



All of my previous trips to our nearby hospital have been marked by blood and bruises. As an especially clumsy individual, I'm used to squeezing paper towels tightly around gashed fingers or pressing ice compresses to a purpling forehead, blinking with the unfocused eyes of someone definitively concussed. Accompanied by my wonderful partner, I am also used to occupying the passenger seat—the designated space of the care-seeker—on these short, 15-minute journeys to our local emergency room. On our recent late-night venture to the hospital, though, I was behind

the wheel, my partner silently agonizing next to me. The glovebox was undisturbed; we had no need of napkins for staunching this time, as there were no obvious signs of trauma. He held his torso all the while, trying to contain his discomfort, and I remember thinking that surely this was an over-reaction to an upset stomach. As Elaine Scarry theorizes, “to have great pain is to have certainty; to hear that another person has pain is to have doubt” (Scarry 7). Indeed, glancing over at my partner as I sped toward the hospital, I was made acutely aware of the separateness of our bodies, his pain unrealizable to me, lodged as it was in the interior of his otherwise unchanged flesh like “some deep subterranean fact... not yet manifested on the visible surface of the earth” (3).

Believing, foolishly, that our hospital trip would be relatively short-lived, my partner and I had packed nothing. Though he was experiencing acute abdominal pain and an inability to eat, we were certain we would return home sometime later that evening, barring a ruptured/rupturing appendix scenario. We checked into a surprisingly quiet emergency room. Regardless, we sat for hours waiting for attention.

To subdue my own anxiety and stimulate any conversation that might distract us from frenzied googling of misdiagnoses, I tried to draw words out of my partner: descriptions of the cramping feelings, a timeline of changing symptoms, assurances that our health coverage could handle the barrage of tests we might face... He struggled to categorize the severity and sensations of this pain, as it came in great waves and fled just as quickly. Is it burning, shooting, throbbing? Can you point to where it hurts? What positions afford relief? Real-time body knowledge is made imprecise by its very articulation, it seems, rendered disputable as soon as it is spoken. Around the time I discerned the unhelpfulness of my inexperienced badgering, the hospital staff made me relocate to a separate waiting room to adhere to COVID-19 protocol. My partner and I agreed later that waiting for care and news, respectively, in solitary silence was altogether worse.

In her poetic rumination on the complicated nature of using formal pain assessments, Eula Biss remarks on the cruel simplicity of attempts to capture our immediate bodily sensations. She laments that preset adjectives and scales refuse to account for duration, the feeler’s history of pain, psycho-emotional duress, or the flattened function of 1-10 rating systems thanks to the “tyranny of the mean” (Biss 15). The communication breakdown between my partner’s gnawing pain and its interpretation began here, upon our entry into this evaluative space wherein an individual must be molded to a rule. According to Foucault’s work on clinics, the medical perspective demands transformation of observable signs of symptoms into signification of disease through scientific verification, declaring itself the sole arbiter of the body’s truths as it affirms “a pathological state, a morbid essence, and an immediate cause,” cleaving away all other explanatory mechanisms and deviations from the norm against which a case is read (Foucault 90).

Over the course of the next three days we ultimately spent at the hospital, we felt largely unheard, as determination of an undesirable treatment plan seemed to take precedence over my partner’s individual circumstances and the increased pain caused by said treatment. Still, we craved the security of labels that providers could offer, even if such identification felt ill-fitted. Given our many disappointing interactions in both the emergency and in-patient units, it was tricky to determine

whether the medical frameworks and language of diagnosis, intervention, and healing helped generate clarity around my partner's illness or instead disrupted the authority of his own perspective as that most proximate to the source of pain. In what turned out to be an idiopathic case in which hospitalization actually engendered further erratic fluctuation of symptoms, the clinical voice here offered us rather little, though I can't blame any one party. As neither patient nor provider but liaison between the two, I was also privy to (and sometimes responsible for) the many complicating narratives that arose.

After several CT scans, x-rays, and stomach palpitations, my partner was told he was experiencing an abdominal obstruction and would need to be admitted to overnight care. Between our arrival at 7:00 PM and his relocation to an in-patient bed around 4:00 AM, we barely understood what was happening, interacted sparingly with doctors, and minimally received means of easing the pain. Additionally, if I thought witnessing the person I love most in the world grapple for hours with both physical pain and unbridled speculation about his future was difficult, then witnessing the person I love most undergo treatment that ostensibly worsened his condition was excruciating. In her memoir *The Cancer Journals*, Audre Lorde describes her hesitancy to pursue a biopsy, arguing that medical intervention to counteract pain often only begets more pain and disease (Lorde 31). I relate to this uncertainty now. The insertion of my partner's nasogastric tube was of course standard practice for a non-surgical obstruction case. But in our memories of this hospital stint, it came to represent instead the primary source of harm, exacerbated by the fact that no one could tell us how long the treatment should take or what normal output for the conduit might be.

Our long night became several long days. The NG tube induced extreme vomiting, unalleviated fatigue, intense throat discomfort, and an inability to swallow or talk. I watched my partner get steadily weaker, far sicker than when we had arrived, and thought of the notion of "curative violence" in which treatment resembles Derrida's *pharmakon*, hovering somewhere between poison and remedy (Kim 14). He spent three days without food, without movement, without being able to verbalize any questions. Flawed and distressed translator, I pressed where I could to no avail. Though I am not a physician, it was abundantly clear that the torturous device was vacuuming out only air, my partner's stomach already cleared of the obstruction. After three days of tube micro-adjustments and repeatedly delayed moments of evaluation despite our protests that intubation was now needless, injurious even, we were left totally deflated, still sans diagnostic language upon which to cling for comfort.

Alison Kafer reminds us that "curative time" can feel harmfully contradictory toward the body's rhythms in the wake of disease and disability (Kafer 27, 28). Indeed, I have become deeply skeptical of the value of elongating painful, seemingly ineffective intervention for the sake of protocol. Adherence to the slow pace of rehabilitation here seemed ridiculous against the sense of urgency we felt noticing how treatment only aggravated symptoms instead of mitigating them. I wonder now, too, who qualifies as the true source on an illness narrative if no nurse or doctor has come by for an observation in hours, yet the patient and bedside visitor have monitored every labored breath?

By all accounts, our three days at the in-patient unit amounted to a somewhat routine hospital stay. Our nurses were very polite. The room set-up was tidy and spacious. My partner and I are privileged with backgrounds and resources that make medical language accessible to us. And yet I could not help but perceive the many structural flaws and communication barriers that made this experience so *inhospitable*. If the patient is intended to play an agentive role in his treatment, then why did the unwanted tube feel like a disabling punishment, a measure based purely on procedural norms against which rebellion was both discouraged and made physically impossible? In the end, we felt too that the only advised remedies emphasized preventative choices and were largely unrelated to my partner's habits: don't consume too much rice; eat more slowly; hydrate constantly... Particularly when care employs recourse to moral scolding and simultaneously produces a physical state of unfreedom in patienthood, the long history of hospitals as hierarchical sites—with all the baggage of systems which perpetuate blame, suffering, and detention—comes into greater focus. This sense of damaging neglect and reprimand were the prevailing sentiments from our hospital visit, though I am not unappreciative of the small kindnesses we saw, too.

I am reflecting on these three days not only because they were severely shocking to us, as two people who had imagined ourselves shielded from hospital-worthy health crises by the protective layers of age, fitness, financial stability, genetics, and sheer dumb luck, but because this experience has given me insight. (And because I now have practice sharing this story with the many people in our lives who have asked for it, which is a good reminder of the importance of recognizing interdependent care networks, as espoused by disability thinkers).

In a sense, as the health humanities demonstrates, there's a very real catharsis in writing about and attempting to characterize medical experiences, even those in which we are but bystanders. In coming face to face with the absolute unknowability of my partner's pain—its origin, its transformation and exacerbation, and its curious recession a week or so later—I have developed new lines of questioning about the personal and interpersonal dimensions of clinical care. If, as Biss says, we remain “devoid of any standard criteria as to what constitutes suffering,” then in what ways does “assigning a value to pain” constitute “a political act” (22,12)? And, what are the power dynamics of a negotiation over how to act in response to such pain?

For me, what might have been simply a lesson in attending carefully to the aches of our bodies and others' bodies (I'd say listening to our guts, but perhaps it's too soon) became simultaneously a lesson in heeding and questioning the language and actions we encounter in clinical environments. At its core, medical intervention does not necessarily guarantee pain mitigation or healing, and the control over its implementation, timing, and potential refusal remains a point of worthwhile dispute—an assertion toward which disability theorization on curative imperatives and the drawbacks of medical intervention helpfully directs us.

My partner and finally went home three days after our initial drive to the hospital complex, eager to see our cat and enjoy prolonged states of sleep. We looked nearly the same as when we had

arrived, if somewhat haggard; a plastic identification band and scattered needle marks were the only signs of what my partner had undergone. We did not feel the same as before our trip.

At home, the abdominal issues persisted for a number of days, though not to an extent warranting a second hospitalization. As we contemplated what kinds of necessary changes we might need to make in our lives, how to go about seeking a medical specialist, and what counted as “normal” or “abnormal” pain during this window of no guarantee, we charted a new relationship to the categorical markers of physical difference, the materiality of my partner’s bodily discomfort threatening to give way to a new future dominated by chronic gastrointestinal issues. In that I recognize the harm in framing changes to the body’s particularities as fearful is perhaps a testament to the advocacy which encourages us to view disability as both an embraced, felt reality and a problematic cultural construction. I had already begun to adopt and really accept this attitude—though body anxiety worms its way in occasionally—when my partner’s symptoms mysteriously subsided a few weeks later. I will say, my vision of a future in which he and I might successfully navigate together health crises *and* a shift from pathological thinking to mutual care for each other’s variable needs is an improved and profoundly grateful one. Nonetheless, I do not wish for our return to the hospital any time soon.

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