


# What we see when we digitize pain: The risk of valorizing image-based representations of fibromyalgia over body and bodily experience

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## Abstract

Fibromyalgia is chronic pain of unknown etiology, attended by fatigue and affective dysfunction. Unapparent to the unpracticed eye or diagnostic image, it is denied the status of “real” suffering given to visually confirmable disorders. It is my customary mode of existence: a contingent landscape of swinging bridges that may or may not give way, everything a potential threat or deprivation. I don’t express it within the framework of acute pain, but I am evaluated by traditional biomedical standards anyway.

Ultimately, the diagnostic image of pain, and the medical and academic discourse used to interpret it, determines my functionality. Such a stance dismisses bodily senses and alternate ways of knowing in pursuit of the ocularcentric objectivity promised by digital health technologies, whose vision remains chained to the interpretive, discursive strategies of human operators and interpreters.

A new poetics of pain is critical not only for rewriting the dominant metaphors that construct and delimit our imaginings of pain but also for rewiring the use and reading of digital technologies, wherein the digital image becomes the new site of the hermeneutic exercise, even when the suffering body lies in plain view. This facilitates a failure to listen and touch in patient care, and the imposition of a narrative based on visual evidence, translated into sanitized language, at the cost of intercorporeality.

If pain strips sufferers of a voice, my body and its affects should be allowed to speak.

## Keywords

Fibromyalgia, diagnostic imaging, narration, metaphor, affect, hermeneutics, pain, pain management, patient care, autoethnography

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## What we suffer is voicelessness

We tell stories to make sense of the world, so it makes sense to begin with one.<sup>1</sup>

September 18, 2014.

I have been in the hospital for an afternoon and night over what will later be identified as a fully ruptured appendix that has been bleeding into my abdomen for at least one month, possibly seven. Right now I am braced on a gurney, one step away from four-point restraints with the way the nurse is holding me down, as the OB/GYN radiologist pushes the transvaginal ultrasound probe inside. The pain I’ve been incubating as just another spoke in the wheel of

chronic pain derails into hysteria. The OB/GYN ignores my frenzy to escape and wiggles the camera deeper, repeating “What is that? What *is* that?,” first with the fascination of finding an anomaly, then irritation that she cannot give it a name.

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I'm cringing up the gurney as the camera's head interrogates all the hard, tender places that prompted a visit to my internist today, that prompted her to order diagnostic imaging tests, which were described to me in surprisingly metaphoric language: "Your pelvis looks like a bomb went off. How are you even standing right now?" I was sent to the emergency room, where the male physician's assistant who admitted me half-listened to me explain that I have fibromyalgia, that I hadn't eaten in weeks, that my bowels were hard and rebelling, that death was preferable to the abdominal pain. He wrote something down, then told me it was pelvic inflammatory disease, or PID, the infection of the cervix by untreated venereal disease. I wasn't sexually active, and said so. He assured me it wasn't linked to sexual activity but asked repeatedly if I was having intercourse, or pregnant. He ordered an ultrasound I didn't think I needed. He told me, "It's the only way to be sure."

I knew he was wrong, but who was I to protest? An unreliable narrator, already suffering from an unreliable disease.

The OB/GYN scolds me for not holding still. Every new twist of the camera wrings from my pelvis new green waves that rise into my mouth like vomit. I can feel, inside, the alien thing she's bruising with it, and I can't stop the screams, which kill me afresh as my diaphragm pushes down. It's a vicious cycle I can't explain when she asks, visibly exasperated, "*What hurts?*"

*Everything* is not the right answer, and I am not rewarded for it.<sup>2</sup>

In the end, she can't get a clear picture, and I'm wheeled away like a recalcitrant little girl who won't learn her lesson, uncontrollably sobbing because fibromyalgia means this pain will echo in me for days.

It's worth mentioning she spent the entire exam staring at her screens, didn't acknowledge my hysteria, never once palpated me, or looked me in the eye.

This, I think, is the lesson.

That the image, and the bland discursive representations it spawns, is everything. My body was abandoned in the rush to find visual proof, wrenched from direct touch, affective assessment or anything I said.

### If you're looking for an argument, this is it

In the series of provocations that follows, one contention inheres in the form: that we should restore other ways of sensing to social science and biomedical scholarship if we are to uphold the cultural studies imperative towards multivocality and a diverse range of genres and practices of meaning-making.<sup>3,4</sup> Otherwise, we risk stagnation, homogeneity, and the exclusion of populations with different ways of accessing and sensing the world.<sup>5</sup>

The primary thread interrogates the ways in which increasing biomedical reliance on vision to identify and assess fibromyalgia comes at the expense of non-digitized senses that have received less attention, such as direct, skin-to-skin touch, or listening and auscultation, which are threatened by the ultrasound, where the physics of sound is harnessed to produce an allegedly more objective image.<sup>6–8</sup> Within this framework, pain in the fibromyalgic subject becomes an ocular diagnosis, and one that must be machine-detectable in order to be confirmed.<sup>9</sup> As the diagnosis is frequently based on a pressure test, fibromyalgia is very much a tactile disorder, usually treated with a combination of medication and physical therapy that privileges massage.<sup>10</sup> If it is locatable anywhere, it is in the fascia, the web of connective tissues encasing muscles and organs of the body, which can be directly palpated but is only visually accessible during dissection.<sup>11</sup>

The problem occurs when clinical practitioners, overenthusiastic about the prospect of infallible vision and certainty about a subjective phenomenon like pain, attempt to extricate the human senses as much as possible from digital health technologies, minimizing doctor-to-patient contact and upholding diagnostic imaging as objective truth. But this pretends it's not a human eye interpreting the final digital image.<sup>12,13</sup>

An interpretation unanchored in the patient's bodily experience, a richer affective site for clues than the objective image, risks mismanaged care, up to and including, as with me, the possibility of death.

This ocularcentrism asks me to leave my body behind in both patient narration and academic scholarship about pain, even though pain emerges and is made sense of through intersubjectivity, using modalities other than sight and the language of a positive science: through vectors that, like language and pain, are affective, corporeal, co-constructed, and contagious.<sup>14,15</sup>

The language we use as scholars, physicians, artists is mutually reinforcing. If I continue to write about pain in scholarly publications in the script of able-bodied normalcy, I am not innocent of the system in which I am enmeshed.

### When we say it hurts, imagination pales

I am diagnosed with fibromyalgia in 2007. It is conferred like a high honor, but it's not really a reward. Fibromyalgia is an idiopathic, poorly understood condition that is—even in prominent clinics—still considered an illegitimate diagnosis because it is etiologically mysterious, or because it is stereotyped as the diagnosis of physicians too green to make a "real" determination.<sup>16–19</sup> Unlike other auto-immune diseases like cancer, multiple sclerosis, or Chiari, fibromyalgia

remains inscrutable to interrogative techniques like diagnostic imaging.<sup>20,21</sup> It is a world where *I'm fine* means *It hurts*, and *It hurts* means *The minutes pass like death*, and *You look so well, how could anything be wrong with you?*

Like a hypochondriac's wet dream.<sup>22</sup>

Whereas credible conditions may take chronic pain as a symptom, fibromyalgia has no referent but chronic pain, and pain, as Scarry has observed, resists objectification, is subjective, interior, inarticulate as a dormant volcano.<sup>23</sup> The image of the body itself, as Crawford has noted, "manifests in relation to and by means of a co-constitutive and ever-dynamic process with others and objects, and as such is characterized by an essential mutuality and openness, intersubjective, irreducible to uncontested stigmatization."<sup>24</sup>

The body's pain is not homogeneous. It is historically contingent and socially constructed.<sup>25</sup> Where pre-anesthetic societies affirmed pain as an inescapable and admissible phenomenon, contemporary biomedicine renders pain eradicable and therefore unacceptable. Modernity's confrontation with the spectacle of pain, and of deviation from its presumed norms, is characterized by repulsion.<sup>26</sup>

In the face of oclularcentrism, we are still pressured to suppress the affective transmissions of pain.

Medical and social failures to read and address pain hail from viewing it as purely biochemical, temporary, oclularnormative, and repugnant.<sup>25</sup>

Pain is biological, but the stories we tell, the images we make, and the discourse we distill determine whether we will address, ignore, or misconstrue it.<sup>27</sup>

Without the diagnostic image, the objectivity and medico-cultural authority of the technological eye, the legitimacy of fibromyalgia rests on "a single partially objective sign—tenderness on palpation."<sup>19</sup> The diagnostic standard in 2007 was that 11 out of 18 points on the body experience unbearable intensity under relatively light pressure, administered by direct touch or a dolorimeter. With the dolorimeter, I tested positive for 17. As I don't outwardly grimace or wince, I had to perform an externalization of my lived experience, a kind of disability masquerade to visually and vocally demonstrate physician expectations of pain I feel regardless.<sup>28</sup> A kind of becoming public, in which deviant bodies emphasize themselves as voyeuristic objects, making themselves distinct to be normalized as such.<sup>24</sup>

There were places I felt pain that weren't even broached. They didn't fit the diagnostic model, and they didn't look like they hurt.<sup>29</sup>

This is the effect of the camera's dehumanizing eye. A crisis of meaning I have to resolve on my own.

Classification is not without its consequences, and the prevailing, troubling assumption in pain classification is that temporary and chronic pain evince the same

symptoms, experiences, and articulations.<sup>30,31</sup> That, as with acute pain, site-specific examination of the fibromyalgic body will identify the ailment—the swelling, the trigger point—and, like good science, be able to reproduce the pain. That chronic pain is an aggregation of transient acute pain and should look similarly incapacitating.<sup>32</sup> That pain is a roar that cannot be ignored, an alien presence inexorably commanding our bodily awareness; thus, it has to be visible.<sup>33</sup> It's an attitude that fails to consider how sensory perception and manifestation change when pain is a normal, ordinary feature of existence, one I can't make visible as often as I feel it without threatening my social and professional stability.

Morris calls the rise in chronic pain a crisis at the center of contemporary life, throwing into sharp relief the problems of contemporary medicine: the blurring of acute and chronic pain in medical discourse, failures to appropriately interpret and classify pain, the implicit quest for perfection, which must end with an objective marker and a vision of recovery, and which reflects poorly on the physician if it does not.<sup>25</sup>

In short, I am not worth the effort.

It's not just that we need to see pain as biocultural, shaped by culture, its myths, and the work of meaning-making we sufferers do. We need to sense pain beyond seeing to fully understand it, and digitized oclarity, which strips the image of its affective intensities and potentials, is not the way to do it.

### Chronic pain is the only sane response to a world gone mad

We think of pain as a survival mechanism, a warning that the body is doing something wrong. Chronic pain is confusing and chaotic only because of this: biomedicine's Cartesian split between physiological pain and mental perception, like if it's not perceived, it isn't there.<sup>27</sup>

The acute pain favored by biomedicine and popular culture is pain that signifies. Chronic pain is pain that tells me nothing. Oceanic crashes that roll mostly below notice once I figured this out. It's a truth the clinic is unable to tell me because they don't accept its validity for themselves.

We look at chronic pain like it makes passive victims and superheroes, but to me it is like a perpetual car alarm that isn't mine. I have had *the worst headache of my life* a thousand times, all the warning signs modern medicine says not to ignore. In me it's just the sound and fury of a disabled body that can't keep up with the demands of my social and professional worlds, but is made to do so anyway.

Before I learned this, I was repeatedly told, with heavy sighs, "It's probably another flare-up."

The undertone was, *Stop wasting my time. There are patients out there who are really suffering.*

In September 2014, my internist scolded me for ignoring the signs, but why would I expect my pain to tell me anything?

Digital imaging is touted as my friend, my counsel, the thing that can help me figure this out by searching it out in the secret, dark spaces of the body I can't possibly put to voice. "Modern medicine works by making the body's invisible parts visible, and the culturally established confirmation of the primacy of the visual also extends to medical technology."<sup>8</sup> The computerized tomography (CT) scan and the transvaginal ultrasound, neither of which confirmed anything; the discursive interpretations that minimized my pain and indicated I was to blame. But also in March 2014, when I told a gastroenterologist that I had pain everywhere below the navel, and he lifted my shirt and glanced at my stomach, noted no distension, poked me in a couple of places while I waited patiently, soundlessly. He looked at my face, and ordered an abdominal ultrasound of everything above the midline.

Naturally, this found nothing.

In the words of van Dijk, "we tend to focus on what the machines allow us to see, and forget about their less visible implications."<sup>13</sup>

It's never really about the one-to-one digital reproduction of the human interior, the condition's validation. It's the subjective perception of the viewer, the interpreter, encoded into the production of the image, whether it's aesthetic or quantitative. After all, the interpreter can only speak in the languages they know, whether seeing or listening, which is shaped by social context and specialized knowledge, skill, and power too.<sup>6,13</sup>

Had I known in advance, I would have embodied their reading of my scanned body image, of a pelvis shredded by and studded with shrapnel, I would have howled like Perillos in the brazen bull, because without a conclusive image to corroborate subjective certainty, I am stranded, alienated from clinicians who point to these scans as incontrovertible evidence, and sit there waiting for me to disavow my pain.<sup>7,8,22</sup>

I need the "sick role" so badly.

At the end of the day, "the basis of postmodern medical thinking about pain is a distinction between acute and chronic."<sup>32</sup> Acute pain is transient, treatable, easy to endure with an end in sight. It should also reveal itself with a flinch, a scream, when aggravated, lay itself bare as a sensuous image, susceptible to repair.<sup>7</sup> As though enduring pain of greater temporality and intensity is impossible to even imagine, and must be impossible to keep hidden.

If all pain must be acute pain, chronic pain can't exist, not without visual validation.

If the myth of total transparency presumes that seeing is curing, then a pathology that isn't "visualizable" defies treatment.<sup>13</sup>

This lack of evidence is antithetical to scholarship, which seeks to prove something too.

We still imagine fibromyalgia as a pain that would get better if we could only get a picture, and validate it, and curb its contagion, because in our limited constructions of pain as an acute biochemical phenomenon, to live in eternal pain is unthinkable.

We are so used to stripping epistemology of the affective potential to touch another body that we don't blink at how the digital image of the interior body is described in sanitized jargon, as though it were any less qualitative or metaphorical than palpation or patient narrative.<sup>2</sup>

In the ER, my pain feels *zero at the bone*.

Emily Dickinson.

Medicine could learn from metaphor.

The risk is tainting a positive science with the naïve subjectivity of art.

The use of language, too, is an objectifying practice; objectification is the purview of all epistemological processes.<sup>8</sup> Where Scarry asserts that "physical pain does not simply resist language but destroys it," a chaotic suffering too excruciatingly immediate to narrativize, even the traditional metaphors of pain as weapon or wound arise from a phenomenological impetus to bestow agency on pain, to make it make sense.<sup>23</sup> We know our fragility from being in, witnessing, experiencing accidents or war. So my spine cracks like a gun going off, my headache is as piercing as lobotomy, my ruptured appendix like evisceration by rusty bayonet.

Traditional metaphor tells us to expect that physical states like pain are agents of war or entities within a person, where orientational metaphors like *up* or *down* connote *healthy and energetic* or *ill and dying*, or pain is something to be contained, with the possibility of being emptied when the container is upended, like a pain *in* the shoulder that goes away.<sup>33</sup>

Chronicity means I am happiest horizontal, pain is almost always referred from somewhere else, I always feel empty, I am always pushing through layers of congealed fat to reach you and all that improves when the pain lessens is the taste, rancid bacon grease or raw beef liver, help me decide which is worse.

It's metaphors that speak to ambiguity and collaboration that we need.<sup>15</sup>

Biomedical technologies render the body as an objective representation of an interior substrate and hypothesize it as internal reality, above and beyond what the patient's body and voice convey. But these technologies overlook the holistic physiological, affective, and emotional landscape of chronic pain sufferers, packaging us into statistical analyses that airily

correlate pain with an inflammation marker or elevated heart rate, which are common to many disorders anyway, and not unique determinants of fibromyalgia.

If anything, the senses should entangle further with technical interventions and the clinical discourse that translates them, always-already affective, because language does not stop being corporeal however much you strip it down, and our usual metaphors, expected and defanged, don't do much for chronicity.<sup>33</sup>

We need to recognize the limitations of standardized expressions of chronic pain and the network of bodies in which fibromyalgics and able-bodied subjects move, to start to dissolve the fixed distinctions between them, and to undermine discourses that frame chronic pain as isolating, unknowable, always suspect, and curable.<sup>27</sup>

Digital imaging is a form of monogeneric capture if nothing else is consulted before, during, after. These images "call on the patient to align herself with their reality, demanding to be read as factual evidence of a match between the inside of the body as 'specimen' and the inside of the body as the private and incontrovertible ground of experience."<sup>7</sup>

The cultural and visual logics of the diagnostic image align personhood (and rehabilitation) with the technological image and biological sample, not with the sensing sense-able body being imaged.<sup>34</sup>

Whatever the OB/GYN was seeing on the screen, she was seeing at the expense of properly sensing me, and her interpretation reflects it. So do the physician assistant's notes, which first state *confirmed diagnosis of PID*, authorizing the transvaginal ultrasound, even though the initial CT scan confirmed nothing, there was nothing but the fact that I was attractive, of childbearing age, and vehemently *denying* intercourse to suggest that I could have contracted it.

Seeing is intervening. It's not for nothing that van Dijk writes that medical-diagnostic interpretations are not univocal and are always value-laden, that medical technologies affect our conceptualization and representation of the body. It shapes our collective view on disease and therapeutic intervention, as dependent on objective visual evidence, and on what the interpreter privileges in her seeing.<sup>13</sup>

If I hadn't been in such pain I would have remembered to perform my pain visibly.<sup>28</sup> To keen like a wounded siren when McBurney's point was tapped.

After the ultrasound, the assistant's notes state *confirmed perforated appendicitis*. Even though that image confirmed nothing, either.

## We see anything we want to see without an anchor

Perception is a bodily structure, as we understand ourselves in the perceptual act not *as* bodies but as *being*

bodies, what Merleau-Ponty calls *Körper* and *Leib*, respectively.<sup>35</sup> "Visual perception is neither necessary nor sufficient, nor should it be raised as the normative example by which all other forms of perception are judged," but it remains the primary sense by which the world is laid out for us and is considered indispensable for the functioning of the mind.<sup>14</sup> In the clinical setting, the instruments that render bodies into discrete quantifiable data understand the body as *Körper*, the material object, not as "our general means of having a world."<sup>35</sup> The subject-body, *Leib*, is not just the bearer of sensations but the horizon of all experience, of all orienting capacities and dispositions, what the body senses it can and cannot do. *Leib* lets us consider that phantom limb or pain syndromes may be distortions in the body's sense of its own possibility, that the body image constitutes a kind of precognitive familiarity by the body of itself and its world.<sup>24,35</sup>

If my body "is my point of view on the world," and if perception is holistic and the subject-body constantly undergoing the distortions of chronic pain, this becomes its precognitive familiarity, the horizon it comes to expect. Its new normal.

No machine in the world could show you that.

But identifying and assessing pain, like everything else, is preconstituted by preexisting ways of seeing in our classified world. Classification, through ocularity and discursive representation, becomes essential to engaging with pain, as it lays the ground rules of pain's being, as a workable object around which biomedicine can organize.<sup>30,31</sup>

Here is a history.

Pathological anatomy was the foundation of medical thought, education, and practice in the 1800s. Dissection and medical pedagogy privileged this, peeling back the sticky folds of the body in search of anomalies, surgeons incising the body and illustrators depicting what they saw. These illustrations are a collage of viewpoints, medical, cultural, and aesthetic, depicting everything from fascia to coloration, often absent in contemporary medical imaging.<sup>36</sup>

It was the attempt to construct a collective empiricism, a "disciplinary gaze" under which "the mastery of scientific practices" could cohere.<sup>37</sup> And yet, artists drew realism with an artist's eye, evident in compositional factors like color, texture, gradation, size: choices that spoke to emphasis, focus, pathology, beauty, the fragility of life, the grief and wonder of death, and the cadaver's secret bounty. Still an imperialist gaze, it was nevertheless one refracted through aesthetic conventions. Illustrating the medical body was artisanal craft, passing through several pairs of fallible eyes and hands.<sup>36</sup> More still life than unbiased depiction, these images retained an affective power. You had to interpret them with the eye of a physician and a viewer of art.

But we end up with a preference for the uncolored woodcut images in the cornerstone of modern medicine, *Gray's Anatomy*, which are “authoritative but utterly devoid of personality.”<sup>38</sup> We lose affect in the biomedical image, and whatever remained in discursive translation, too, is slowly eroded away.

Diagnostic imaging gives us new tools and procedures for the management of the body, changing the foundations of knowledge production, distribution, and application, a response to the spreading notion that “scientific and medical image-making should, like so much else in the nineteenth century, be isolated from the bias and imprecision of human craft through automation.”<sup>36</sup> The image rendered through mechanical eyes is infallible, as the photograph is supposed to capture without bias and is presumed objective, authentic, and evidential.<sup>39</sup> The power to bestow authority on photographs comes from all the conditions of their production, circulation, and consumption within a particular social context, including accompanying text, interpretive standards, and so on.<sup>40</sup> In the clinic, the photo substitutes for patient experience, as the patient in “real” pain would have no voice, given the incommunicable dimensions of suffering, and, allegedly, is far more objective than an unreliable narrator. Diagnostic imaging amplifies ocularity to commute the mysterious inner workings of the body into objective matters of fact; thus, they are imbued with the power to legitimate disorders like fibromyalgia that are imperceptible or confusing to the senses.<sup>41</sup>

Biomedical authority is predicated on the use of technological instruments to make disorders visible while reducing reliance on the patient’s subjective evaluations.<sup>2</sup> But fallibility and subjectivity don’t just disappear. Imaging techniques still consist of a configuration of experts, patients, instruments, and medical programs that generate routines and protocols and discourse that can assign or withhold the medical and social status of suffering.<sup>42</sup> The positivistic realm of technical rendering permits the assembly of these moving parts into a gestalt whose conclusiveness hinges on the objective component—the radiological image. This image is both a diagnostic component and an extension of the biopolitical project of the State to monitor and ensure (re)productivity in its subjects by surveilling, predicting, and intervening where bodies deviate.<sup>43</sup>

The camera more closely scrutinizes, with an allegedly superior and benevolent gaze, to better capture an invisible population than organic vision, better document it via standardized, computerized, comparable images as opposed to artist’s illustrations or metaphorical descriptions in which the work of interpretation could provoke an empathetic reader response. These technologies transform pain from subjective and personal to objective and objectively interpretable pain.

This is the illusion.

The fallible human eye is never replaced entirely. Simply shifted a lateral degree or two. The language it falls back on, whether clinical or metaphoric, is human, through and through.<sup>12,42,44</sup> “Images are the products of instruments; but instruments are also the products of our imagination,” what we culturally conceive of as worthy of visualizing, magnifying, curing.<sup>13</sup> We select and view based on the visual codes that have come before, which is why, moving forward, these codes must change.

The objectivity of medical imaging, as part of the epistemology of science, insists on “the existence and impenetrability” of boundaries between facts and values, between emotions and rationality, but the knowledge claims exerted by imaging devices, and by their operators and interpreters, are partial and situated, and treating the body as an object requiring efficient, scientific management generally overlooks this.<sup>44</sup>

After all, the quadrant of the body that the machine fixates on is determined by a physician, who must first assess the patient’s body to determine a course of care. But, for modern medicine, the clinical gaze encompasses not the whole body but the parts where symptoms are expected to appear.<sup>2</sup>

Where is that in the patient who says it hurts everywhere?

With the modern question of medicine, “Where does it hurt?,” the clinic advances into the realm of positive science, a site of empiricism where the technologically mediated gaze opens up the body and lays it bare, parting observation and (dialogic) discourse, reorganizing even the possibility of a discourse about disease.<sup>2</sup> Digital health technologies nudge fibromyalgia further into a politics of certainty, born of the capacity for increased surveillance over and into the body. Experts tend to agree that these machines cannot diagnose, but they insist on a quest for metrication, as though this could determine the social value of the patient to be rehabilitated, or incarcerated, or abandoned. In the quest to stake defensible legal and medical claims about medically indefensible diagnosis on a body part, I become less a body than a potential picture, an imperfect representation wielding real power over my medical future. “A transparent interior—medically translucent and endlessly modifiable—seems a *sine qua non* for a perfect exterior,” and with so much at stake my body is to blame for ruining the image, and I am to blame for my body.<sup>13</sup>

### **We don’t want to suffer, but you won’t let us, either**

In my medical records from March to September 2014, after months of malnutrition and internal leakage and

fusions, *well-appearing*, *well-nourished*, and *makes eye contact* feature prominently.

So does *in no acute distress*. And *depressed*.

Where verbs get used, *denies* is the most common.

This is in accordance with incremental pain scales that use numerical ratings and visual analogues, with lower and upper endpoints, as though pain couldn't exceed a 10 or fall below 0. These scales ignore the multiple dimensions of pain, or categorize it as psychological, or reject attempts at complexity or nuanced explanation: as Williams et al. find in their study of pain scales, patients are "often" or "always" influenced by feelings of fraudulence if they rate their pain low but require assistance, or if they individualize pain scales by redefining them, excluding the lower half as irrelevant, formulating idiosyncratic meanings and metaphors that transgress conventional conceptions of pain. "An alternative framework, closer to that of creation of meaning within the context of shared social meanings and demands of the assessment context, acknowledges that we are asking patients to communicate their complex pain experience to us, described and delimited by terms which are rarely of their choice, and recognizing the communicative, reflexive and recursive aspects of doing so."<sup>45</sup>

Perhaps the biomedical reliance on ocularity could augment this, if it were instead enlisted to produce individualized representations of the body.<sup>7</sup>

When I first sought medical care for fibromyalgia, before I had a diagnosis, a physician said to me with a conspiratorial laugh, "But you look so well, there can't be anything wrong with you!"

I end up with a very specific construction of a self in pain whose pain cannot be authenticated by modern technologies of capture, and who thus threatens the stability of (medical, scholarly) expertise by presenting an unreliable body whose invisible parts can't be parsed.<sup>2</sup> Diagnostic imaging allegedly "sees" specific elements of the body, isolating (and helping to define and normalize) social behaviors like the expression of pain. Subjectivity becomes value-laden alphanumeric code, weighted with social status.<sup>46</sup> Suffering becomes not only biomedical datum but also social status, to be bestowed or withheld.<sup>27</sup>

You have to know what you're looking for to find it on the machine, but my massage therapist is able to locate these places with her hands, and with open-ended dialogic questions that harken back to galenic medical discourse, "Tell me what you're feeling."<sup>2</sup> Her fingers and mine are able to intimately track the full shape of the hard, immobile mass in my abdomen, well before the CT scan or ultrasound.

Thinking through the skin, paying attention to "the small dance of the body," affords new ways of sensing

to guide and complement the imaging procedure, and to broaden techniques of therapeutic management.<sup>11</sup>

But the voice pales as an instrument of objectivity, and as an amateur I don't get to know what I'm talking about. I don't get to be reliable.

Listening, too, is irrelevant unless it produces an image. But the body has a voice, and indeed itself is an "acoustic space" that requires specialized listening practices. Auditory aptitudes like auscultation are part of the professional medical skillset in diagnostic practice, but are potentially obsolescent, replaced by the ultrasound. Mine showed nothing but the same inflammation in my CT scan. The sensory intricacies of auscultation might have revealed what I'd noticed myself, that my noisy gut was quieter than it had ever been before.<sup>6</sup>

I am always witnessing these failures, of the performance of expertise, on their part, and mine.

This experience is not uncommon. The risk of letting my voice rise is that any unauthorized narrative could be imposed.<sup>47,48</sup>

In the ER, even when the source of pain is technologically rendered—that mysterious vascular mass in the place I myself pointed to—I am not put in the surgical rotation. I remain too *well-appearing* to get the "sick role."

We forget too frequently that the diagnostic image circulates like currency, like a chain letter, to be accepted or critiqued with second or third opinions. Like a positivist's game of telephone no one wants to end for fear of finding the outcome riddled with errors, and all those involved caught in the subjective act of interpretation.

As pain robs the sufferer of speech, it's not surprising that the discourse of pain is created by those who aren't in its chokehold but speak like experts for those who are.<sup>23</sup>

There is already a long medical tradition of ignoring pain or denying its status in the clinic when it can't be visually confirmed.<sup>25,29</sup>

Pain itself is an affective call.<sup>49</sup>

You can't deny patients this.

Biomedicine reads me into a Procrustean template of bloodless descriptions in which I have no say, and how could I, when monogeneric academic conventions tell me to lose the poetic in my scholarly telling, too?

### This is the problem, distilled

The OB/GYN resident writes:

Pt is a 30 y.o. virginal female with 3 week hx of severe right lower quadrant pain, slightly improved since initial onset. On exam patient has stable vital signs, easily brought to tears during exam but *unable to voice what is*

*bothering her besides pressure from the vaginal probe.* Her abdomen is soft with moderate tenderness to deep palpation and rebound in right lower quadrant. No CMT or adnexal tenderness on bimanual exam. Pt with very low risk sexual history to suggest a clinical picture of PID or TOA; suspicion is very low. Per further discussion with radiology, they agree that clinical presentation and radiologic findings may be more consistent with subacute distal appendicitis causing pelvic inflammation, *especially in the setting of elevated lipase and amylase, which would not occur in a GYN pathology.* Likelihood of GYN pathology as the primary etiology of patient's clinical symptoms is very low given overall clinical picture, but would recommend further workup by primary team [emphasis mine].

This is visual authority in Western medicine.

You can't hear my screaming in these words. Would it matter if you could? Even this kind of sonic exteriorization, the medical acoustic techniques it demands, involves personal interaction between doctor and patient, fostering sympathy and empathy.<sup>6</sup> The signifying power of a basic, inexpensive instrument like the human voice is increasingly underestimated as Western biomedicine depends more and more on digital health technologies to diagnose or authenticate.<sup>50</sup> Pain is the concretization of the negative, aversive, and unpleasant, saturated with social stigma and organized through trajectories of urgency and repulsion. It is "not a sensation but a perception dependent upon the mind's active ongoing power to make sense of experience."<sup>27</sup> It is the negation of speech, silent or screaming, approaching the limits of absolute muteness at both ends.

But. Pain still communicates. Even as it elides standard clinical diagnostic measures. As Gonzalez-Polledo and Tarr observed, mediated chronic pain narratives use creative processes and multiple media to express pain, transforming traditional illness narratives and indicating that pain may exist at the borders of language but is articulate, if you know how to listen.<sup>51</sup>

But in the clinical encounter I offer to you, pain is a quest for proof that risks becoming solely ocular with the increased reliance on digital health technologies—especially radiological imaging—which should be deployed as auxiliary procedures to augment patient narrative and palpation. In chronic pain expression outside of the clinic, in memes, on social media, pain expressions and sufferers configure their experiences through multimodal means, creating alternate pain scales, networked narratives, temporal manipulations, challenging biomedical frames and definitions of intensity, chronicity, and linguistic and metaphorical limitations.<sup>52</sup>

Modern concepts of pain are supposed to move towards a holistic approach, including cognitive and affective dimensions.

Even if we continue to privilege the visual as authentic, there are other ways to deploy the image.

Like Padfield's creation and use of photographic representations of pain that are not literal depictions or attempts at diagnosis but aim to promote doctor–patient communication, collaboration, exploration. Images that reflect invisible pain are an oasis of relief in the clinical setting where we must prove we are in constant pain.<sup>15</sup>

See how this takes us from a biogenic model of pain to something socially situated and co-constructed, a divergence from the body–mind dualism that haunts visual medical technologies. See how we can re-vision pain as an agent of change, reorganizing the foundations of "normalcy" through chronicity, the environment, others, our cultural understandings, if we "recognize the role of the self-referential brain embedded in an autopoietic living system."<sup>53</sup>

It shouldn't always be about the thing—the disciplined body, the (re)productive subject—that comes into focus under Power's roving eye. The decision to image the body is contingent on what the medical gaze sees as significant and not what I say, so that certain outward expressions of affect become medical currency, a permission slip for biomedical intervention or the treatment bestowed on Camus' Mersault, so baffling it leads me to death.

I haven't said so yet, but I only received laparoscopic surgery because I tried to leave.

Just as brain imaging promises to render personality objective, visible, and confirmable, the CT scan, ultrasound, and other forms of diagnostic imaging promise to construct a picture of pain that is irrefutable, in contrast to assertions that the experience of pain is the experience of certainty that there is pain only to the sufferer, while onlookers are left in doubt.<sup>34</sup> It is a practice of subjectification rooted in the imaging procedure, which somaticizes individuality and reduces personhood to an investigative technique.<sup>12</sup>

The fibromyalgic self itself becomes transformed by biotechnological interventions.

As my intake suggests, we become *unreliable*.

I still don't understand why it wasn't enough to insist that a diagnosis of PID made no sense, to invoke my elevated liver function tests myself, to finally show pain the way it was expected of me: sobbing, screaming, cringing, begging. But showing or not showing with body and affect, it makes no difference if I show nothing to the camera. If the machine can't find it, the failure is on me.

I keep hearing that biomedicine seeks to cure fibromyalgia as though it is the same as acute pain, but sometimes it seems as if it is epistemological doubt my doctors seek to cure, and not me.<sup>2,25,32</sup>



## Whose language is excluded from the academy

Fibromyalgia lives in the gap between “is” and “ought.” What this reality is. What, according to the biocultural presumptions of pain, it ought to be. Who has control of the very questions that ought to be asked, and how the pursuit of objective markers legitimates or downplays those questions.

In the academy, everyone is suffering and they wear it with pride. We call every bodily state *stress*. Unlike fibromyalgia, this is a badge of distinction, a rite of passage, which fibromyalgia disallows me. Professors and colleagues chat cavalierly about sleepless nights, of too much caffeine. Too little sleep on my medication, and I become dysphasic. Too much coffee and I feel the scar tissue in my gut like glass in my shoe. Everyone has heard me screaming in the bathroom before I go to teach my class, even if no one asks me why. Mine is too real, not a badge of honor.

Pain wears all its civilized disguises in the academy, as sterile as the clinic in its pursuit of knowledge.

As Leder notes, even “a chronic pain for which one has no solution continues to grab the attention with undiminished intensity. To an extent, one can accept or become accustomed to such pain. But it still retains something of an episodic character. It is as if the pain were ever born anew, although nothing whatsoever has changed.”<sup>49</sup>

When I try to articulate it, everyone hurries to remind me, “Oh, well, you look great, though!”

Really, it’s *pain is private, shameful, barbaric*.<sup>26</sup>

Nothing left to say but *thanks*.

When I wryly mention to colleagues that I vomited from pain while writing this paper about pain, oh the irony, I kill the mood. No one knows what to say, or how to suggest I don’t have what it takes to be an academic, that I don’t belong here.

Your exclusions are never clearer to me than in the language you ask me to use.

## To produce a body of words is to act on the flesh of the world

The craft of writing could let us wrest back the official clinical discursive representations legitimated by digital health technologies like the imaging procedure described above and below. Such digital images possess an evidential force, assuring us of an authentic existence. By extension, so do the discursive representations derived from (all too) human interpretations of those images. It is as though we forget “that *every* photograph is the result of specific and, in every sense, significant distortions which render its relation to any prior reality deeply problematic and raise the question of the determining level of the material apparatus and

of the social practices within which photography takes place.”<sup>40</sup>

In the clinic, the imaging procedure legitimates the patient narrative and determines a course of treatment, but this is ultimately effected through discursive interpretation, a significant social practice framing photographic capture. Particular forms of language that make up the dominant discourse of the clinic translate the image into tradable currency for physicians who lack radiological expertise, while continuing to exclude laypeople unfamiliar with medical jargon.

We see this especially with pain, which is widely considered incommunicable, defying language, despite the fact that it expresses itself multimodally, affectively, outside of the clinical encounter.<sup>51,52</sup> To be in pain is to have certain knowledge that one is in pain, but to react to another’s pain is to doubt its existence.<sup>23,50</sup>

Those with chronic pain disorders like fibromyalgia, faced by increasingly exhausted, frustrated friends, family, and medical personnel who want to cure or counsel based on proof, eventually revert to silence, rather than face this doubt.<sup>50</sup>

I never see my language in the official record. I think in metaphors that exceed the official discourses of pain, which limit me to woundedness or weaponization, as I tick off all the boxes on standard clinical questionnaires that ask if my pain is *stabbing, burning, aching, shooting, throbbing, dull, sudden, gradual, transient, insistent*, reducing the quality of pain to intensity and temporality.<sup>23,30</sup>

Like lovers in a crowded bed, my pain and I have coexisted so long we share flesh and tongues. In the doctor’s office, I call it “my shadow” or “the body casting me as a shadow behind it.” I say of my bodily state, “My gut feels necrotic, I’m muddling through the atmosphere of a sick planet,” or “I can see, but the world has whitewater edges.”

Always this gets distilled to “Patient complains of generalized abdominal pain” or “Patient reports higher fatigue than usual.” Nothing to indicate linkages between flare-ups and visual snow, or even that my metaphors spoke more and more of rot as my appendix melted inside me.

Coincidence, maybe, or an indication that language begins in the body.<sup>54</sup>

Language is not solely cognitive. It is affective. It is corporeal. It takes its “basis of articulation in the body, the way bodies and affects are coded within the melodies of speech.”<sup>54</sup>

Writers are thus positioned to stage an empathetic reader response, and to address, or even reverse, the fibromyalgic’s inclination toward isolation and silence.<sup>27</sup>

I am communicating all the time. You could sense it too, if we admitted metaphors into our discussions of the signs.

But dominant discursive structures predetermine pain as negative, interior, prelinguistic, and ultimately unsharable. The universalized descriptions of pain become weaponized or victimizing, confining the sufferer to distinct and dire roles. As though the only way we can grasp the enormity of suffering is by imagining minor experiences taken to extremes: the papercut made over into amputation, the static shock becoming internal electrocution, constantly.<sup>23,33</sup>

We say things like *no pain, no gain*, evoking parables and myth.

Or we construct it like torture, without heroes, without anything but the plea for it to stop.

It's this same poetics that academia calls *expertise*, that captures me with normative injunctions surrounding the able body and mind, no different from the clinical camera's roving, endlessly unsatisfied eye.

I may be coded "unreliable," but Scarry suggests that the physician's task is to piece together "the fragmentary language of pain," except that too often physicians do not hear or trust the patient's voice, perceiving the voice of the patient as an "unreliable narrator" of bodily events, although "to bypass the voice is to bypass the bodily event, to bypass the patient, to bypass the person in pain."<sup>23</sup>

Padfield reminds us that "one of the dangers of language, particularly in the health setting, is that participants assume they understand each other when at times they are speaking of very different experiences."<sup>15</sup> Doctors may not verify what patients' words connote, and what the patient hears may not be what the doctor intends. If we insist on ocularity, mediating our language via the aesthetic spaces opened by photographic representations of pain or multimodal memetic communications "force[s] us to recognize the chasm between our different individual perspectives and the limits of language available to cross this space."<sup>15</sup> Enhancing doctor-patient dialogue in this way, by making tangible the range and banality of chronic pain sensations with regard to the *subjective* experience of pain, provokes the co-creation of new ways of knowing around images that tolerate ambiguity and polysemy.

Poetry, too, is ambiguous, polysemic sustenance. Where language struggles to convey pain, "visual language can invigorate verbal language and vice-versa."<sup>15,23</sup>

In official discourse, the experience of pain is interruptive, monolithic, and impossible to endure; expressing it is a sign of weakness. This is the description authored by technical rationality, which "excludes other forms of knowledge and practice by generalizing, quantifying, in a word, normalizing experiences."<sup>50</sup>

I'm trying to write against this normal. To employ the sensory invigoration Rice urges, by attending to sound, smell, taste, affective immediacies that impinge

on the experience of pain but hide their face in scholarship about it.<sup>6</sup>

I am trying to say that this discourse is influenced and reinforced by writers: of fiction, of scholarship, of clinical reports.<sup>54</sup> We use received language and conventions, when we could turn our craft to redesigning the system to better attend to the non-normate bodies we discursively absent, by admitting a wider poetics of pain into consideration instead of focusing on the kinds of evidence and scholarly structures we count as legitimate.

### Writing against normal

As Gibbs asserts, "metaphors have philosophical consequence."<sup>4</sup>

Our dominant metaphors of pain are dictated by a normative economy of the body and in turn seek to shape the body normatively. Poetic metaphors—those that an autoethnographer or novelist might call "creative" without feeling like a traitor to social science epistemology—reverberating throughout a text may prove points of entry, or flight, to all readers, to the disabled scholars who are among us but who are so rarely considered when we design our scholarship.

I am battering myself against a window with a view to future scholarship about the perception and assessment of chronic pain, the disparities between patient experience and clinical expectations, discursive representations as told by the physicians who belong to the priesthood of expertise, and the patient voice that is bypassed. I am giving you language and forms unexpected in the clinic and, here, in social science scholarship as an act of resistance, a step away from conforming to the appearance of able-mindedness.

After all, we favor objective proof in scholarship, too. When it's nowhere to be found, we call the paper *pointless, useless, unworkable, a waste of space and time*.

If you think about it, it's the same metaphors at work.

What we choose to represent, and how we choose to do so, prefigure what we will or won't do to intervene.<sup>50</sup>

Writing can reinvent suffering. Creative modes of expression are at liberty to conjure up juxtapositions, permutations, metaphors that validate or invalidate certain experiences as pain.<sup>27</sup> We are not limited to metaphorical expressions that refer to causes of bodily damage, as though this were the only way to elicit an embodied simulation of pain in listeners, and therefore the only way to solicit empathy. "The intersubjective *third space*, from which new therapeutic possibilities can arise," based on collaborative interpretations of ambiguity and not a static pre-given master narrative of pain.<sup>53</sup>

Writing with detail, creativity, and textual complexity may elicit empathy for chronicity. Metonymy and

metaphors of pain can expand beyond the purely mal-  
evolent, incapacitating.

Writing that solidifies the traditional epistemology  
of pain does not do this.

As Kleinman puts it, what we need is a language of  
alarm, distress, panic, grief, all the ugly affects we try to  
minimize in our day-to-day descriptions that are a far cry  
from the stagnant terminology of policy and pro-  
grams—like *acute inflammation*, *functional impairment*,  
*limited range of mobility*, which I know as excruciating  
but which are cleansed of dynamic affective potential.<sup>50</sup>  
And we need a language of chronicity, of normalcy, of the  
full complexity of the reactions we can have to others’  
pain, by pushing the boundaries of the embodied simula-  
tion of pain our language allows us to imagine.

To call it how it feels rather than what it is, to let a  
language of pain body forth into other bodies as a plea for  
recognition, may offer a more valid means for describing  
what is at stake for individual pain and for social suffer-  
ing, because health is a social indicator, a social process,  
and there is more at stake than triaging or treating me.

“Genre not only shapes content and sways under-  
standing but it constrains what we are *permitted* to  
say.”<sup>27</sup> I draft this paper in a leaden fog of knowing  
the work I do is not allowed in your journal, or any  
journal of merit. As Das describes, “I find that the lan-  
guages of pain through which social sciences could gaze  
at, touch, or become textual bodies on which this pain  
is written often elude me.”<sup>55</sup>

Well. That’s because it isn’t there.

Short-form scholarly genres about pain look like  
this: 25–30 pages expunged of poetics and obscenities,  
titles with colons, an appearance of originality like  
*addressing a perceived gap*, obviousness and handhold-  
ing, specialized diction that places a tacit premium on  
able-minded intelligence—excluding those outside the  
Ivory Tower.<sup>56</sup>

Our scholarship makes pain look *easy*. It entrenches  
a process of sanitization in epistemology. It frames  
chronic pain as an intractable and irresolvable situ-  
ation—but one that can be made orderly on the page.

Academic language, as it stands, emphasizes the cog-  
nitive at the expense of the body. It’s language that, like  
any language, seeks to represent the phenomenological  
world, and the grammar it’s developed to do so is dis-  
embodied, depersonalized, careful to avoid provoking  
affective reaction, objective, crafting the only appropri-  
ate response as cerebral. We can intellectualize about  
pain all we want, but to experience it is to be both  
utterly bored and driven mad with desire to repeatedly  
stab the sites of pain, as though only violence of greater  
intensity will persuade the unwanted tenant to leave.  
Solely cerebral expression, which seeks a solely cerebral  
response, will never be sufficient to the task. Verbs, sans  
modifiers, like “is,” “feels like,” “hurts,” or “causes”

are not adequate either. Nor are the expected, hardly  
evocative metaphors offered by pain scales, in which  
any understanding of pain is condensed to a perform-  
ance of violence. Nothing to acknowledge that constant  
nomadic pain becomes something else. *My gut hurts*  
means nothing to me anymore without qualifying it,  
likening it to crumpled cardboard being squeezed  
through a shrunken nylon, or the rotor of a dough-  
mixer pointlessly whirring in too much paste. It’s the  
corporeal work that metaphors do for us daily, ousted  
from scholarly writing in obeisance to the false prin-  
ciple that “real” knowledge, objective knowledge,  
knowledge worth knowing is experienced with the  
brain alone.<sup>33</sup>

But if the knowledge is worth knowing, there are no  
limits to experimentation with the language, the form,  
the body it assumes.

Scholarly writing is thus easily positioned among the  
infrastructures Yergeau et al. call designed to make the  
non-normate body disappear: the arbitrary standard of  
conformity that nobody ever exactly fits, but that vio-  
lently reshapes everyone.<sup>5</sup> These infrastructures are pre-  
dictated on ableness or apparent disability, and their  
pages echo the imperative of orderly, managed care.  
The norms that shape the writing on the page reach  
beyond the page to touch our bodies, too. Good schol-  
arship is characterized as linear, clear, concise, cohesive,  
structured. It flows well. It conforms to all the necessary  
surface features, like 12-point Times New Roman font,  
one-inch margins, specific citation styles. Poor scholar-  
ship is digressive, recursive, free-form, nebulous, convo-  
luted. It may look like an experimental lyric essay,  
resisting indented paragraphs, incorporating white  
space, mixing generic styles of writing and citation, play-  
ing with rules of appropriate grammar and usage.<sup>56</sup>

In this view, editing becomes a “purification of lan-  
guage” in which we prune linguistic and generic errors  
as though smoothing over bodily aberration.

If writing is somatic, and my somatic state is fibro-  
myalgia, writing in accordance with normalcy is a  
Sisyphean task the academy is always insisting I per-  
form. My fibromyalgic body makes contested spaces  
wherever I go, and the social science and medical schol-  
arship I want to make to explore those spaces insists I  
leave my body behind, ignoring its counsel, or chopping  
and contorting it into a mold of normativity that—like  
the clinical records that control my survival—strip me  
of the ability to analyze my own experience with any  
empowerment or authority. Like other venatic technol-  
ogies of capture, the sanitized, linear page imposes a  
narrative on me. Be straightforward. Be productive.  
Be *clear*, when my daily survival is determined by a con-  
dition that is anything but. Fill the page with a voice,  
when suffering is metaphorically voiceless in the sense  
that silence signals unknowability, inaccessibility—not

unlike the use of blank space in visual narratives about trauma, or littering the pages here.<sup>27</sup>

In other words, the monogeneric strategies of conveyance and interpretation deployed in academia and biomedicine have serious ramifications for knowledge production and the construction of the pained body. Our scholarship about digital health mirrors the rhetoric of the clinic in that “modes of delivery assume an audience of normate bodyminds, [such that] the creators of that infrastructure therefore declare certain other bodyminds (e.g., disabled ones) not present, even if such bodies are physically present.”<sup>5</sup>

That is, the digital rendering presumes a well-behaved body that will willingly surrender its signs, just as the scholarly paper will offer its sanitized, finely honed point, without meandering.

But as Padfield notes, “Chronic pain disrupts narrative, and perhaps having that seen, heard, and acknowledged is more important than trying to frame the narrative linearly.”<sup>15</sup>

When we say that bodies matter, we must include suffering sick-woman bodies like mine that lack the material freedom to relate and conjoin with other bodies.<sup>57</sup> The world of the person in pain is accessible in their creative frame through metaphor, formulated and negotiated in a state of togetherness, from doctor to patient, reader to writer.<sup>53</sup> This move towards recentering craft, with all its trappings of style, voice, rhythm, wordsmithing, is meant as an empowering one, as craft necessarily retains the body, as its operation is the anticipatory foresight of how “the direct action of a few startling words on an unsuspecting body can threaten the very integrity of self,” that “the imbrication of mind and body through the medium of affect is, after all, what it means to be ‘embodied.’”<sup>58</sup>

“It matters who reads, it matters who engages, and it matters who is conceptualized as a reader.”<sup>5</sup> What this means for me, the fibromyalgic writer, is that I am not able to divorce my fibromyalgic subjectivity from my craft, that I labor harder to prove to you I am able-minded by offering you work that is alien to me: linear, with clean-cut paragraphs and gently sloping turns on utterly stable ground.

What this means for you, the academic reader/reviewer/critic, is that until now I have hidden my embodied process from you, and that it matters who reads and engages and who is conceptualized as a reader, and I do you a disservice by surrendering to formulaic schema that presume you are incapable of parsing a complex, unfamiliar structure.

Experience is shaped by official representations but can also push back against them by bending language unexpectedly, distorting received ways of expressing pain, distress, and desperation, transforming the experience of suffering through inflections and infractions of

institutional language.<sup>50</sup> Pain is intersubjective, not completely hidden from view. Language is one of the dimensions that construct it. Defying academic conventions is an intentional move meant to highlight the centrality of discourse in the use, reading, and circulation of digital health technologies and the way we scholars write about them. It is a recognition that the text does more than explicate.

But.

In the end I can craft whatever I wish. I can draft in fragments, include white space for cognitive and emotional processing that I know will disappear in the final copy, compose my subheadings in such a way that they comprise a narrative of their own. I can seek to challenge normative, ableist notions of sense and sense-making in academia as much as I like. But I require readers willing to read and write with me, against the normal, and the technical rational capture it legitimates in the clinic.

For understanding of pain to change, our metaphors must change first.

### **It's the narrative that legitimates the image-making, after all**

This is what the attending physician, the one who did my intake and ordered the transvaginal ultrasound, wrote down.

Patient presents with abdominal pain x 3 weeks, PID confirmed bt CT scan today. Pain location RLQ, pain quality aching and sharp, does not radiate, pain severity moderate. No diet changes, not awakening from sleep, no anorexia, no chest pain, no constipation, no diarrhea, no fatigue, no nausea, no vomiting.

A 30 year old female with a past medical history of rheumatoid arthritis presents to the ED with complaints of abdominal pain for the past three weeks. She states that the pain is not as constant but just as severe. Pain is worsened with movement and eating. She went to her doctor and had a pelvic examination and sent to have a CT performed. On the Ct it was noted that she had PID vs a perforated appendicitis. She states that she has never been sexually active with a man. She states that she has noticed minimal vaginal discharge. She denies any fevers, chills, nausea, diarrhea, constipation, or any other complaints or symptoms. She is oriented to person, place, and time. She appears well-developed and well-nourished.

So much is incorrect, so much the exact opposite of everything I said.

I reported constipation and diarrhea every day. I awoke in a cold sweat every night. I stopped eating. I lived on coconut water and the occasional smoothie for three weeks. My skin had developed a gray

undertone. Towards the end, I wandered the city with no idea of where I was or where I was going, gripped by a sense of impending doom.

Much of this is reflected in the surgeon's notes, and the notes of the senior RN in the in-patient ward. But not in this, the intake summary that determined my care regimen, that insisted on more digital imaging to visually confirm the narrative he had imposed on me, because I showed no outward pain, *made eye contact*, was *alert*, had *a normal mood and affect, normal behavior, normal judgment and thought*, when I radiated agony wherever I was touched.

If he'd only touched me in more places than the one he expected to hurt, or listened to my bodily interior, in addition to my words. If he'd heard my metaphoric language the way I meant it.

If it hadn't been a monogeneric hermeneutics at work.

As vision is a selective sense, what it privileges about the pained body is how that body becomes classified and ordered in an attempt to "make pains the same."<sup>30</sup> More specifically, the lack of expected facial cues is interpreted as a lack of pain, whereas an excess of pain is seen as a hypochondriac's or addict's approval-seeking exaggeration. I never get to differentiate between physiological types of pain, indicate if pains feel referred, or map their intensities. I must operate within a limited comprehension of pain that forecloses other verbal articulations of it. The language of weapon and wound, no ordinary affects allowed.

Narratives of suffering undergo subtle changes depending on their form, and our understanding of suffering, and the values at stake, changes with them.<sup>27</sup> I try to see it through his eyes: a woman of child-bearing age who appears functional, says she is a virgin, talks too much and too articulately, how could it be appendicitis, something so routine that all physicians should recognize it at a glance?

### What we want are the senses, restored

If there was a miracle at all, it was that the surgeon who spoke to me after I demanded to leave took my pulse with his hand, not the finger monitor; pressed my entire abdomen, listened to me recount my symptoms, acknowledged that my fibromyalgia was real and this was not it. His summary notes match our dialogue. He corrected the impression created by previous notes, stating, *Patient anxiety and depression exceeds normal fibromyalgia and patient in such pain willing to undergo surgery.*

He is the only physician who codes me *reliable*.

Ultimately he uses a laparoscopic camera to extend his sight into my abdominal cavity, and at my post-op follow-up, he describes the procedure when I ask, using

metaphor without prompting: my gut a constricted tube, organs glued together like wet paper, like the texture of cheese gone bad.

His notes, less metaphoric, remain descriptive, subjective. He is surprised to find my uterus and rectum fused together in all that mess. He worries that if he tries to slide the knife between the two, one or the other will split. He records colors and smells, in addition to quantity.

Is it really so hard to broaden our genres of reception and interpretation, when lives and identities are at stake?

I have been too tired to rebel. But I am also tired of *looking too good to be sick*, of being asked if I *feel better yet*, of purposely misplaced palpation in the clinic as though referred pain were a myth, when bodywork practitioners universally acknowledge that one part of the body may communicate intensities that are only felt in the receiving area, not the point of origin.

I am tired of objective, emotionally distancing language and vision being the sole modes of meaning-making, yielding taxonomies that mystify chronic pain.<sup>30,50</sup>

If as scholars and meaning-makers we work to denaturalize the biomedical representations and identifications through which our experience and knowledge of a suffering world are filtered;

If we inject these mutations into the biomedical discourse that reproduces social and political identity in our bodies;

If we can destabilize how we look and what we look at and why we're only looking when we telegraph our pain in realms beyond the visual;

If we can establish that the human sensorium in its whole, wild, comprehensive range must precede and accompany digital imaging and diagnosis;

Here, at the limits of absolute muteness, we could speak.

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