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Extended Bodies

By Alli Morgan

I count tiles. As I lay supine, leg extended in the air, the ceiling tiles become my roadmap. Twelve straight before the right-hand turn to get out of the unit; if we are going to radiology we make a sharp left, pause for the orderly to press the automatic door button, six more to get to the elevator. We descend into the basement, and pick up speed on the long stretch of twenty-eight tiles, hang another left and I am in the realm of the imaging where the hidden becomes visible. The first line of offense in treatment, the last line of defense in the validation of a patient's experience is the technical ability to "see" the pain. The surgeon can ascertain the physical pain of the patient not through empathizing, but through visualizing. If this visualization isn't happening in the surgical suite, his preferred field of practice, he will delegate this exercise to a third party, the radiology department, in order to get an explicit understanding of bodily truth. If we make another right after passing the six imaging rooms, we arrive at the interventional radiology suite. Here, my veins were extended with synthetic otherness in order to provide my medications and feedings. "Interventional" is a misnomer. Intervention implies the act of intervening, *to occur between*. Instead they are extending the physical body, prolonging the experience of patienthood. My vasculature is obstructed, scarred from the years of placing these lines. To the outside observer, one without the medical gaze, my arms look like those of a heroin addict. Speckled with bruises from attempts to gain peripheral access, even the vasculature of my feet is collapsed. Even with the aided gaze of the fluoroscope, my anatomy provides no unobstructed channel to feed the guide wire from my brachial vein into the superior vena cava. It was here, where several radiologists were called in to break through the scar tissue, and at last, my PICC line was inserted.

If we keep going straight out of the unit instead of taking the left to radiology, we are likely going to surgery. If I see Dora the Explorer on the ceiling tiles it means I am in pre-op holding area one, the blue stars belong to room two, and Finding Nemo is in room three. These pediatric decorative practices are ubiquitous in the children's hospital; while I imagine they may bring comfort to small children during long stays, they seem to be cruelly mocking the parents and older patients. They serve as reminders of a normal childhood that will never be attained; the suspension of the pediatric patient in age, the object of care that allows for little development of individuality. To the older pediatric patient, these characters are reminders of an extension of childhood through an extended period of dependency, certainly out of synch with their "well" peers' burgeoning independence.

Today, we stop at X-ray, a seemingly banal technical practice when held in juxtaposition to the more impressive types of imaging that my body has endured.

Pins extend from six places, two in the femur, two in the tibia, and two in the first metatarsal of the foot. The pins are embedded in the bones, and extend upwards through the muscle, fat, and skin and protrude a few inches out from the body. From here, the pins are connected with rods and brackets to form what is termed an "external fixator," a medical device seemingly closer in relation to a child's erector set than to any device we are accustomed to seeing in contemporary western medical practice. The surgeon connects these rods in a fashion that fully extends the leg, ideally providing a range of motion of zero degrees, completely straight, completely immobile. The boundaries between the flesh and the pin and the outside environment must be carefully attended to. At the junction of the pin and the body, the flesh begins to grow up the pins like vines up a trellis, but red and angry. This tissue is pushed back down by the wound care nurse, impeded from growing, much like the pushing back of the cuticle during a pedicure, except this is a pedicure with blood and pus. When the pins in my foot begin to grow loose, the integrity of this vehement insistence on straightness is compromised. Having no feeling in the metatarsal the screws are embedded in, I move them with my fingers, transfixed on the way in which some pins are being rejected by the bones, while others are being engulfed and welcomed into the body. Neither phenomenon is acceptable to my surgeons. The pins must sit in a perfect equilibrium with the body, neither working themselves loose, nor becoming too attached. They are lightning rods for the introduction of bacteria into the bone, synthetic extensions of the natural body, a natural body that has been extended physically and temporally. Their waywardness is what has beckoned us to radiology today.

The scans of my leg are awkwardly tucked under the arm of the resident as he and his attending enter my room. I haven't bothered to remember this one's name. He's just another cutter. One of the many surgeons in training who will use his tools to subject my body to hours of controlled trauma in the operating theatre. The surgeons attempt to make small talk, but talking about the weather with a patient who hasn't even looked out of a window in a month is not the quickest way to garner respect. I tell them to get to the point, motioning towards the scans. Proof of my body's misbehavior, the scans spell out, literally in black and white, what my descriptions of feeling couldn't completely elucidate to the physicians. "Osteomyelitis--infection of the bone, just as we expected." Ah, the universal "we." Often thrown around in medical practice, the "we" can mean any one of a variety of social relations. The "we" of a medical team, the "we" of the hospital, the "we" of the doctor-patient dynamic. I agree that "we" should do surgery, or rather, my mother signs the consent forms that "we" will go under the knife.

The hospital stay hits the one week mark, breaking the limits of what could be someday be brushed off or reduced to a hospital stay of the otherwise healthy body; the patient who becomes a bit too dehydrated and needs a few days of intravenous fluids, the surgical patient who needs to stay a few extra days to stabilize, the new mother who just gave birth. No, stays that stretch into weeks are those of the broken. These are the patients with charts as thick as phone books, with an almost comparable number of actors involved. Upon my admittance this time, the extensions placed on the double lumens of my peripherally inserted central catheter (PICC) line were removed. The tubular extensions were connected to the ports that extended a few inches from my upper arm, allowing enough distance to allow for the use of both hands, thus giving me the autonomy to push my own medication at home. I had anticipated the loss of the usual suspects upon this hospitalization; the ability to wear one's own clothing, the modesty, the door, but what I hadn't expected was the symbolic impact of losing these extensions. While I certainly knew that I wouldn't be controlling my medications in the same way I had at home, never mind actually pushing them, their removal was confirmation of the little power I had.

By the one-week mark, the novelty of being in the hospital begins to wear off, not just for the patient but for those in the outside world as well. No matter how frequently the patient is hospitalized, the first few days bring phone calls from family and friends, feigning worry, foddering gossip, and initiating the prayer chains. They frequently state, "I can't imagine" when all they are doing is precisely this. They don't seek to understand the pain or the uncertainty as I/we are experiencing it, but imagine what it were to look like if it were overlaid on their lives, their experiences. But after the first few days, we see two distinct phenomena present in those involved, but not physically present in the patient's life—they either become increasingly concerned by this prolonged hospitalization and retreat for fear of interfering with what they can only imagine is a traumatic scene at the bedside, or their concern begins to dissipate and is replaced by the tangible worries of their everyday life. Either way, the absence of their phone calls is a pleasant reprieve for the patient and those with the patient. By the one-week mark, the patient's outside life begins to fade away, sometimes naturally, sometimes in an act of forced repression.

August turns to September as we mark one month of hospitalization. Long forgotten are the worries of the outside world, other than the lingering worry of whether I will return to it. I'm sometimes reminded of the existence of the space beyond the curtains of my room when a nurse will tell a story about their child's soccer game or when my mother's clothing choices reflect a change in season. We don't discuss the possibility of my "going home" anymore. While going home marks the terminal goal with most prolonged hospitalizations, for me, going home would signal the exhaustion of all medical resources, the failure of the diagnostic process, and the loss of hope for a future. The provider-patient bond is no longer fostered through shared discussion of anticipatory narratives. While we once grew close over the disclosure of our identities as people outside of the hospital, with this existence in realistic jeopardy we don't engage in conversation alluding to its possibility.

During this extended hospitalization, I quickly become a student in the art of discerning medical specialty from the length of white coat alone. The short white coats of the third-year medical students were particularly starched in July when they started their first rounds on the wards. The stains on John's white coat were not the battle stains from lives saved in long overnight shifts, as sometimes seen on the coats of the experienced residents, but instead, the stains of battles lost in the hospital cafeteria. By this point I was well versed in judging practitioners quickly, sometimes before they ever entered my room. With little else to do, I would assess how long they washed their hands, with what tone the used to speak to the nurses, and note if they were wearing brown shoes with black pants. I was particularly quick to cast judgment upon the medical students.

I immediately disliked John. He was shaky, hesitant, and stared at my leg for too long. Tasked with completing a medically unnecessary physical exam, his hands were cold and clammy. As he slipped on the exam gloves, he ripped a hole in one as he shook. His hand trembled as he reached for his stethoscope and awkwardly reached into my gown. Usually, the stethoscope became the medium for seeing in; the refocused object of the medical gaze. But to the medical student, who oftentimes has his earpieces in backwards, the stethoscope isn't a means of seeing or hearing in, it's an exercise in learning the delicate art of invasion. "May I take a listen?" is undoubtedly easier than, "Please tell me about your medical history." At first, I wasn't sure why he became so flustered when he reached into my gown. I soon found out that he was confused and dumbfounded by the presence of my bra. A small exercise in resistance and an effort to retain some sense of humility, I would attempt to wear my own clothing during my non-emergent hospital stays. We all knew that I would break down within a few days, and agree to wear the hospital gown that dozens before me undoubtedly died in.

Even before John was finished with the exam I began to dread the month he would spend on the pediatric unit. I was sick of explaining my story to the medical students. They didn't *listen* to my narrative, they *took* my medical history. But just after John finally succeeded in throwing away his used gloves after an extended struggle with the foot pedal on the garbage can, he redeemed himself. John extended his hand to shake mine. What may seem like such a small and usually obligatory display of formality became an incredibly powerful gesture to the patient who is usually only treated as a body, a disease, a condition. The handshake implied a personhood, a trust, and a physical touch that only so far occurred under the auspices of medical treatment, with the barrier of the gloves protecting from any actual contact. While the handshake is not uncommon in outpatient visits, it is rarely seen in the inpatient setting, at least directed towards the patient. My father was often offered the hand of the male physicians, and my mother usually only upon their first meeting. The patient is a customer of the physician in the outpatient setting; the physician must work to keep the business of the patient. In the hospital, physicians are assigned patients with the patient having little say in choice of physician, with no room for movement.

A week after finally being discharged from the hospital, I lay in the back of my parents rusted old Ford Taurus, foot propped where the window meets the door, head propped on pillows that can't seem to shake the smell of blood and infectious fluids despite my mother's nearly pathological relationship with our laundry machine. The smell has almost become comforting; the harsh contrast of the antimicrobial detergent and the smell of the most natural of biologic processes indicate what lies beneath the frequently changed pillowcases. Underneath lie stains of varying colors and sizes; sometimes overlapping, they provide a visual chronology of my body's slip into illness. The large faded red-brown splotch of concentric circles denotes that morning, months past, when I woke to a large hemorrhaging of my leg. The yellow splotches cover one side of the pillow in a Rorschach like pattern; the pus from my infected pins leaked with reckless abandon, leaving traces of their microorganism ridden biomes onto the pillow, each with their characteristic color and pattern. These stains are often precursors to the *stains* that will come next, the physician's culturing of the wound in efforts to name the bacteria. The stains on my pillows and dirty bandages are as much proof of the death that is harbored inside my leg as the stained culture slides, though, this visual history bears little clinical weight compared with the results that will come from the pathologist's office after a few days wait. While I can tell how fast the blood was flowing based on the chronology of stains on my dressings and my pillows, my physicians do not and cannot put my pillows and contaminated gauze into my medical chart as fact. Like a bad grade on a report card, the stains mark the wrongdoing of the body, the straying from normal, the social significance of a body that cannot contain itself, neither to the body proper nor to one clinical provider.

My mother extends my multi-page medication list to the triage nurse of the Emergency Department, we are whisked away to a room, and I extend my arm for the emergency blood cultures to be taken. The results of these cultures bring us to another illustration of this extension of the body, the very legal document that bears its name, the "Extension Doctrine."

Upon consenting to a particular surgery, the patient also consents to a potential extension of treatment at the discretion of the physician. My last encounter with the act of clinical extension ironically came through the employment of this doctrine. Agreeing that my now trusted surgeon could make an assessment during surgery and “extend” what I agreed to in the surgical consent form, we all knew what this could mean. When he saw that the leg was not worth saving, he extended the bone saw and went to work. Today, my biologic body is extended by means of artificial prosthesis; no longer extension of pain or time, this is an extension that makes mobile, makes whole.

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