

## LIVING WITH CHRONIC PAIN

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The prompt asked the authors to muse about the phenomenology of sickness in current times. *What, it asked, are the possibilities of a critical phenomenology and where are its limitations?* This is a question I've had for several years. Phenomenology has always been anchored in lived experience. It studies what is given in experience—the subjective “inside” of the world—and thus posits a more-or-less stable *subject* of experience. In certain moments of sickness, phenomenology is certainly a useful lens of analysis, but I wonder about the limits of starting from lived experience.

Consider chronic pain. Countless times I've writhed on the bathroom floor, whimpering in pain and waiting with desperation for the world to end. Within periods of acute pain or nausea, the intensity of lived experience might increase but, for me at least, it takes a decidedly anti-futurist turn. Twisted on the floor, I quite literally cannot conceive of a future—a tomorrow or next week beyond the pain. There is no becoming for me nor for my place in the world. There is, it seems, only the certain despair of a self-devouring now.

Pain is singular and thus disposed to phenomenological analysis. We can speak of collective and intergenerational pain, yet pain is still a necessarily subjective phenomenon. It pops only at the surface of consciousness—as if willing us to acknowledge its power. Pain is, in fact, so singular that it eludes both quantitative and qualitative measure. *How much pain do I have on the bathroom floor?* What does a crude proxy like “10” even mean after a decade of pain? *What does pain feel like?* This question is especially tricky since pain is a type of “non-experience” (Heyes 2020). If feeling requires a subject of experience—one who feels—pain reveals the limits of starting analysis from lived experience. Pain disassembles the habituated performance of social codes and even the human itself. Coiled in the waiting room and moaning loudly, an aspect of “me” knows that “proper humans” do not act this way. But the concepts of me-ness and humanness (each ableist in their own ways) are precisely what pain calls into question. In other words, my grasp on the world as a me and a human requires an ongoing and coordinated effort that pain disrupts. Pain does not mask my true, authentic, self any more than it exposes a primal self buried under layers of habituated

social codes. Rather, pain reopens what we think sealed—the ontogeny (beginnings and development) of our subjectivity.

The cold bathroom floor stages an existential drama on which I thrash between radical humanism and radical post-humanism. One moment I hear a voice from my childhood cry aloud for Jesus, the next a surge of pain shatters any illusion that I am a self. Pain raises questions that push beyond the perceiving-volitional subject to get at the very nature of subject formation. Questions of despair —*Can I project a future? Can I desire a self in relation to that future? How long until I return to this floor?*—foreground other existential themes like thrownness—*Am I predisposed to end up on this floor?*—and freedom—*Have my own life choices cursed me with pain? Am I somehow responsible?*—and, of course, hope.

Hope is a troubled concept for me these days, but its presence in the long hours on the bathroom floor is undeniable. In the midst of acute pain, hope dons the form of a superhero—*God if you exist I beg you to either rescue or kill me!* But more mundanely, when thought about from some distance, hope is much less extra-ordinary, much less individual and volitional. Hope is the slow endurance of things. In an affective sense, Jasbir Puar explains that hope is “a capacity, emblematic of a futurity that speaks to the body’s tendency to be affected or affecting, its capacity for change, evolution, transformation, and movement” (2009, 162). Hope is not heroic; I persist whimpering on the floor not as an individual that wills-to-live, but through an ecology of social and material relations that is always open to transformation. What is the phenomenology of pain, of becoming undone as a self and then remade?

If the non-futurity of the bathroom floor is one pole of living with chronic pain, the long endurance of time marks the other. In other words, the experience of waiting for the bathroom floor is the backdrop of returning there. People experience sickness in drawn-out intervals of *expectation* for appointments, test results, prognoses, medication half-lives, relapses, remissions, etc. Citing Sarah Jain’s work on cancer, Puar (2007) notes that under a financialized neoliberalism, much of the Western world lives as patients-in-waiting. This is a temporality of pre-sickness, or “prognosis time,” that is both future-directed—*How long until I get cancer?*—and speculative, replete with statistical probability and risk calculation—*How long until I too get cancer?* For Puar, this shift signals a larger move from the practice of governing bodies through normalization to the practice of optimization. “Neoliberal regimes of biocapital produce the body as never healthy enough,” Puar writes, “and thus always in a debilitated state in relation to what one’s bodily capacity is imagined to be” (167). Here, the monolithic categories of ability and disability give way to fluid sites of what she calls “capacity” and “debility.” When standards of health and well-being are free-floating, are no longer indexed to social codes, the body becomes a site of ongoing biomedical improvement and optimization. And, as Sunder Rajan states, within the neoliberal age of Big Pharma, Big Data, and therapeutic dominance, we are “patients-in-waiting” inevitably transformed into “consumers-in-waiting” (2006, 144). Far more value and utility can be extracted from a body never-fully-well than from one normalized by the categories of ability and its pathological other.

There is of course a phenomenology of sickness-in-waiting. The lived experience of prolonged waiting is akin to what Jay Dolmage describes as abeyance: states of temporary suspension “perhaps allowing for access, but disallowing the possibility of action for change” (2017, 77). Neoliberalism (but not only neoliberalism) constructs disabled people as buffers that suffer for the good of society. The subject of abeyance is made to endure and suffer privately like, to quote Tolkien, butter scraped over too much bread.

Following Puar, the notion of debility problematizes the subject of lived experience and questions the limits and usefulness of phenomenology as a conceptual platform. Puar questions “the predominance of subject formation itself, thinking instead of disability and debility in terms of *assemblages*” (2009, 167, emphasis added). She invites us to consider the body as comprised of flows that assemble in the mode of congeniality. As Ada Jaarsma writes, “we are ecosystems, not bounded individuals; we are embedded creatures, porous and symbiotic participants in complex systems” (2017, 40). Both the phenomena of chronic pain I have discussed—a present that self-annihilates and one out of joint—resist lived experience in their own ways and expose, rather, the ontogeny of the subject. A critical phenomenology of sickness might thus attend to the unravelings of lived experience in order to bear witness to the vectors of our becoming. For we are relations—connections and disconnections—stitched into time, all the way down.

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