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They were perceived as dens of death. Desolate, decaying spaces for sick persons desperate for relief, who were admitted and faced with the likelihood never to return home. These were spaces of discovery, where technology, expertise, and experimentation banded together to take up arms in the battle against disease, spaces where bodies were stitched back together, where hope reigned again. More than mere institutions, since the nineteenth century, hospitals have defined the parameters of health and illness—often along class, racial, and gendered lines—even altering the landscape of healthcare delivery during disease outbreaks.

Hospitals are also spaces of pain. As the loci for recovery and rehabilitation, they become contested spaces between patients and professionals, where the clinic is pitted against the body and where expertise over diagnosis, validation, and recognition is continuously negotiated. Julie Anderson writes, that for medical rehabilitation to be successful, it needed to be intensive and controlled, often by regulating the space whereby the therapy took place, with the spaces then becoming a significant part of patient experience.[1] Specific spaces were created for specific diseases, though their architectural design did not always safeguard the embodied experience of rehabilitation. For endometriosis survivors in particular, hospitals are vexed spaces: a place where pain is dismissed and symptoms are ridiculed, but the only place with lifesaving technologies to transform their lives. This essay tells the tale of three hospitals where I received starkly different levels of care and the trauma that persisted long after I was discharged. Together, all three hospitals reveal expectations about the ethics of care, and the importance of creating and understanding the interconnections between bodies and space.

Pain narratives offer a crucial approach for understanding the ethics of care and how patient experiences can be shaped by the spaces that encompass them, whether it is a hospital, clinic, or at

home. Disability scholars philosophize that pain has a distinct experiential quality that is only perceived through first-hand, personalized experience—either as a feeling-sensation or as an emotion—with pain phenomenology providing us the tools to understand the nature of pain as *pure* experience.[2] Outside the realm of biology and sociology, pain blurs the fluid line between illness and disease. Pain manifests, Travis Chi Wing Lau tells us, and “diagnostic imaging realizes that pain by bringing it to light from its hidden recesses within the body. Yet even when it manifests, the experience of pain remains so idiosyncratic to the individual.”[3] With endometriosis, you live in a land administered by crimp time, existing in a liminal space controlled by flareups sending tendrils underneath the flesh, binding organs together, scarring muscle and tissue. The pain overwhelms you, steals your time, and twists your bodymind into grotesque forms such that you no longer recognize yourself. You mourn the loss of previous capacities and imagined futures.[4]

Elaine Scarry taught us pain exists outside of language, and Havi Carel convinced us illness is the cry of the flesh.[5] Can pain exist outside of space? I think pain is grief.

We lived across the street from Hospital 1, in a busy part of a Canadian city. It became somewhat of a monthly—then weekly—routine to go to the emergency room and spend a lot of time waiting. Sometimes I was brought there by ambulance and sat in a wheelchair for hours, wrapped in a blanket, my pajamas, and socks. No shoes, of course, because the paramedics came too quickly for me to grab them. Sometimes I was quickly assessed and sent home with pain meds and no diagnosis. Other times, my partner and I gave up and walked home, me in my socks and no shoes. Hospital 1 was also where I screamed in agony, sobbed uncontrollably, and demanded an expert consultation as scan after scan showed no evidence of pain. I was sick and tired, but I was “fine.”[6] After weeks, it became the space where my pain was finally taken seriously, and I was admitted for further consultation and treatment. My deafness was acknowledged—they noted it on the patient chart—and the reality of a possible malignancy and hysterectomy sensitively handled. But perhaps cruelly, I was admitted to suite in the maternity ward, because no beds were available in general surgery. One night my screams sang the same song as the laboring person in the next room; our pain joined together in shared suffering.

It became clear I needed surgical treatment that Hospital 1 could not provide. One evening long after visiting hours were over, two orderlies and a nurse came to take me to the ambulance transfer, explaining I was being admitted for surgery within the next day or two. When the orderlies went to reception to register me in Hospital 2, they learned a bed was not yet available; I waited in the wheelchair for what seemed like hours—on a hydromorphone drip, you lose your sense of time—before I was on a bed, in a shared room, maybe a third of the size of my former suite. There was no chair for my partner. The hallways were overcrowded with supplies and equipment. The lights occasionally flickered. This was a ward where people wait for surgery or death, a place with no security or comfort. Here, a patient becomes a subject and not a person, their autonomy stripped like the sheets the orderly took from my bed while I slept. I went without food, because they forgot to update my chart; my calls for help went unheard through the empty corridors, and when

someone came, it was usually because my IV drip loosened from my arm, sending off alarm bells that I could not hear.

At Hospital 2, I was constantly terrified. My partner had no space to sit or work, so he went to the lounge and stayed in touch with me through text chats. Decisions were made without full explanation, though they kept reminding me I was here for surgery. Every day, they told me, was my surgery day. Every day passed with no answer. Then one afternoon, shortly after my partner left to pick up lunch, the surgeons arrived to tell me I was being discharged: the cancer they suspected I had was “merely” an endometrial mass and thus, outside their jurisdiction. I went home, with the eight- or nine-centimeter mass—sometimes they told me it was six or seven—still in my body, crestfallen and terrified at the prospect of suffering for a few more months until it would be removed, if it would even be removed at all. At this time, I had no guarantee, only fleeting promises of cure.

Eight months later, I was admitted to Hospital 3. It was two months since I had the surgery to remove the mass, and I was experiencing unusual complications—fever, rash, and anaphylaxis—which indicated I was having an allergy attack, even though I had no documented allergies. An EpiPen shot helped to stabilize my symptoms, but only for a little while, as there in the emergency room, my temperature soared as my blood pressure dropped to dangerously low levels. Specialists were called for an assessment. Hours later, with little improvement, I was taken to the sleek and sterile intensive care unit. Pain meds were provided at easy disposal, and for the next few days, numerous specialists came into my room to take my vitals, draw more blood, examine me, in what seemed like a futile quest to diagnose my mystery illness. While with the previous hospital experiences I never worried about the costs, Hospital 3 was different—it was American, as we had relocated to the U.S. for my new job. With every test, expert, medication, I silently calculated what it would cost me and how much would be covered by insurance; the stress of this affected my ability to rest, as much as the ill-equipped waterbed did. The lights were hardly turned off, and thus my mind was always running, worrying about how we would survive not just this latest encounter, but our future. How could we live our dreams if we were straddled with immense debt, mere months after starting a new job? I couldn't sleep. I had nightmares. Days later, I had enough of being poked and prodded without any improvement and discharged myself against medical advice.

For so long, I've been an unwell woman with an uncertain disease, repeating patterns of others who “emerged from the annals of medicine like so many matryoshka dolls.”^[7] Within these different spaces of healing, I found myself performing differently. I made myself invisible when I thought it best to defer to the hierarchical order in the hospital. Or, I screamed as loud as I could so they could testify to my agony, trying to cut through what Alex Haagaard describes as the “process of invisibilization mediated by the clinical gaze,” to demand the pain of my illness receive clinical recognition. This became a constant negotiation of carefully crafted responses so I could receive the care—if not cure—that my suffering body was yearning for. And in the process of waiting for the end of suffering, Bharat Venkat's words echo through my mind: “What happens when cures

instead come and go, when you can be cured and then cured again?”[8] Cure then becomes a fragile accomplishment, temporarily existing within the spaces where it resides.

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Image Source: “Watercolor of the London Fever Hospital, Liverpool Road, Islington,” by Nurse Flower (1891). Wellcome Library,

Notes

[1] Julie Anderson, “Disease, Rehabilitation and Pain,” in *The Routledge History of Disease*, ed. Mark Jackson (London and New York: Routledge, 2017), 322. See also: Dana Arnold, *The Spaces of the Hospital: Spatiality and Urban Change in London 1680-1820* (London and New York: Routledge, 2013).

[2] Saulius Geniusas, *The Phenomenology of Pain* (Athens, OH: Ohio University Press, 2020), 4-5.

[3] Travis Chi Wing Lau, “The Crip Poetics of Pain,” *Amodern 10: Disability Poetics* (December 2020).

[4] Emma Sheppard, “Performing Normal but Becoming Crip: Living with Chronic Pain,” *Scandinavian Journal of Disability Research* 22.1 (2020): 39-47.

[5] Elaine Scarry, *The Body in Pain: The Making and Unmaking of the World* (Oxford: Oxford University Press, 1985); Havi Carel, *Illness: The Cry of the Flesh*, 3rd Edition (London and New York: Routledge, 2018).

[6] Havi Carel, “‘I am well, apart from the fact that I have cancer’: Explaining Well-being within Illness,” in Lisa Bortolotti (ed.), *Philosophy and Happiness* (Palgrave, 2009), 82-99; Emily K. Abel, *Sick and Tired: An Intimate History of Fatigue* (Chapel Hill: The University of North Carolina Press, 2021).

[7] Elinor Cleghorn, *Unwell Women: A Journey through Medicine and Myth in a Man-Made World* (London: Weidenfield & Nicholson, 2021), 14.

[8] Bharat Jayram Venkat, *At the Limits of Cure* (Durham: Duke University Press, 2021), 167.