HOLLOW ME, HOLLOW ME, UNTIL ONLY YOU REMAIN

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Titles in Newcastle Rusty, Body in Chaparral Pro, Action Behaviors in Just a Moment

AUTHOR BIO



Dr. Vyshali Manivannan (she/her) is a disabled scholar-artist with fibromyalgia (FMS), myalgic encephalomyelitis (ME), and postural orthostatic tachycardia syndrome (POTS). She received her Ph.D. in Communication, Information, and Media from Rutgers University and her M.F.A. in Fiction Writing from Columbia University. She began designing interactive fiction, visual novels, and tabletop RPGs

for her digital dissertation project, **This is about the Body, the Mind, the Academy, the Clinic, Time, and Pain**. She lives and writes on the unceded lands of the Lenni Lenape in New York and serves as a Clinical Assistant Professor in the Department of Writing and Cultural Studies at Pace University – Pleasantville.

A NOTE ON DESIGN

Hollow Me, Hollow Me, Until Only You Remain (CC BY-NC-SA 4.0) is powered by <u>Texture Writer</u>, an interactive fiction engine created by Juhana Leinonen and Jim Munroe that relies on a WYSIWYG browser editor and a "word-on-word mechanic." Texture Writer is not easily accessible to those with visual or motor impairments, as it requires the ability to navigate precisely with a mouse and lacks keyboard compatibility. This "companion" booklet contains the full transcript of **Hollow Me**, organized by Action Behaviors and their consequences.

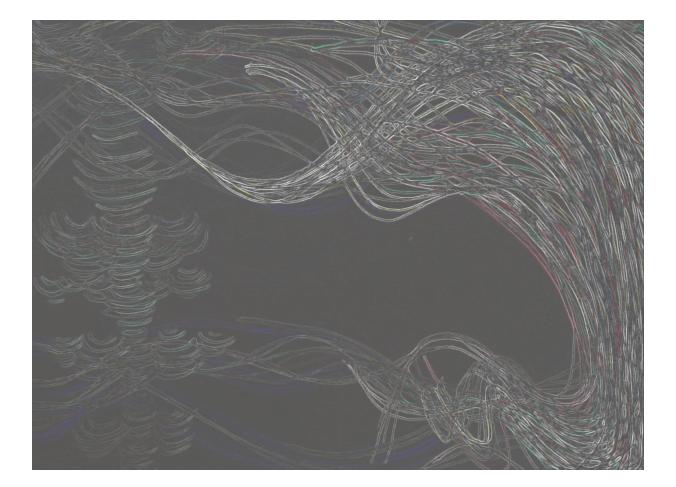
The interactive fiction game can be played online <u>here</u>.

The games created for **This is about the Body, the Mind, the Academy, the Clinic, Time, and Pain** will remain open-access and free, but please credit me appropriately if you use my work in your scholarship or teaching.

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PART 1 CONTEXT & INSTRUCTIONS

INTRODUCTION

A choice-based interactive nonfiction game, *Hollow Me, Hollow Me, Until Only You Remain* plunges you into the simultaneously tedious and harrowing experience of entering NYU Langone's emergency room as a fibromyalgic nonwhite queer woman in crisis. You arrived here because you *are* in a state of emergency: something inside you is rotting; for nine months, doctors have dismissed it as a flare-up of your usual chronic pain and fatigue; your body's defenses, buckling under this negligence, are finally breaking down.

As a chronically ill patient, you know all too well that your skin color, gender presentation, and non-apparent pain will impact the care you receive.

Your only recourse is to aggressively engage with your medical records as various emergency physicians assess and reframe you in the patient intake process, crafting a patient identity for you that is sharply antithetical to what you are trying to convey.

FOREWORD

Hollow Me, Hollow Me, Until Only You Remain was originally composed online for my digital dissertation. It is an autoethnographic inquiry into the violence perpetrated by curative logics, ableism, and medical paternalism. An interactive, immersive resource for writing studies, media studies, and disability studies classrooms, this "game" is a rhetorical analysis of the medical gaslighting, gender- and race-based stereotyping, and narrative imposition I endured during a weekend-long emergency room visit in September 2014, nine months after my appendix had perforated. As an Eelam Tamil woman living with chronic pain and fatigue since 2006, I present and interpret my pain in ways that don't align with ocularcentric medical standards. I sought care from multiple specialists starting in January, but—due to my articulateness, my dress choices, my gender and model minority status—I was repeatedly told not to worry; "it's probably a flareup." By September, I could barely eat, drink, or walk and felt constantly disoriented and relentlessly pursued by a sense of impending doom. Finally, a doctor ordered an emergency abdominal CT scan which revealed extensive inflammation ("Your pelvis looks like a bomb went off; how are you still standing?" the radiologist marveled), and I was sent to the emergency room at NYU Langone.

While this experience is detailed in full in my dissertation project, *Hollow Me* focuses on my medical records from that weekend to expose how selfreporting by chronically ill women of color is so quickly and easily undone by physicians who do not believe us, who insist that their expertise and authority over our bodies supersedes our own, who stereotype us, (re)traumatize us with unnecessary, painful procedures, and—most damningly—rewrite our patient records to reflect their specializations and beliefs, even if that means erasing previous diagnoses and associated regimens of care.

Texture Writer lets you drag verbs (Action Behaviors) from the bottom of the screen to hot spots in the main text, which modifies or replaces the highlighted text; appends new text to the hot spot or at the end of the page; or takes the player to a new page. In *Hollow Me*, players use Action Behaviors to engage with my medical records from my 2014 ER visit. Hot spots are designated around the inaccurate, biased additions and changes made by physicians without my knowledge or consent that imperiled my future health care and my life itself.

Countless stories like mine—disabled BIPOC women whose descriptions of pain are doubted, dismissed, or reframed according to Euro-Western biomedical standards and gendered and racialized expectations—do end tragically, with loss of treatment or death. I got lucky: a surgeon believed me and overwrote the edits to my record. If he hadn't, it's likely I wouldn't be here today.

Complicity plays a significant role in the emotional power of stories driven by player agency. Whether I intended it or not, disability justice is built into this game. In immersing players in this all-too-common experience, **Hollow Me** values the teachings of bodyminds like mine, centering the knowledge of those most impacted. It emphasizes the importance of intersectionality and affirms that the disabled patient's identity is that of a whole person whose worth isn't dependent on normativity or (re)productivity. And through many of its Action Behavior "consequences," it asks that academic writers be mindful of the fact that scholarly writing about the body—devoid of embodied language as it is—can reify the absence of poetics in clinical practice, which in turn has material consequences for patients who rely on metaphor to describe the embodied experience of chronic pain. Especially disabled women with a decolonial framework for pain, whose pain is regularly considered suspect.

By envisioning this experience as an interactive nonfiction game, by making players complicit—in either accepting the clinicians' version of events or making edits that reclaim my patient identity—**Hollow Me** requires players to examine their own preconceptions, challenge the oppressive logics and practices of medical spaces, and consider what self-advocacy, collaborative resistance, and collective liberation might look like.

TRANSCRIPT

Hollow Me begins with my patient intake at the ER and takes the player through my surgical admission. My medical records are unaltered save for the anonymizing of medical staff through the use of pseudonyms and modified staff titles and times. Segments that were purely clinical data, like vital signs, lab tests, and antibiotic and fluid administration, were excluded.

The following text-only transcript is copied and pasted from the game. Hot spots are indicated in red in the main text and are also listed as headings after a discrete portion of main text. Applicable Action Behavior verbs are written alongside those headings, with their corresponding actions listed after an arrow symbol: e.g., "Verb Hot Spot \rightarrow Action."

Sometimes, when hot spot text is

Caption: Screenshot of the narrative map as it appears in the Texture Writer console.

highlighted, the Action Behavior verb is reworded; if so, the new wording is listed after the original verb with a backslash: e.g., "Verb/New Verb Hot Spot \rightarrow Action"—such as "Translate/really? confirmed \rightarrow change to" (p. 14). The changes that result from choosing that Action appear under these headings.

When a heading indicates a new page, the heading is written as "Action Behavior Hot Spot": e.g., "Tell Me What Happens." These headings are followed by the resulting main text. The game's progression is influenced by the player's choice of Action as well as the order in which Actions are selected. It is possible to complete the game without revealing all of the content, and I can't predict the order in which a player might select Actions in the Texture Writer game. I have chosen to organize this transcript in the order that Actions appear on the screen, except for narrative branches that return the player to a previous screen; those Actions and their consequences appear first.



PART 2

THE GAME

Tell Me WARNINGS

In the dominant biomedical approach, patients—especially nonwhite, darkerskinned women—are objectified and gaslit by physicians who view them through their medical specialization's narrow focus. Medical records are impersonal and sanitized, but by revising, challenging, and narrativizing mine, you enact a biocultural approach, in which pain is understood as an intersubjective, coconstructed experience. The more you engage, the more you will uncover experiences of medical gaslighting, sexism, and racism, references to sexual violence, and descriptions of acute and chronic pain.

Tell Me HOW TO READ

Click-and-hold a given verb at the bottom of the page to reveal highlighted text in the body of the page. Drag-and-drop the selected verb to a highlighted word or phrase to change it, add to it, or go to a different page.

Tell Me WHAT HAPPENS

Intake. Date of Service: 9/18/2014, 5:05pm. Filed: 5:30pm. Signed: MTJ, PA.

Triage Chief Complaint: Patient presents with: Abdominal pain x 3 weeks, PID confirmed by CT scan today, sent to ER for treatment.

Translate/really? CONFIRMED \rightarrow change to:

questionable given that nothing conclusive could be seen

Translate TREATMENT \rightarrow change to:

a TVUS to exclude PID, a possibility Pt denies because she isn't sexually active (really? you're sure?) and her elevated blood enzymes aren't gynecological markers (your Google search ≠ my medical degree)

Embody MTJ \rightarrow change to:

Mitchell T. Jones, a cis white man who appears to be in his thirties

Embody PID \rightarrow change to + add after paragraph:

pelvic inflammatory disease

That I resist this diagnosis for 15 heated minutes, insisting, "Don't most cases result from an STD, IUD, douching, other penetrative activity? How else could I have contracted it?" has no place in the official record. Other omissions include that Mitch asked me very few questions about PID symptoms, such as smell, fever, or pain during sex. He'd already made up his mind. Expertise-as-paternalism justified it (Segal, 2005).

Theorize TRIAGE \rightarrow change to:

Triage prioritizes treatment of those who are most ill, but this often means those who look the most ill. My pelvis might burn bright on my CT scan, but I look able-bodied and stoic, a South Asian punk girl wannabe with this

Embody PATIENT \rightarrow turn to: embody PATIENT

Embody SERVICE \rightarrow turn to: embody SERVICE

Theorize INTAKE \rightarrow turn to: theorize INTAKE

Embody PATIENT

Me, a queer Eelam Tamil 30-year-old woman, with frizzy hair and sunken eyes, wearing a hospital gown.



Theorize INTAKE

The intake is the ritualized, agonistic demonstration of authority over the patient's body among members of the field, who remain members by continually asserting their expertise. This exchange demonstrates two of the rhetorical values Segal (2005) identifies: paternalism, where the physician has control over the patient and how she's represented; and atomism, where the physician fractures the body to be read through the system-specific fields of medical science (p. 88). Attempting to extract a stable identity from a body in flux, the PA resorts to paternalism when I assert my experience of my body, and, barely palpating me, atomism when he hears what sounds to him like PID, ignoring the parts of my narrative that suggest otherwise, altering my words to fit his medical preferences. As the GYN noted later, all signs pointed to a GI issue. Because I lacked the classic visual presentation of appendicitis, the PA hunted for zebras.

Embody SERVICE

I tell the on-duty nurses I'm in incredible amounts of pain. Because I was able to walk in, though, I'm directed to wait in a wheelchair instead of the empty cot next to it. The ER is freezing. The one blanket I'm given does nothing to warm me. Sitting upright compresses my thick and stony middle, forces quick and shallow breathing, spikes my brain fog and muscle stiffness and joint pain. I'm offered OTC regular strength pain meds. The cot is given to a white dudebro with a gashed pinky. Because of course. Whiteness and blood are believed.

Lolwut MEDS \rightarrow add:

that don't do shit on a good day and I practically 🤣 🤣 when I decline

Lolwut WHITE DUDEBRO WITH A GASHED PINKY ightarrow add:

because his finger hurts; he feels faint; he needs to lie down



🔣 WAIT



"...Miss Manivannan?"

Feels like () AND $\overline{z} \rightarrow$ change to:

hell help me please god agony what am i doing here i shouldn't have come fuck ઉநாகு ந help me 器யா christ forever look at me already fuck freezing please believe me ઉநாகு ந nonono come on hell no one sees me hello i'm right here you assholes ஐயோ for fuck's sake how much longer kill me kill me i'll kill myself PLEASE i want amma help me i don't want to die i can't hell they forgot me it hurts it hurts make it stop i want to scream FUCK YOU help me i should go home shit why is this happening what am i supposed to do i can't i can't i want to go home so cold ஐயோ ஏலாது i'm going to die here please torture fucking hell so much left to do how am i still here this is unbelievable christ what the hell please help IT HURTS dying no one cares hell fine i'm leaving fuck you and ever ஏலாது

→ SENT

The history is provided by the patient. Pain location: **RLQ**. Pain quality: **aching** and **sharp**. Pain radiates to: **Does not radiate**. Pain severity: **Moderate**. Onset quality: **Gradual**. Duration: **3 weeks**. Timing: **Intermittent**. Progression: **Unchanged**. Context: **eating**. Context: **not alcohol use**, **not awakening from sleep**, **not diet changes**, **not laxative use**, **not medication withdrawal**, **not previous surgeries**, **not recent illness**, **not recent sexual activity**, **not recent travel**, **not retching**, **not sick contacts**, **not suspicious food intake**, and **not trauma**. Relieved by: **None tried**. Associated symptoms: **no anorexia**,

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no belching, no chest pain, no chills, no constipation, no cough, no diarrhea, no dysuria, no fatigue, no fever, no flatus, no hematemesis, no hematochezia, no hematuria, no melena, no nausea, no shortness of breath, no sore throat, no vaginal discharge and no vomiting. Risk factors: no alcohol abuse, no aspirin use, not elderly, has not had multiple surgeries, no NSAID use, not obese, not pregnant and no recent hospitalization.

Theorize HISTORY \rightarrow turn to: theorize HISTORY

Theorize NONE \rightarrow turn to: theorize NONE

Translate/means $RLQ \rightarrow$ change to:

right lower quadrant of abdomen

Translate/means DYSURIA \rightarrow change to:

discomfort while urinating

Translate/means HEMATEMESIS \rightarrow change to:

vomiting blood

Translate/means HEMATOCHEZIA \rightarrow change to:

blood in stool

Translate/means HEMATURIA \rightarrow change to:

blood in urine

Translate/means MELENA \rightarrow change to:

dark tarry stools

Challenge MODERATE \rightarrow change to:

I wished every day for death

Challenge GRADUAL \rightarrow change to:

Increased for 7 months, abruptly spiked, then plateaued

Challenge WEEKS \rightarrow add:

since the flare-up, initial onset 8 months prior

Challenge INTERMITTENT \rightarrow change to:

Constant pain, intermittent agony

Challenge ANOREXIA \rightarrow change to:

appetite, inability to eat solids without pain

Challenge NO [CONSTIPATION] \rightarrow change to:

bouts of

Challenge NO [DIARRHEA] \rightarrow change to:

bouts of

Challenge NO [FATIGUE] \rightarrow change to:

preexisting chronic

Challenge NO [HEMATOCHEZIA] \rightarrow change to:

suspected

Challenge NO SHORTNESS OF BREATH \rightarrow change to:

stuck diaphragm

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Challenge NO VOMITING \rightarrow change to:

occasional, painful mini-vomit

Theorize HISTORY

Popham (2014), in her study of authority and juvenile mental health records, writes:

The ethos of the scientist, and, I argue, the physician/medical expert is cleverly constructed by denying its appeal to itself. When physicians and/or other medical experts focus on the role and ethos of patients by including data and evidence of the patient visit or the statistics of patient non-compliance, they construct their own ethos as experts, by simultaneously letting the expert data and evidence stand in place for their ethos, rather than constructing an ethos that is consciously and directly self-focused. (p. 333).

Mitch translates my patient narrative into evidence that simultaneously discredits my self-knowledge and supports his interpretive biases and prescribed course of action. He reasserts his belonging to the medical field by constructing an ethos based on authority, and other physicians who read this document that substitutes for my corporeal body will miss: (1) his shock and skepticism over my queer leanings and sexual abstinence; (2) his doubts about my 2007 fibromyalgia diagnosis; (3) his discursive framing of my reported symptoms, particularly the GI ones, to align with his gynecological narrative; and (4) his construction of me as noncompliant, *denying* activity, *trying nothing* to better my condition before arriving at the ER.

Theorize NONE

I tried everything: Pilates, organ massage, acupuncture, coconut water, low carbs and high protein, intermittent fasting, less exertion, a cocktail of different medications: sulfasalazine, omeprazole, Flexeril, hyoscyamine, methotrexate, NSAIDs, Tylenol 4, tramadol. *None tried* for 3 weeks suggests I was malingering, suspiciously able to do the impossible: cohabit with extreme pain. Paternalistic expertise and scientific ethos reinforce themselves by pointing to my unwillingness to alleviate my own complaint (Segal, 2005; Popham, 2014). It contributes to the groundwork necessary for Mitch to establish a post hoc justification for his PID diagnosis, ignoring the biocultural explanations for my pain expressions to do so (Morris, 2000). I might have been spared that traumatic transvaginal ultrasound if he'd engaged in rhetorical listening, "a stance of openness that a person may choose to assume in relation to any person, text, or culture" (Ratcliffe, 2005, p. 17), but instead, his inaccurate characterizations leave me with indelible conflicts in my medical records, framing me as unreliable even *in extremis*, and since these electronic records are permanent and available to my doctors at a keystroke, I become an always potentially problematic patient.

→ PROVIDED BY THE PATIENT

A 30 year old female with a past medical history of RA presents to the ED with complaints of abdominal pain for the past three weeks. She states that over the past three weeks she has noticed that the pain is not as constant but the pain is just as severe. The 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 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, vaginal bleeding, nausea, diarrhea or any other complaints or symptoms.

Refute/should say $RA \rightarrow$ change to:

fibromyalgia

Refute/should say PID \rightarrow change to:

appendicitis

Refute/should say APPENDICITIS \rightarrow change to:

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PID

Refute/not quite CHILLS \rightarrow add:

(but asserts cold sweats)

Refute/wrong NAUSEA \rightarrow change to:

nausea

Refute/wrong DIARRHEA \rightarrow change to:

diarrhea

Refute/also wrong SYMPTOMS \rightarrow add:

except for what was recorded in her 3-page symptom log that no one wanted to read

Contextualize MAN \rightarrow add after paragraph:

Mitch asks 3 times successively, as I shiver in the wheelchair, if I'm pregnant. I stare at him like he's a dumbass before I remember to say no. He's incredulous. I add that I've never had penetrative sex with a man and lately it's been women only, no genital-to-genital contact. His face and voice convey his disbelief, that a fit-appearing woman in her reproductive years is still a "virgin." Despite the biomedical desire for detached objective language, that word, with its connotations of purity and innocence, is somewhere in my record, lending credence to exoticizing Eurocentric stereotypes about good South Asian girls and chastity. The patient body is racialized aloud but deracinated in the record and colonized by discursive assumptions of and around whiteness, making it easy to treat her pain as biological, not biocultural (Morris, 2000).

Theorize MEDICAL HISTORY \rightarrow turn to: theorize MEDICAL

HISTORY

Theorize $VS \rightarrow$ turn to: theorize VS

Theorize MEDICAL HISTORY

Rewriting my patient narrative with the more established, visualizable diagnosis of rheumatoid arthritis instead of fibromyalgia reflects how little the PA believes in its medical legitimacy. He rhetorically modifies his reading of my bodily reality to exaggerate the facticity of his account, framing himself as the bearer of indisputable truths, sanctioning the conclusions he draws about me (Greenhalgh, 2001, p. 255). Altering my record as an expert, whose ethos and authority of argument derive from the fact of being expert, is a rhetorical move to assure other physicians of the validity of his opinion: i.e., he accrues social and symbolic capital by "correcting" a diagnosis that, however longstanding it is in my record, remains scientifically contested in the field (Wolfe, 2009). The authority he confers upon himself by conflating ethos with logos lends credence to his claim that PID is "confirmed" on the CT scan (Miller, 2003). This is despite the fact that the interpreting radiologist couldn't verify a single diagnosis and leaned more towards appendicitis, writing:

the phlegmon associated with the distal appendix, and poor definition of the distal aspect of the appendix and asymmetric inflammation centered on the right fallopian tube and sigmoid is suggestive of a chronic perforated appendicitis without drainable abscess visualized. However, pelvic inflammatory disease cannot be definitively excluded.

Order of diagnosis in the instance of two competing diagnoses isn't unheard of, but, from a rhetorical standpoint, the first in the series is emphasized. Mitch begins with PID, and by virtue of his position as white male expert, assures future physician-authors of my body that the visual evidence supports this sequence. Miller (2003) writes that the scientist's reliance on expertise is an argument from authority, within a disciplinary expectation that hypotheses should be supported by empirical evidence and sound reasoning (logos) without a turn to emotion (pathos) or character (ethos). "By treating expert opinion as data and detaching it, to the extent possible, from the character that authorizes it, [the medical expert] rhetorically transforms ethos into logos" (p. 184), at which point physicians can rewrite patient bodies with impunity. The PA's misdiagnosis of me carries the force of this expert-ethos rhetorical appeal, is justified as "past medical history," becomes in my patient records my new past. Despite its falsity, if I say that it's wrong, I challenge this expertise; I effectively present myself as noncompliant.

Translate SEQUENCE \rightarrow add after paragraph:

Really what he's saying, by changing my diagnosis, is that I'm unreliable, meaning, from chronic to acute pain experiences, I shouldn't be believed.

Theorize VS

The ICD-9-CM Official Guidelines for Coding and Reporting states:

In those rare instances when two or more contrasting or comparative diagnoses are documented as 'either/or' (or similar terminology), they are coded as if the diagnoses were confirmed and the diagnoses are sequenced according to the circumstances of the admission. If no further determination can be made as to which diagnosis should be principal, either diagnosis may be sequenced first. (p. 89)

Order matters. The first radiologist who orders and interprets my CT scan sequences it "appendicitis vs PID" but the order is switched here, a rhetorical choice that subtly, credibly furthers the PA's argument (Miller, 2003): that the CT scan somehow suggests I'm one of the rare unlucky few who get PID without vaginal symptoms, urinary symptoms, or fever, with elevated liver and pancreatic enzymes, all while abstaining from sex.

→ OTHER

Review of **Systems**.

Constitutional: Negative for fever, chills, diaphoresis, fatigue and unexpected weight change.

HENT: Negative. Negative for sore throat.

Eyes: Negative.

Respiratory: Negative. Negative for cough and shortness of breath.

Cardiovascular: Negative. Negative for chest pain.

Gastrointestinal: Positive for abdominal pain. Negative for nausea, vomiting, diarrhea, constipation, blood in stool, melena, hematochezia, abdominal distension, anal bleeding, rectal pain, anorexia, flatus and hematemesis.

Genitourinary: Negative. Negative for dysuria, hematuria, vaginal bleeding and vaginal discharge.

Neurological: Negative.

Psychiatric/Behavioral: Negative.

Pain Score: 3 - Three

Fact-check/wrong FATIGUE \rightarrow change to:

fatigue

Fact-check/wrong UNEXPECTED \rightarrow add:

(loss of 10-15 lbs)

Fact-check/wrong NAUSEA \rightarrow change to:

nausea

Fact-check/still wrong VOMITING \rightarrow change to:

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vomiting

Fact-check/wrong again DIARRHEA \rightarrow change to:

diarrhea

Fact-check/how can you be this wrong CONSTIPATION \rightarrow change to:

constipation

Fact-check/wrong again RECTAL PAIN \rightarrow add:

(not constant but intermittent, stabbing, excruciating)

Fact-check/are you even listening to me ANOREXIA \rightarrow change to:

anorexia

Embody DISCHARGE \rightarrow add:

a primary symptom of PID

Embody/come the fuck on [NEUROLOGICAL:] NEGATIVE \rightarrow change

to:

Pt describes episodes of confusion and disorientation, failure to recognize familiar surroundings, inability to concentrate, poor coordination

Embody/you're not even trying are you

[PSYCHIATRIC/BEHAVIORAL:] NEGATIVE \rightarrow change to:

Pt prefers death to the pain, describes high anxiety, constant sense of impending doom

Embody/ $\langle 2 \rangle \langle 2 \rangle \langle 3 \rangle$ - THREE \rightarrow change to:

>10. The last time I was a 3 was before my sophomore year of high school, when I told the nurse my pain was a 7/10 and she called me "a trooper," and since 2006 I've never reported anything less than a 6, and since the beginning of this year, nothing lower than an 8.

→ REVIEW

Physical Exam.

Constitutional: She is oriented to person, place, and time. She appears welldeveloped and well-nourished.

Head: Normocephalic.

Eyes: Pupils are equal, round, and reactive to light.

Neck: Normal range of motion.

Cardiovascular: Normal rate and regular rhythm.

Pulmonary/Chest: Effort normal and breath sounds normal.

Abdominal: Soft. She exhibits no distension and no mass. There is tenderness. There is rebound and guarding. Generalized tenderness noted upon palpation of the RLQ, soft, round, guarding noted with palpation of the RLQ

Neurological: She is alert and oriented to person, place, and time.

Skin: She is not diaphoretic.

Psychiatric: She has a normal mood and affect. Her behavior is normal. Judgment and thought content normal.

Translate NORMOCEPHALIC \rightarrow change to:

Without significant abnormalities

Translate DIAPHORETIC \rightarrow change to:

She is not perspiring heavily

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Fact-check/no WELL=DEVELOPED \rightarrow change to:

to have lost approx 10 lbs since her previous clinical visit and is gaunt-faced with prominent costal cartilage

Fact-check/no WELL=NOURISHED \rightarrow change to:

she hasn't eaten solid food in 3 weeks, surviving on coconut water and 1-2 protein shakes daily

Fact-check/still no NORMAL \rightarrow change to:

Fixed, esp limited to the left, range of motion

Fact-check/sigh NORMAL RATE AND REGULAR RHYTHM → change

to:

Pt has a recorded history of tachycardia, pulse ranging from 90-140 bpm at rest.

Fact-check/not quite MASS \rightarrow add:

(oh, it's there, but missed because Mitch doesn't palpate where I point)

Theorize NORMAL \rightarrow turn to: theorize NORMAL

Theorize NORMAL

"Normal": an invention of European industrial society, a constellation of words that enter European languages and consciousness between 1840-1860. "The 'problem' is not the person with disabilities; the problem is the way that normalcy is constructed to create the 'problem' of the disabled person" (Davis, 1995, p. 24): a person who is deviant, depraved, unfit, abnormal, pathological. In the emergency room, I *want* to be pathological. My "normal" is already deviance, but even by my standards, I was decidedly not myself, which a dialogue about the biocultural dimensions of pain might have revealed.

→ EXAM

Emergency GYN Referral

Amylase: 111, Lipase: 488

Pt is a 30 y.o. virginal female with 3 week history 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. TVUS does show a right pelvic mass that may represent an inflamed fallopian tube? Patient 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.

Translate/means $AMYLASE \rightarrow add$:

pancreatic enzyme

Translate 111 \rightarrow add:

(normal range being 23 - 85 U/L)

Translate/means LIPASE \rightarrow add:

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pancreatic enzyme

Translate 488 \rightarrow add:

(normal range being 0 - 160 U/L)

Translate/means $CMT \rightarrow change$ to:

cervical motion tenderness

Translate/means $ADNEXAL \rightarrow add$:

(area of the uterus, ovaries, and fallopian tubes)

Translate/means TVUS \rightarrow change to:

Transvaginal ultrasound

Translate/means $TOA \rightarrow$ change to:

tubo-ovarian abscess

Embody TEARS \rightarrow change to:

hysterical sobbing and hyperventilation, gasped pleas, vayiru nohuthu, ai aiyo

Embody VOICE \rightarrow add:

through her screaming and begging, "Don't, it hurts,"

Embody TEAM \rightarrow add after paragraph:

No matter that the radiologist, Dr. Tamas, looks South Asian and my age. Pathos undermines the expert's reliance on logos, and like many South Asian women I encounter in professional settings, she has something to prove. She is sharply exasperated with my body's opacity. She demands I "hold still," berating me for the arhetorical involuntarity that proves I'm genuinely in pain.

Theorize/ஏலாது UNABLE → turn to: theorize UNABLE

Theorize UNABLE

Pain is viewed in Western modern biomedicine as subjective, interior, and unshareable (Scarry, 1985). Others have argued that pain is intersubjectively constructed and understood, or must be understood as biocultural, or that modern understandings of pain are filtered through bourgeois propriety and the advent of anesthetics (Halttunen, 1995; Morris, 2000; Graham, 2009; Padfield, 2011; Selznick, 2017).

But some corollaries stubbornly inhere in the discursive framing of acute pain and chronic pain, as the two are frequently conflated. Drawing on Yergeau's (2018) work on autism, rhetoric, and the agency and value of autistic people, we can say that:

- **1.** Pain is sensorily overwhelming. Nothing else matters until the pain is dealt with.
- **2.** Given that it's overwhelming, pain is incommunicable.
- **3.** Pain is involuntary. For the duration of the pain experience, this involuntarity is perceived, medically and popularly, as something that

prevents individuals from exercising free will and precludes them from accessing self-knowledge and knowledge of human others. Its subjects are not subjects in the agentive sense of the word, but are rather passively subject to the motions of brains and dermis gone awry. (Yergeau, 2018, p. 8)

The movements of pain, such as hysterically backing further and further up on a gurney to escape a vaginal probe that inexorably presses in, or flailing blows at my bodyworker Sara during massage, or otherwise resisting experts who ostensibly want to help, signify *lack*: "a lack of purpose, a lack of audience awareness, a lack of control over one's own person" (p. 8).

4. As an incommunicable, involuntary state that can't be switched on and off, pain severs the sufferer from the world, medically and popularly constructing her as *mindless*: you *go out of your mind* with *real* pain, reduced to animal noises, non-human responses, pey pidichittu, ghostly possession. It doesn't matter what my scholarly credentials are; when I cease passing as nondisabled, when I/pain mutually embrace, I become arhetorical, a canvas for discursive interpretation and technological intervention.

These corollaries manifest in my records and my clinical encounters in the emergency medicine department. How I become a passive, emphatically gendered and deracinated patient, deemed incapable of normative Euro-Western rhetorical performances of pain, such that no sound, spasm, or headwaggle I produce signifies (Segal, 2005; Yergeau, 2018).

Embody DERACINATED

The transvaginal ultrasound calls to mind every story I know of Tamil women raped in the course of war and triumph. I'm a thousand-yard stare forgetful of the gaze staring back, the OB/GYN radiologist resident-expert who can now impose any interpretive grid or diagnosis on me without my narrative input, because I've succumbed to rhetorical involuntariness (Yergeau, 2018); my moans and convulsions communicate, but modern Euro-Western biomedicine reads in them only helpless lack and need. All I can do is scream, so others get to speak for me, and as educated as I am, I am told nothing. An easy defusing of the threat I pose, the patient who claims self-knowledge and wields it like Vasavi Shakti to cut through Ghatotkacha's illusions. I must part this veil by ordering the clinical encounter notes I am not automatically given, by closely reviewing my patient records for critical details that were not said. In them, I am not present as coauthor, subject of discourse, or even object of study. So much of me is rewritten as someone's colonialist, gendered fiction of pain and lack. The more I follow the paper trail, the more I expose my desire for knowledge or accountability, the more I erode my chances of receiving care. Damned if you do, damned if you don't. This is the game you are playing.

Contextualize/a $\rho e^a \varsigma^o \hat{y} A \neq VASAVI SHAKTI \rightarrow change:$

Karna's terrible and powerful astra, Indra's own

Contextualize ILLUSIONS \rightarrow add:

to perceive the truth of what was there on the battlefield, Karna was forced to use Vasavi Shakti, which he'd reserved to kill Arjuna, to defeat the halfrakshasa Ghatotkacha

Theorize GAME \rightarrow turn to: theorize GAME

Theorize **GAME**

In his explanation of illusio, Bourdieu (1994/1998) states that "agents welladjusted to the game are possessed by the game, and doubtless all the more so the better they master it" (p. 79). Paternalistic expertise and this "feel for the game" give rise to "pre-perceptive anticipations, a sort of practical induction based on previous experience" (p. 80). The notion of illusio ascribes importance to the social games in a professional field that are natural and invisible to enculturated members, and legitimacy to the professional capital specific to the field. The medical professional obtains the necessary qualifications and credentials and behaves according to the field's habitus. The clinical practitioner accrues symbolic capital by evaluating and treating patients with swiftness and accuracy. Correct pre-perceptive anticipations demonstrate an expert "feel for the game" that is "the product of a relation of ontological complicity between mental structures and the objective structures of social space" (p. 77). I am not an MD, not supposed to recognize the game or the aspirations of its players, not meant to have a feel for it, and yet I have a vested interest in doing so. As a chronically ill patient who is chronically misbelieved, attaining a "feel for the game"—assessing how practitioners accumulate symbolic capital in pursuit of the field's rewards can mean the difference between life or death.

Such was the case here.

Translate A PROFESSIONAL FIELD \rightarrow change to:

medicine, in this case,

Translate ENCULTURATED MEMBERS \rightarrow change to:

doctors, med students, but also chronically ill patients who become embedded in the field

→ HERE

ERS Attestation. Han-jae Kim, MD.

Pt is a 30 y.o. G0 virginal female with history of fibromyalgia, spondyloarthropathy, anxiety and depression c/o 3 week history of severe abdominal pain that came on suddenly. Patient reports pain that initially started at the umbilicus and progressively radiated to the right lower quadrant. During the first week of pain she said it was so bad she would have "rather died." She had associated nausea, 1 emesis that week, with anorexia and diarrhea. The pain has improved slightly but persisted. She is now tolerating PO and reports constipation with hard pellet stools; last episode yesterday morning. She has been unable to go to work on several occasions because of severe pain. She has tried an "antispasmodic," Motrin and tramadol which Have not relieved her pain. Patient denies fevers, chills, current nausea or vomiting, sob/cp, dysuria, hematuria, urgency, frequency, dizziness, SI/HI, abnormal uterine bleeding, abnormal vaginal discharge. **PMH**: fibromyalgia, depression, anxiety (hx of suicidal attempt at age 20) spondyloarthropathy. **GYN Hx**: 14/28/4-5 with frequent intermenstrual spotting + dysmenorrhea and menorrhagia x 2 days [...] History of LOV cyst 4cm in 2012 that resolved while on OCPs. Patient is sexually intimate with females but denies sharing of genital body fluids, last contact in July. Denies male sexual intercourse. Gen: Crying during exam reporting feeling a lot of pressure with vaginal probe and pain with abdominal probe. **Skin**: Carved skin scars on bilateral thighs of imagery which patient says represent "working tools."

Translate/means $\mathbf{G0} \rightarrow$ change to:

zero pregnancies

Translate/means $PO \rightarrow$ change to:

per os (by mouth)

Translate/means $SOB \rightarrow$ change to:

shortness of breath

Translate/means $CP \rightarrow$ change to:

cerebral palsy

Translate/means $SI \rightarrow$ change to:

suicidal ideation

Translate/means $HI \rightarrow$ change to:

homicidal ideation

Translate/means DYSMENORRHEA \rightarrow change to:

menstrual cramps

Translate/means MENORRHAGIA \rightarrow change to:

heavy menstrual bleeding

Translate/means LOV \rightarrow change to:

left ovarian cyst

Translate/means OCPS \rightarrow change to:

oral contraceptives

35 — THE GAME

Embody INTERCOURSE \rightarrow add:

but denies is a strong word to use so cavalierly. Its use here exonerates the PA for doubting my queer sexual history, for seemingly presuming a South Asian girl must be chaste and straight and letting that presumption dictate those first traumatic tests.

Embody CRYING \rightarrow change to:

Hysterically sobbing and hyperventilating

Contextualize ATTESTATION \rightarrow add:

the first attempt to rectify the errors earlier in my clinical encounter notes, though those errors can't be erased

Contextualize $MD \rightarrow add$:

It occurs to me that East and South Asian male doctors most accurately represented my embodied experience of internal rupture.

Contextualize $HX \rightarrow add$ after paragraph:

In retrospect, I should never have admitted this. I gave them the tools to sculpt me into a hysteric, the most prescientific and contemporary of female maladies, "a convenient diagnostic box for imprisoning women whom male doctors were unable to cure" (Morris, 1991, p. 109).

Contextualize WORKING TOOLS \rightarrow add after paragraph:

Quoting me is significant, even if the quote is incorrect. Dr. Kim sees me as rhetorical, if not a co-author, able to influence the construction of my record. But he filters my descriptions of my scarified imagery of hacker "tools of the trade" through the expert lens of Euro-Western medical science, which views body modification as "a highly deviant appropriation of medical procedures" (Pitts, 2003, p. 174) that furthers my appearance as a noncompliant, denaturalized body. "Carved" itself is a strange description. It's the strongest verb in my emergency room records, and without a pronoun or referent performing the action, and with my listed history of suicidal attempts, the phrasing almost suggests I did it to myself.

→ UMBILICUS

General Surgery Encounter Notes. Sandeep Sattva, MD

Unclear history. High level of anxiety and pain that is significantly worse than typical fibromyalgia. Constipated. Passed out recently from straining for BM. Tender in lower midline, not RLQ. Exam not typical of appendicitis, but patient in such pain, that she is interested in a diagnostic laparoscopy.

Source of Information: patient. Reliability: good

Embody $MD \rightarrow add$:

a young doctor of South Asian descent who looked like the kind of cousin I'd call அண்ணன், and who spoke to me like he understood that the nonverbal involuntarity of pain continues to rhetorically convey.

Contextualize FIBROMYALGIA \rightarrow add:

We're not the same kind of South Asian, but he's like my desi homeboy when he says, "If you have fibromyalgia and you're calling this pain excruciating, it must be really bad." Re-diagnosing me with "fibromyalgia" here is a welcome corrective, even though the previous attribution of RA remains.

Contextualize DIAGNOSTIC LAPAROSCOPY \rightarrow add after paragraph:

I was hesitant to ask, the same way you learn not to ask for painkillers as a chronic pain sufferer caught in a "discursive system that offers a cure through consumption, condemns the individual for using that cure, and holds the individual responsible when the cure does not work" (Patsavas, 2014, p. 210). There are easier ways to be clinically blacklisted than chasing surgery without the medical authority to justify the demand. But I pounced when Dr. Sattva suggested surgical exploration himself. Finally, a way to see and feel it, literally in the flesh. "Just cut it all out," I say. "I'll sign off on anything if the pain ends." I accidentally point to my rhetorical instability with this comment, but he laughs, and I decide for the first time in months that maybe I get to live.

Contextualize GOOD \rightarrow add after paragraph:

Being acknowledged as a reliable narrator of my pain experience legitimizes my patient narrative in the clinical setting, which is the first step in receiving care. It's significant that I'm only coded "reliable" at the end of my ER stay.

→ INFORMATION

During my search for a diagnosis from 2006 to 2007, I learned I couldn't easily win over physicians by acting like a compliant "good girl" out of my depth and desperate for a medical expert to cure me (Greenhalgh, 2001). I can't embody white femininity even when I perform its codes; tears belonging to a brown, hyphenated identity aren't strategic: crying might signal helplessness, but as Accapadi (2007) notes, "certain stereotypes of Asian-Americans characterize them as unfeeling and/or devoid of emotion" (p. 209), so my tears might be construed as manipulative. My low-pitched voice and my habit of speaking confidently about my bodily experience in medicalized language and asking questions without feminine dissembling contribute to an overall picture of me as more masculine than feminine. I fail the basic criteria of the model minority woman: being tractable, subservient to experts who expect faith based on their credentials, not on my understanding of the medical science being used to apprehend my body. And the fact that I'm inquisitive, that I know medical terminology, that I insist on understanding my diagnoses and treatment plans, makes me a would-be trespasser into the scientific domain. Once I understood

what my doctors wanted chronic pain to look like, and their notion of illusio, I learned my script for survival. But in the ER in 2014, starving, internally leaking for months, sexually traumatized by the TVUS, burning with the kind of righteous fury Kannagi Amman used to torch Madurai, I forgot my lines. I complained. Issued ultimatums. Didn't bother with sycophancy. Precluded the possibility of disability masquerade for myself, because I had no idea what a ruptured appendix was supposed to look like, and I didn't have a physician like Dr. Birnbaum, my diagnosing rheumatologist, to tell me how to exaggerate abdominal guarding or rebound tenderness in the right places, how to breathe, how to deploy my voice, how to facially cringe. So I did none of those things, and probably earned myself the overnight stay by being so articulately noncompliant, asserting I had chronic pain, I knew my interiority, I had two Ivy League degrees and was working on my doctorate, I didn't need their painkillers or blood work so much as a physician who gave a damn, and if I knew enough to take myself off methotrexate then I knew enough to make demands, and they couldn't keep me here, so if I wasn't attended to soon, I'd walk out and die. Silly, apologetic girls get treated, and I was the angry brown woman, discrediting my position with my rage.

good (white/straight/middle-class) girl

\mathfrak{S}/ω hich is METHOTREXATE \rightarrow change to:

an immunosuppressing medication no one told me to stop taking,

→ WALK OUT AND DIE

"Male privilege positions the nature of womanhood, while White privilege through history positions a White woman's reality as the universal norm of womanhood, leaving a woman of color defined by two layers of oppression" (Accapadi, 2007, p. 209). Given the caricatured stereotypes of South Asian

American women, who can't be queer and must stay chaste or lie about it, the white man PA interprets my pain as sexually derivative and is increasingly entrenched in this decision the more I push back against it—the clinician's version of flexing. It's a moment that demonstrates how prognosis and treatment are shaped by patient and physician belief, not just beliefs about disease, as Eisenberg (1988) argues, but also beliefs about the body being treated, the script of Eurocentric imperialism with its fantasy of the exotic, carnal South Asian woman who will always profess virginity. So he orders the TVUS to catch me in the lie. In GYN radiology, Dr. Tamas deems me histrionic without reason, as though because she can enact "model minority woman" in our exchange, I should be able to as well. Hers is not a co-constructed exploratory mission. She's rooting around in me for an objective picture based on what Mitch ordered, ruling out (or proving) PID. If she can't keep me still enough to image my pelvis, she's a failure, too, and how dare I, a fellow South Asian woman, undermine her. Ultimately her conclusion, that nothing in my labs suggested a GYN issue, echoes my assertions during the intake. Even this isn't enough to send me to the OR, I suspect because in the first set of clinical notes, the PA effectively recorded an unproven diagnosis as more established than it was and altered my chronic pain diagnosis and preexisting history to accord with his position, erasing my body and its rhetoricity. His notes are persuasive for every subsequent doctor, not because he used persuasive rhetoric but because the ordinary medical rhetoric of my record serves as an argument from authority. The white coat is all he needs to be assigned a smaller burden of proof. Expertise prevails until sufficient evidence refutes it, and the GYN couldn't get a clear, "objective" picture. The burden of proof continues to lie with me, the one vehemently disputing the initial expert presumption. Additionally, these were experts employed at NYU Langone, a prestigious teaching hospital, elevating their credibility and perhaps bias in favor of their eminence (Miller, 2003, p. 188). Regardless, the cascade of specialists and notes that follows reads like an adversarial display of competing expertise, each an attempt to position itself as more expert, more authoritative, in the game of their social field. Respecting the rules, the GYN doesn't directly challenge the PA, softening the blow by ending with "would recommend further workup by primary team," returning the expert role to the PA. The surgeon is the only one who

firmly overwrites the notes that preceded him, by recording "fibromyalgia," a biocultural interpretation of pain, and "reliability: good."

\rightarrow GOOD

These clinical encounter notes speak to a series of arguments from authority in the absence of reproducible, objective images that, as the truism goes, equate seeing with curing (van Dijck, 2005); the arguments *ad verecundiam* here coerce agreement based on respect for authority between members of the field (Miller, 2003), such that agreement means accepting the physician-author of the record as a fellow expert. One of the ways power relations manifest in the field. One of the ways experts accumulate the social capital that buttresses their expertise. All it takes is the conventional discursive construction of the patient as disembodied, misinformed, lying. I wonder if biocultural constructions of pain collided with racial expectations, given that the white man PA is so wrong and the South Asian man surgeon so right. The PA views me and my pain through Euro-Western medicine and caricaturization; the GYN sees me as noncompliant, struggling against the objectifying TVUS camera that could give me a definitive, authoritative answer; but the GI surgeon understands that I am risking everything—model minority status, credibility, life itself—by being adamant. Perhaps because he too is brown, and knows what happens when you speak up or talk back before you've earned the privilege. He has. He's as pedigreed as I am. He studied at Harvard and worked at Columbia, and at the rank of surgeon, and a male one at that, he has the authority to directly overwrite the PA's inaccuracies, correcting both my diagnosis and my reliability. I only get to be reliable, I think, because his own cultural background stops him from beginning with "good South" Asian girl," so he can rhetorically listen to me and perceive me as an Eelam Tamil American with vicarious trauma, a reflexively poetic Ivy League educated writer, a fibromyalgic woman qualified to assess and describe her bodily intensities, a person with "really cool" body modifications who understands how to cope with and harness pain. To him, I am a different kind of expert. I don't cease being rhetorical. His notes return my rhetoricity.

It's not lost on me, in the course of this discourse analysis, that I was lucky a brown surgeon was on call, that he respected my Ivy League degrees, believed I had fibromyalgia, and perceived my patient narrative as an argument from authority.

Against all odds, I survived.

~END

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