

OTHER PEOPLE'S PAIN

*“The function of stigma is to remove credit from an individual or a group, marking them as **unworthy of belief**.”* – Erving Goffman, 1963¹

*If the source of stigma is publicly visible, stigma is deeply discrediting; if concealed from others, the stigma renders the affected person “discreditable.” In either case, it is internalized as a spoiled identity, a feeling of being inferior, **degraded, deviant, and shamefully different**. It invokes other cultural categories of **what is ugly, feared, alien, and inhuman**.* – Arthur Kleinman, “The Illness Narratives,” 1988²

Program in Bioethics and the Humanities
ROBERT D. SPARKS WRITING CONTEST
Carver College of Medicine
The University of Iowa

Submission
March 23, 2021

Chief Complaint

I spent the entirety of February 15th at the hospital, primarily occupied with the aftermath of an ice storm. Arriving well before 5:00 that morning, my first few hours were spent chasing a group of trauma surgery residents as they power-walked from one patient room to another. The first trauma cases of the day were announced via the resident's aggressively loud pagers, which foreshadowed a new patient's impending arrival. Even early in the morning, the trauma bay of the Emergency Department (ED) could feel like a crowded party: providers of all kinds would descend upon the ED from across the hospital and the room would start to produce a bright and upbeat hum as people came and went. As a third-year medical student rotating on the trauma surgery service, I often felt as if I was riding along on an adventure into the unknown. Extracting the story behind a new patient's injury and the circumstances leading to their presence in the hospital felt something like drawing back a curtain and peering into one of an infinite number of previously unknown worlds. The new patients who presented that morning of the 15th, however, were relatively predictable and narratively less exciting. A series of recent storms had covered seemingly every surface in the state with alternating layers of snow and ice, and each patient told a similar story about the events that had brought them into the hospital. Nearly every patient's presence was the result of slipping on the ice, and as the morning transitioned to afternoon, I wondered aloud if there was a single pregnant person or patient over age 65 who had yet to sustain a fall on the ice. Weather-related musculoskeletal injuries would prevail as the primary reason for ED admissions that day, with nearly every patient telling a story of a fall on the ice. Because of this, I was unprepared for the suspicion and disbelief that a story of "a patch of ice and a slip" would elicit when I returned to the hospital with my partner, Andy, later on that evening. It was 19 days before Andy would die.

Earlier that evening when Andy left work, he slipped on a patch of what Midwesterners refer to with only a mythical sense of reverence: *Black ice*. Walking to his car, he was unable to make out the slick patch on the sidewalk in front of him, and when he began to fall, Andy reached out for the metal railing that ran alongside the sidewalk. But he grossly overestimated the necessary reach, and his arm landed awkwardly across the railing. The metal bar twisted and pushed his arm in the opposite direction of his falling body. With a pull, then a burst, he felt his humerus leave its home in the glenoid cavity. It took him only a moment to recognize the resultant pain, and it matched the sensory experience he had once experienced, as a teenager, when dislocating his shoulder while skateboarding. Anterior shoulder dislocations are not an uncommon injury, especially in adolescent boys, but Andy had torn several ligaments in his rotator cuff at the time, which caused the shoulder to dislocate repeatedly until surgical repair could be performed. In the moments after his fall, he lingered on the ground, contemplating the shock of the pain. Unable to extend or rotate his shoulder, he determined himself unable to drive and called me to come and get him.

In the time it took for me to drive across the river to meet him, Andy had settled on the self-diagnosis of a dislocated shoulder. As I helped him into the passenger seat of my small SUV, he showed me the google search results for tutorials on how to reduce a shoulder dislocation. At that point in my medical education, I had largely ignored the entire domain of pathologies that can be classified under the umbrella of musculoskeletal injury. I found them to be regrettably dull and intellectually a bit uninteresting, so as I lifted up his arm and began to examine it, my differential diagnosis was remarkably limited. Nevertheless, Andy professed a deep confidence in my knowledge and skill and suggested that he would read aloud from the internet's stepwise instructions while I maneuvered his arm to reduce the dislocated shoulder. At

a traffic light, I began examining his arm at the fingertips and worked my way up, looking for any sign of interrupted blood flow or damage to the suprascapular / axillary nerves. In the dim light of the car, it was impossible to determine if his forearm had a blue tint from the streetlight overhead or due to vascular compression. I looked up at his face to see Andy clenching and unclenching his jaw, squeezing his eyes shut and then slowly opening them. He seemed to be bracing himself against an army of internal pain signals, mobilized to fire at full volume in his brain. Andy was resolute that he would not be going to the hospital. As I drove towards the emergency department entrance, his pain seemed to worsen. Beads of sweat emerged at his hairline and poured over his forehead as he became increasingly agitated. For Andy, a faint level of anxiety permeated nearly every moment of his life, and it seemed to magnify the momentary pain he felt. The Harvard anthropologist and psychiatrist Arthur Kleinman describes the way in which the creation of a pain, as a sensory experience, can be multi-factorial:

Where stress occurs over a prolonged period or where a chronic medical or psychiatric disorder is present, existing pathology may be exaggerated by the meanings of situations and relationships, or by institutional constraints. But such somatization also stems from our prior experience of the symptoms and our current anticipatory fears of, and need to control, symptoms exacerbation.²

Andy's shoulder pain was likely intensified by the general experience of living with anxiety, but as we drove closer to the hospital, the pain seemed to amplify further. If his past experiences with the healthcare system were any indication, setting foot inside the hospital was only likely to accelerate the magnitude of his pain.

Pain's Existential Crisis

Pain is often believed to be immensely boring as a medical phenomenon because of its unremarkable underlying pathophysiology. The challenge of understanding pain and its neurologic complexities almost seems to be coated in a repellent against physician intellectual curiosity. Pain is messy and imprecise. It is highly subjective and fundamentally lacking in that

which is holy and beloved to clinicians: the biomarker. A Professor of English at the University of Pennsylvania, Elaine Scarry published in 1985 a profoundly delightful meditation on pain that feels no less revelatory nearly 40 years later. Scarry argues that in our attempts to understand the meanings of pain, there are essential truths that must be applied:

For the person in pain, so incontestably and unnegotiably present is it that “having pain” may come to be thought of as the most vibrant example of what it is to “have certainty,” while for the other person it is so elusive that “hearing about pain” may exist as the primary model of what it is “to have doubt.” Thus pain comes unsharably into our midst as at once that which cannot be denied and that which cannot be confirmed.³

If understanding pain means acknowledging its inherent dichotomies, then an alternative framing of what it means to be in pain is proposed by the English Historian Joanna Bourke. Bourke’s argument is that people in pain carry two types of burdens: First, the onus of their own pain, and second, the burden of being props in the political theatre to which pain belongs.³ The experience of pain is profoundly shaped by culture, which allows individuals to create language and stories through which the sensation of pain can be interpreted and given meaning. In this way, we become able to share our experiences of pain with others and prepared to meet the fundamental challenges of communicating about pain. This process in and of itself is believed to recursively shape the experience of pain itself.⁴

Often, the targets of these stories and explanations of pain are physicians, who must interpret the pain causing a patient’s suffering through the patients verbal and nonverbal claims, and then determine the level of compassion and relief from pain the patient deserves. Bourke describes physicians as *pain authorities*,⁴ who hold considerable power over a patient’s pain and its potential alleviation. As figures of authority who prefer to live in the world of objective truths and scientific absolutes, occupying the role of an authority who must make decisions based solely on the subjective creates conflict and uncertainty. Bourke notes that physicians at first rely on a patient’s narrative history and physical exam to understand their pain, but at some point are

bound to become suspicious of their claims given the inherent subjectivity of what it means to be in pain. Scarry³ and Kleinman² describe a similar process of medical disbelief – and the patient's resultant efforts to appropriately act out their role in believable fashion.

As physicians determine who is experiencing pain and how much relief they deserve, they draw on meanings and narratives of pain that are culturally produced, as well as their own moral philosophy. Medical historian Keith Wailoo asserts that questions about pain and compassionate responses to suffering become highly politicized and involve – subconsciously or consciously – ideas of deservingness, entitlement, citizenship, liberalism, conservatism, and ideas about the kind of society in which we ultimately wish to live.⁵ Historically, physicians have shied away from playing the role of public authorities on pain, both out of ambiguity and uncertainty in how pain should best be defined and relieved. In their absence, judges, politicians, and courts have since stepped in to fill the vacant role, and for more than half a century have functioned as the ultimate arbiters of who is in pain, and what constitutes a compassionate response to pain. A series of significant policy decisions and judicial rulings during the 1980s established responses to these fundamental questions that have served as a baseline for future definitions. Importantly, this period also established a dominant ideological discourse in American politics regarding what traits or characteristics make an individual deserving of support, assistance, and compassion, especially in the setting of pain. The era most notably gave rise to the myth of the 'Welfare Queen' and popularized rhetoric suggesting that some individuals were fundamentally lazy and lacking in personal responsibility but believed themselves to be entitled to the "fruits of other people's labor," attempting to generate empathy for themselves as a tactic of manipulation.⁵

While medical professionals possess a number of qualities that may be unique and render the group distinctly different than the general public, the ethical values of medicine are a reflection and distillation of the broader culture in which a medical system and the health care providers who work within it are embedded. Wailoo argues that the judicial system and Reagan-era narratives surrounding pain would go on to permeate medicine and subsequently influence the ways physicians understood their own patient's pain – in a way, coming full circle.⁵ Thus for any patient who enters the doors of a hospital or clinic and claims to be feeling pain, their experience is bound to become inherently complex, as physicians struggle to interpret the meaning of pain as it has manifested in the person before them – and the patient, in turn, attempts to surmount the many barriers to establishing validity of their pain and achieve a performance that will deem their pain believable.

Andy

I met Andy shortly after he was released from prison. Introduced through our shared Harm Reduction work, I liked him immediately. Those who knew him from prison often described him as fundamentally out of place within the world of the justice system. His demeanor was unusual among those who had been toughened or bristled against the system – he was soft spoken, profoundly gentle, and ultimately, kind. At 5'7" and slightly built, he was not particularly intimidating. Sometimes when I would remark upon his lack of body fat – miraculous when considering the amount of his daily Mountain Dew intake - he would laugh and suggest that he had perpetually adopted the body of a heroin addict – slender as the result of a chronic caloric deficit. Yet, his physical appearance often drew comparisons with the English actor Tom Hardy, whose personal life had numerous parallels to Andy's own. Hardy had spent much of his teens and 20s using drugs and escaping legal trouble. Andy's adolescence had

followed a similar trajectory, marked by an addiction to heroin and later a series of felony charges leading to his incarceration. Like Hardy, his legal troubles were not those of a person who causes violent harm to others. They were admittedly the struggles of men who had entered the world and encountered a place of both excessive sensory stimuli and unbearable uncertainty, leaving them paralyzed with anxiety unless they should encounter temporary relief in the form of a chemical salve. In this way, Andy was at many times unable to navigate the world at all without using heroin to soothe his mind.

Andy had no formal education beyond the 12th grade, but possessed a nimble, expansive, and rare mind that others immediately recognized upon meeting him. From a young age his interest in the natural world had driven him to accumulate knowledge across the physical sciences: chemistry, biology, physics, astronomy. In the seventh grade, the Dubuque, IA “bomb squad” was called to his junior high. Upon the fire marshal’s arrival, Andy calmly and enthusiastically explained the explosives he had created in the chemistry lab as he waited for the other students to complete the day’s assignment. The fire marshal, slightly amused, declared Andy’s knowledge of chemistry and explosives far beyond his own. But he was otherwise a shy, quiet child who saw few good qualities in himself. By 17 he had established a habit of regular drug use, and he envisioned a life before him that offered few moments of excitement: decades of manual labor and conjuring ways to ignore one’s rapidly deteriorating body. In spite of his lack of formal education, he developed a remarkable capacity for self-instruction and took a disciplined approach to advancing his own knowledge. When he experienced his first period of prolonged incarceration, he fought off boredom by completing open access courses in organic chemistry. He used the money his mother sent for snacks and toiletries to purchase second hand medical pathology and pharmacology textbooks. And using the prison’s computer lab, he

became proficient in multiple coding languages. Largely unattended to here are the experiences with trauma that he began to collect through his addiction career. But, as he would routinely argue, the impact of his increasingly stigmatized identity caused much more damage to his spirit and his health than did his actual drug use itself. Kleinman describes the trajectory of how illness-related stigma is experienced, which characterizes Andy's own life exceptionally well:

The stigma can begin with the societal reaction to the condition: that is to say, a person so labeled is shunned, derided, disconfirmed, and degraded by those around him. ... Eventually, the stigmatized person comes to expect such reactions, to anticipate them before they occur or even when they don't occur. By that stage he has thoroughly internalized the stigma in a deep sense of shame and a spoiled identity. His behavior, then, becomes shaped by his negative self-perception.²

Although drug use, stigma, and incarceration had dominated parts of Andy's life, they were rarely on my own mind when I thought about who he was and his place in the world. There were many things that defined who he was as a person seeking to make meaning out of the world, and these were the things that made Andy beautiful. He drew joy from building telescopes in eager preparation for astronomical events; photographing unusual insects he found in his yard; or devoting many hours to exploration of a rock store. It is often alluring to witness a person whose intellect seems to experience no limitations and exceeds any kind of expectation. We derive joy and pleasure from observing a person whose mind operates in a way that we believe is far greater than it should. The "*Good Will Hunting*"-esque phenomenon makes it feel as if we have seen something rare or truly special and thus something that is suggestive of the potential for magic to exist in the world. In the evenings, Andy would often study with me as I prepared for shelf exams. But he was better at it than I was, and he was somehow fluent in the language of physiology, which allowed him to achieve higher practice exam scores than my own.

Andy had a magnetic sort of force that pulled you towards him due to the way that each of his qualities functioned in contrast. Against the backdrop of his intellect, he was acutely aware

of the betrayal present in the sound of his voice. A particular type of Midwestern inflection – or perhaps more so an intonation common amongst rural Americans, regardless of region - marked him as the sort of man who was likely fluent in the language of tractors, jails, and drug deals – but undeniably uncomfortable if asked to read from a menu of a French restaurant. An edgy, hardened exterior that seemed to reflect the masculinity of traditional Americana added further contrast against the genuine joy he experienced from watching Carl Sagan's Cosmos again, and again.

A number of years removed from the experience of active addiction, Andy became a case manager at the local needle exchange program which I had founded. He was tasked with preventing the occurrence of the sorts of harm that had once defined his life: IV drug use, hepatitis C, endocarditis, overdose, felony charges, incarceration. Clients trusted him because he was “just a regular dude” and “had been where they'd been.” One day as I watched him work, I realized that people were infinitely more comfortable talking with him than any of the agencies 100s of other staff and volunteers, despite his quiet and reserved demeanor. Andy had outfitted every drug user he could find with naloxone (the antidote used to reverse an opioid overdose) that he could count reports of over 500 instances where the naloxone had been used to successfully reverse an overdose and cause a life to be saved. As the needle exchange program's medical director at one point claimed, Andy was directly responsible for preventing more deaths in a single year than most physicians will be in their entire careers. But despite the life beyond drug use and incarceration that he had built, Andy struggled under the weight that comes with being permanently labeled as something less than human: a felon and a junkie. There were few places where these identities seemed to stick with him more than healthcare.

One Body, Two Patients – or, Alternative Facts

By the time we sat on a bed in the Emergency Department, Andy's shoulder pain had lasted long enough that it had begun to make him cranky, if not somewhat on edge. Shortly after we were roomed, a nurse entered the exam room and began to ask a series of questions.

"Do you smoke or drink alcohol?" She asked.

"No," Andy's responses were brief, and as he spoke while gritting his teeth in pain, it gave the false indication that he was angry. In an effort to soften the interaction, I added, "He used to smoke cigarettes but now he vapes." I tried to arrange my face in a way that would show the nurse that I was likeable, friendly, and above all, reasonable.

"Do you use drugs?" She continued reading through the standard set of questions in the electronic health record. I knew them well, along with the order in which they would come.

"No," Andy repeated.

"- well, some..." I tried again to catch the nurse's gaze, to somehow deliver the message that we were *nice people* – honest and transparent. It felt medically relevant that he sometimes took a benzodiazepine (unprescribed), or occasionally mixed the herbal powder, kratom, into a tea. I wouldn't mention that every so often, when he had extra cash on hand, he might do a little ketamine. It was highly unlikely that this nurse would know of or understand ketamine's resurgence among millennials in coastal cities and replacement of past "party drug" trends (i.e. cocaine, MDMA).

The nurse glanced back and forth between us. "Well which is it? You do or you don't?"

Andy repeated, "No, no drug use." I detected a subtle eye-roll from the nurse, who clicked a series of buttons on the keyboard, navigated out of Andy's chart, and left the room.

When she disappeared into the workstation, Andy looked over at me, “Why would you tell her that?! There is *no* reason she needs to know that, and you know it.”

The nurse eventually returned to the exam room and began a new series of questions. As she addressed Andy, a resident entered the room. I recognized her from earlier in the week when we had a shared case in the trauma bay. Without pausing to introduce herself, or make eye contact in acknowledgement of her patient, the resident stepped past the nurse. When she glanced at me, I registered no indication of recognition or familiarity on her face. She positioned herself next to the bed, just behind Andy and beyond his line of sight. I watched as she exchanged a quick look with the nurse, and then abruptly drew her body adjacent to Andy's. Reaching out her arms, her hands landed on Andy's arm and shoulder, positioned as if ready to reduce the dislocated glenohumeral joint. Surprised by her touch, Andy let out a yelp and pulled away, his dominant arm (the injured one) folded into his chest like a wounded bird wing. He scowled over his shoulder at her, “What are you doing?!”

With her eyebrows raised, the resident glanced over at the nurse and asked, “Did you see that? He just tried to hit me.” Not looking at him, she slowly stepped away from Andy and folded her arms across her chest. Without having fully absorbed the disconnect between what I had observed – my boyfriend recoiling from an unexpected touch in an effort to protect his painful injury – and the resident's words describing an alternate scene, I kept smiling at both providers. It would take several moments before I realized that two strikingly different events had just taken place.

Several days later, I would learn from another ED physician that the resident had tried this surprise maneuver as a means of evaluating the authenticity of his injury. She had glanced briefly through Andy's medical record and noted his history of opioid use disorder. The mention

of methadone maintenance, of viral hepatitis infection, of past incarceration. She guessed that he had likely come to the ED in search of narcotics. Andy's injury was perhaps a fabrication, a manipulative attempt to receive a prescription opioid. For a drug seeker with a fake injury, the element of surprise might cause a disruption in their performance. If the resident began to adjust Andy's shoulder without notice or warning, he would be unprepared and thus unable to play the part of a patient undergoing a painful adjustment. But when the resident's surprise maneuver resulted in genuine pain and defied the resident's suspicions, her ideas about Andy's identity did not dissolve. While we had both watched his body react in response to her touch, we had assigned his movements two very different meanings. Her understanding of the story was not complicated by the mechanics of a shoulder dislocation (that would later, upon autopsy, reveal itself to be complicated by a rotator cuff tear). Medical students are trained that the patient with an anterior shoulder dislocation – and certainly the patient with a rotator cuff tear – will display limited range of motion in shoulder extension and abduction. These are the very motions it takes to hit someone, or to push another person away. But despite what X-ray findings would go on to confirm about the state of Andy's shoulder, the resident had assigned her patient a narrative before entering the exam room. Regardless, Andy's performance of pain, no matter its "legitimacy," had failed.

The Healthcare Experiences of Patients Who Use(d) Drugs

It should not be controversial to assert that stigma associated with drug use is common in medical settings and non-medical settings alike. But what does stigma actually look like? We know it exists, but it's when we try to describe the form it takes that people begin to take offense of some sort. By one definition, stigma manifests as pervasive stereotyping, prejudice, and discrimination.⁶ In reading an endless number of papers regarding the stigma associated with

drug use, there is one finding that I struggle to process the magnitude of: drug-related stigma is experienced as worse than discrimination based on race, sex, sexual orientation, poverty, incarceration history, or mental illness.⁷ And in some ways, this makes sense. This is the one form of discrimination that is structurally reinforced. There are laws that criminalize people for their drug use, and by way of this, laws that criminalize a class of DSM-V diagnoses. There are no laws that forbid discrimination against people who use substances recreationally⁷ but quite the contrary – there are new laws routinely entertained that permit new means of discriminating against such individuals.

The healthcare setting is routinely identified as a site where internalized stigma manifests and is expressed. The epidemiologist Dr. Robin Pollini and clinical psychologist Dr. Catherine Paquette conducted ethnographic interviews with people who use drugs, finding a general preoccupation with past experiences of judgement or poor treatment from medical providers and cataloging stories of drug users who felt they were treated “poorly and with disdain,” being given “dirty, snotty looks,” “being looked down on,” being “treated like garbage,” or receiving substandard medical care as a direct consequence of their drug use history. Paquette and Pollini observed that this led drug users to fear medical providers learning about their drug use (former or current) and to believe that drug use “marked” them as “second- or third-class citizens” whose lives were believed to be less valuable than the lives of other patients. The study found these experiences to be routine and universal among the participants and documented that over time drug using patients became increasingly avoidant of healthcare, ultimately choosing not to seek care even in cases of emergency.⁷ Ultimately, the experience of discrimination creates a sense that healthcare settings are unsafe and healthcare providers untrustworthy.⁹

Much of the anxiety that Andy felt in the moments before we entered the hospital that night – the anxiety that magnified his shoulder pain – stemmed from the experience of receiving judgement or discrimination within a medical setting. There were the “weird looks.” There was the time that he woke up in the hospital following an accidental heroin overdose and was told by the attending physician that he did not deserve to have lived. In every story about the experience of stigma is the sense that it becomes a sort of death by one thousand tiny cuts. While each experience may be minor in and of itself, the additive effect is a permanent and significant wounding. For Andy – and any other patient with an established history of drug use - to associate injury or pain with the act of revealing their drug use, then a logical avenue for avoiding harm involves obscuring information. Lying to providers about one’s drug use is not a reflection of a desire to manipulate or deceive but is a strategy for self-protection and a tactic to avoid the harms of stigma.⁹

When patients with a history of drug use report stigma and discrimination in health care, it may be natural for medical providers to assume that a misunderstanding has occurred. But physicians are human, and thus influenced by subtle and overt socio-cultural messages that can lead to the formation of judgements and implicit biases. Healthcare providers are not immune to the pervasive social stigma that surrounds illicit drug use.^{9,10,11,12} And so while we may want to assume that the experience of stigma exists solely in the imagination of our patients, a large body of research confirms that what healthcare providers believe about drug using patients matters – a lot. The largest literature review of physician beliefs regarding drug using patients found that physicians by and large believe that patients with such a history are a) not trustworthy, and b) unreliable.¹² In other studies, physicians use words such as “manipulative” or “deceptive” to describe drug using patients,¹³ in addition to “unreliable” and “untrustworthy,”¹⁴ believing that

such patients frequently lie in order to gain access to narcotics.¹³ Maybe most concerning, but also illuminating in the case of Andy's own experience, is the degree to which physicians believe drug using patients to be dangerous - prone to outbursts of aggression and physical violence and a threat to the immediate safety of healthcare providers.^{7,9,11,12,13} But out of all of this, what I find most interesting among this research is the question of whether or not physicians *like* working with patients who use drugs. Do doctors *want* to spend their time taking care of patients who might sometimes put a needle into their arm? Who might have intimate knowledge regarding the types of substances one needs to apply heat to before drawing up into a needle, or the substances one can just let dissolve in water, no heat required? The answer is a resounding *no*.^{10,11,12} Which introduces a new question: does it matter? The answer to this, apparently, is a resounding *yes*. Rather than existing only in the imaginations of physicians, these negative attitudes and beliefs play a significant role in how stigma causes harm.

It is one thing for a physician to prefer caring for certain patients over others – in many ways this is inescapable. There is nothing inherently problematic about enjoying the experience of caring for some groups of patients more than others. But these preferences take on new significance when they begin to impact quality of care and ultimately, health outcomes. Physicians' general disregard for drug using patients transforms from a harmless preference into a set of beliefs that influence diagnostic and therapeutic decision-making. In this process of transformation, ideas – or, in the context of stigma, judgements - permutate into choices and actions. Several studies,^{18,19,20} beyond the scope of this essay, suggest that physicians' negative attitudes towards drug using patients influence the care they give in multiple ways, but most significantly, lead to underdiagnosis and undertreatment of physical health issues among people living with mental health and substance use issues. The resulting escalation of physical health

issues not only prevents early intervention, it also contributes to an increased risk of emergency situations, adverse events, and premature death.^{9,16,17}

The Power in Sticking to a Single Story: Delusion, Danger, and Disease

As Andy and I waited in the exam room waiting for something to happen, I noticed his nurse in the workstation across the hall. Talking to a colleague, she made an audible mention of “hepatitis C.” I listened harder. Perhaps unaware of the ease with which we could hear her from the exam room, she told another nurse that with an aggressive patient like Andy – one who had reached out to strike a resident – she would be take no chances of being stuck with a needle and exposed to hepatitis C. Andy would receive an intra-nasal dose of medication, rather than a more standard intravenous dose. A recent note in his chart reported that Andy had been cured of hepatitis C, but I guessed it would make little difference if she knew this. Her fear was not unique, but part of an established historical pattern.¹⁷ The association of injection drug use with HIV and hepatitis has long given added meaning to these viruses, but for some – including healthcare providers - it has justified an idea that the bodies of queer and drug-using individuals are not just abnormal, but dangerous.¹⁷ For Andy, this added yet another layer to the story being written for him.

When the attending physician, resident, and nurse arrived back at the exam room together, Andy and I made a series of attempts to shift the interaction. I smiled and made eye contact with each provider, apologizing for Andy’s grouchy mood. I asked what medication would be administered prior to reducing his shoulder and suggested that because of his former opioid dependence, he would require either a non-opioid analgesic or an adjustment to the dosage of an opioid. I hoped that my transparency about Andy’s history of drug use and knowledge of narcotic tolerance / dosing might signal, “We are honest, we are *like you!*” But I

was naïve in thinking that any physician would ever consider themselves *like* someone with a substance use disorder history.

The attending physician explained the steps Andy would take to administer a medication to himself via his nostril. Pausing, Andy asked if he might be able to know the name of the medication he was to receive.

“Midazolam,” the doctor said, seemingly annoyed and bothered by his question.

When he asked if they planned to give him an analgesic, she replied that the midazolam was for pain. Andy’s brow furrowed in genuine confusion – he did not understand the mechanism through which this short-acting benzodiazepine might decrease the firing of nociceptors causing pain in his shoulder. Andy was gentle with people and had an uncomplicated desire to understand anything about which he was not knowledgeable. He looked up at the attending physician and asked, “Why not give me the meds through an IV? It would be faster absorption, right? To bypass first-pass metabolism?” While he wanted to understand the clinical reasoning, he may have also wanted to demonstrate that he was not ignorant. He wanted to be actively informed, rather than a passive body on which unexplained interventions were done. But when the attending answered, I knew that we had failed to exorcise negativity from the interaction. We had revealed information about ourselves in the hope that the doctor would come to see us as *‘like her.’* But in that moment, we were so dissimilar that we may have been barely human. She delivered her response via a cold tone that conveyed authority and explained that “as a physician [she] would know about first pass metabolism.” Towering over a seated Andy, she signaled to the nurse to hand him the medication.

The benzodiazepine took affect quickly, and Andy began to relax. The resident moved into place to perform the shoulder reduction as the attending gave feedback. I held Andy’s hand.

He held his breath and grimaced as his humerus slipped back into its normal position. The sharpness of the pain dissolved quickly, causing a small smile of relief to converge on his face. His shoulder was sore, but better. The attending left the room, and I asked the resident about next steps. What would provide adequate pain control for the evening? Would Andy need follow up care, given his past history of surgery on the shoulder, and history of repeat dislocations? She suggested ibuprofen and exited the room, the remaining questions unaddressed.

Leaving the hospital, Andy's irritation had not fully subsided, "I should have known better than to go in there. Should have just put it back myself. They didn't give me anything for the pain, which was the *only* reason we even went there in the first place. What do they really think one hydrocodone is going to do to me? Honestly?! One pill is not going to get anyone high. Jesus if I wanted to get high, I'd go and buy a bag. I wouldn't choose to pay thousands of dollars more and sit in a hospital being humiliated..." The evening's visit would be Andy's second to last encounter with the healthcare system. Eventually he would return to the same hospital, but in a body bag. This time, he would be taken to the basement, where the medical examiner and three of my classmates would perform an autopsy.

On the day following the ED visit, his shoulder would dislocate again as he opened the refrigerator door. But the experience of the night before would hover at the edge of Andy's conscious, and he would attempt to reduce the shoulder himself, stealing himself against the pain until the bone slipped back into place. Over the days that followed, this would become a pattern: first the humerus dislodging from its cartilaginous home, then a relentless and severe pain, followed by a painful maneuver to place the bone back in the correct location. Once established, the pattern increased in frequency and was repeated four to five times each day. The severe pain, however, would not resolve. Even when in its correct anatomical position, the shoulder hurt.

Each day, he would consider returning to the hospital. But the pain left him exhausted and on edge, unable to entertain the prospect of repeat disbelief. Within a matter of days he would become desperate, secretly buying a small plastic bag of grey powder from a friend and shooting it into his arm. The heroin, in many ways similar to morphine, would give him a few moments reprieve from the pain, sometimes enough to sleep. It was a temporary solution, meant to last only until a surgical fix could be found.

Other People's Pain

As physicians, we make a moral choice about how we will approach the pain of other human beings. We set out with the simple idea that we will attempt to alleviate all pain, struggling to imagine ourselves as people capable of doubting or disregarding any patient's suffering. This desire to soothe the pain of others comes from a capacity to imagine the pain as our own: as humans, we are arguably hardwired for empathy. Mirror neurons in the brain's prefrontal cortex and insula allow us to observe a person experiencing pain and to understand or imagine it by activating pain sensations of our own.^{23, 24} The brain is, by default, primed to represent others' pain as our own pain.²⁴ But this process can fail or be disrupted. Mirror neurons are typically activated in response to human, but not animal, actions.¹⁹ Empathy is not produced if the brain does not believe what it's observing is real.²³ We feel the pain of others only when we believe it to be credible or see the other person as like us – as human.

This is what fundamentally gives stigma its powers. The association of drug use with deception lends itself to disbelief, while the link to criminality establishes a sense of separation and dissimilarity. Ultimately, this disrupts our very capacity as physicians to respond to the pain of others. Patients who use drugs or experience addiction come to wear so many markings of

difference and be linked so closely with disbelief, **that any expression of pain is interpreted as if originating from a non-human object and is effectively rendered invisible.**

An interruption in “normative” cognitive processing inhibits our capacity for recognition of a person in pain, and the formation of an empathy-based response. What is it that allows our brains to establish a kind of shield and not allow this process to occur, beyond the mechanisms through which an established sense of stigma transforms human into non-human? The story telling process in which we are engaged from our earliest moments begins to offer up the images and ideas that will subtly inform how our psyche stitches together a full narrative of who and what people who use drugs are, constructing a story that blends Reagan era archetype with more modern belief systems about criminality and deviance.

The consequence of the identity that was assigned to Andy by three health care providers is not one that can be attributed to physician burn out, resident sleep deprivation, or lack of *professionalism*. The investment in an idea that some patients’ pain is more or less real than others’ – and a presumption of authority that allows physicians perform secret tests of legitimacy – combined with open confirmations of a general disregard for the essential human-ness of certain patients, should be cause for the dissolution of the full theatre of medical professionalism. Healers pick and choose among their patients, requiring some to present evidence to support their worthiness. For others, they are unwilling to acknowledge the efforts of the patient to secure their (the physician’s) concern or belief. Such failures to reconsider the narratives placed upon the patient can produce consequences that are severe and profound. Ultimately, it appears seemingly unimaginable for practitioners of medicine to consider a resignation from their role as authorities of pain. Dealing in the legitimacy of another human being’s internal and subjective experiences of suffering is not the work of healers, but part of a world that values the use of

judgement and punishment. Although the punishments performed by the profession of medicine may be opaque or non-linear, their consequences may be profound.

On the morning of March 5th, I left for the hospital before 4:30 AM. I said a silent goodbye for the day to Andy, who had fallen asleep in a chair next to his computer. Around 3:00 PM, he was found in the same chair. The toxicology report would identify the cause of death as a “mixed substance intoxication” due to morphine (the metabolite of heroin) and etizolam.

The night before, Andy came home late from work. While I slept, he left me a voice message: He said that his shoulder hurt. He was exhausted. He felt tired of being told he was worthless. And last, “I love you very much, good night.”

REFERENCES

1. Goffman, Erving. "Stigma: Notes on the management of spoiled identity." Touchstone Books, 1963.
2. Kleinman, Arthur. *The Illness Narratives: Suffering, Healing, and the Human Condition*. Basic Books, 1988.
3. Scarry, Elaine. *The Body in Pain: The Making and Unmaking of the World*. Oxford University Press, 1985.
4. Bourke, Joanna. "The story of pain: from prayer to painkillers." 2017.
5. Wailoo, Keith. "Pain: a political history." Johns Hopkins University Press, 2014.
6. Link, Bruce G., et al. "Public conceptions of mental illness: labels, causes, dangerousness, and social distance." *American journal of public health* 89.9 (1999): 1328-1333.
7. Paquette, Catherine E., Jennifer L. Syvertsen, and Robin A. Pollini. "Stigma at every turn: health services experiences among people who inject drugs." *International Journal of Drug Policy* 57 (2018): 104-110.
8. Biancarelli, Dea L., et al. "Strategies used by people who inject drugs to avoid stigma in healthcare settings." *Drug and alcohol dependence* 198 (2019): 80-86.
9. Urbanoski, Karen, et al. "Defining culturally safe primary care for people who use substances: a participatory concept mapping study." *BMC Health Services Research* 20.1 (2020): 1-12.
10. Brener, Loren, et al. "Challenging stereotypes and changing attitudes: Improving quality of care for people with hepatitis C through Positive Speakers programs." *Psychology, health & medicine* 18.2 (2013): 242-249.
11. Merrill, Joseph O., et al. "Mutual mistrust in the medical care of drug users." *Journal of General Internal Medicine* 17.5 (2002): 327-333.
12. Van Boekel, Leonieke C., et al. "Stigma among health professionals towards patients with substance use disorders and its consequences for healthcare delivery: systematic review." *Drug and alcohol dependence* 131.1-2 (2013): 23-35.
13. McCradden, Melissa D., et al. "Ambiguous identities of drugs and people: A scoping review of opioid-related stigma." *International Journal of Drug Policy* 74 (2019): 205-215.
14. Fox, Lindsay, and Lewis S. Nelson. "Emergency department initiation of buprenorphine for opioid use disorder: current status, and future potential." *CNS drugs* 33.12 (2019): 1147-1154.
15. Tsai, Alexander C., et al. "Stigma as a fundamental hindrance to the United States opioid overdose crisis response." *PLoS medicine* 16.11 (2019): e1002969.
16. Avery, Jonathan D., et al. "Attitudes Toward Individuals With Mental Illness and Substance Use Disorders Among Resident Physicians." *The primary care companion for CNS disorders* 21.1 (2019).
17. Brener, Loren, William Von Hippel, and Susan Kippax. "Prejudice among health care workers toward injecting drug users with hepatitis C: Does greater contact lead to less prejudice?." *International Journal of Drug Policy* 18.5 (2007): 381-387.
18. Mendiola, Cecelia Kathleen, Giorgio Galetto, and Michael Fingerhood. "An exploration of emergency physicians' attitudes toward patients with substance use disorder." *Journal of addiction medicine* 12.2 (2018): 132-135.
19. Mamede, Silvia, et al. "Why patients' disruptive behaviours impair diagnostic reasoning: a randomised experiment." *BMJ Quality & Safety* 26.1 (2017): 13-18.
20. Ding, Lin, et al. "Predictors and consequences of negative physician attitudes toward HIV-infected injection drug users." *Archives of internal medicine* 165.6 (2005): 618-623.
21. Jones, Simon, Louise Howard, and Graham Thornicroft. "Diagnostic overshadowing: worse physical health care for people with mental illness." (2008).
22. Bink, Andrea B. "Stigma and Discrimination in Behavioral and Physical Healthcare Settings." *Commissioned Paper for the Committee on the Science of Changing Behavioral Health Social Norms*. Illinois Institute of Technology (2015).
23. Murrow, Gail B., and Richard Murrow. "A hypothetical neurological association between dehumanization and human rights abuses." *Journal of Law and the Biosciences* 2.2 (2015): 336-364.
24. Lamm, Claus, and Jasminka Majdandžić. "The role of shared neural activations, mirror neurons, and morality in empathy—A critical comment." *Neuroscience Research* 90 (2015): 15-24.