However, pathways toward sobriety have thus far largely failed to pick up where outpatient clinics left off; many drug users have favored diverted buprenorphine to 'punitive' treatment (Kavanaugh and McLean, 2020). Additionally, drug overdoses due to illicit synthetic opioid use, primarily fentanyl, sharply increased following the 2016 mandate for California physicians to check the PDMP database (CDC, 2020b). The opioid crisis has worsened during the COVID-19 pandemic; at time of writing there is a continued rise in synthetic opioid use, out of the clinic's control (CDC, 2020a), and in the streets and home residences where emergency response routinely administers large, withdrawal-precipitating, punitive doses of naloxone, the antidote for opioid overdose; the resultant agitation and pain to which drug users are subjected during their premature return to consciousness has on occasion led to deadly encounters with police (Kavanaugh, 2020).

As we have seen, in this case and in the last four years, powerful interests have been working to sow doubt in the trustworthiness of physicians and other experts. As experts ourselves, we are not opposed to professional accountability; nor are most physicians we know. At the same time, it is worth questioning whether it is reasonable for systems of professional accountability to be reliant on private corporations that are themselves largely shielded from accountability. Intellectual property laws should not be a shield for a lack of accountability. Further independent, state-funded investigation is warranted.

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