

A Medical Model

I wanted to begin by expressing my gratitude for Travis's most recent post, "Taking Stock: Disability Studies and the Medical Humanities." There, he provides a brief and cogent outline of the ongoing negotiation between a medical model of disability—in which disability is identical to impairment—and the OG social model, where disability is *only* manifest through social relations, and bears no necessary relation to embodied difference. That area of tension is precisely what comes to a head whenever I teach courses on disability in literature—courses that are used to recruit pre-med students, that are billed within the university as "medical humanities".

To complicate things, I am one of a much smaller number of humanists working on disability in a "global" frame—that is, not centered on the United States or Europe. The field's limitations are so pronounced that even *critiques* of ethnocentrism the one put forth by Chris Bell (and cited by Travis), are themselves confined to a purely Americanist perspective. But scholars like Michael Davidson (2008), Ato Quayson (2007), and Daniel Mont (2007) show us that disability is unevenly distributed around the globe: it is often the product of environmental, political, and economic risk falling disproportionately on impoverished or socially marginalized groups in the Global South. In addition to the literature I study, I also work directly with people impacted by those uneven risks. Like one of my informants who walks with a limp because polio, which has been eradicated almost everywhere else in the world, still lurks in his small pocket of India. There were no comprehensive vaccination campaigns in this area for the same reason that there was no electricity for a twenty-year period starting in the early 1990s: it is a place that was selectively abandoned by generations of colonial and then postcolonial state actors. In such conditions, to deny the negative impacts of impairment and insist on the *purely* social character of disability is to be willfully blind to structural violence.

The "pure" social model also risks minimizing the *distress* caused by disability, as scholars like Susan Wendell have illustrated. That's really at the heart of what I want to write about today. Distress, etymologically, is the process of pulling apart—that classic scholarly act, revealed in all its potential violence. Recently I've noticed an academic trend that distresses me and which I would like to distress in turn. In an effort to avoid "medicalizing" their research subjects, certain social scientists seem to have all but abandoned medical knowledge as an explanatory framework. I wonder what this means for the future of interdisciplinary scholarship, especially for the way

Medical Humanities can take seriously the category of distress as a marker of personal meaning and a window into structural critique.

Dis-gust, Dis-tress, Dis-trust

All of these thoughts began in the classroom, of course. I had assigned what I thought was a deeply disquieting book, Juan José Saer's *El entenado* (translated as *The Witness*), which contains graphic scenes of cannibalism. To my surprise, however, almost none of my students were particularly troubled by the novel. Good little ethnographers in training, they approached all that people-eating with a detachment born of an odd kind of libertarian cultural relativism—*I'm a vegetarian, but you do you!* The one exception was a premed student who had picked up the novel directly after his cadaver lab. The whole business of eating human flesh felt very *real* to him, because he was, you know, working with human flesh. This suggests, contra to Godfrey's wonderful series on empathy, that sometimes what readers need is a deeper, *more* empathetic engagement, one that, at minimum, takes seriously what is at stake when cultural practice reveals its violent edge.

A few weeks later we read a second text about potentially distressing gustatory practices. This one was non-fiction, an essay by Lucas Bessire about “hypermarginality” among indigenous people in Bolivia (2014). Bessire focuses on a set of informants who are set apart in this category of the “hypermarginal” based, in part, on their shared practice of grinding up and eating sewage-soaked bricks. Describing brick-eating in clear, vivid prose – somewhat distinct from the dense thicket of his theoretical overview—Bessire seems intent on provoking disgust in his readers. In this way he mimics the responses of other actors in the same social space who load this practice with profound symbolic charge. It is both literally and ritually unclean.

Of all the names given to brick-eating in the article—*vicio*, *puyai* – one is marked by its absence: *pica*. Why, I wonder, does Bessire never mention the medical name for what his informants do? Consuming non-food is common all over the world; building materials and feces are some of the non-foods most frequently ingested. Pica, moreover, arises in conditions of intense stress and chronic malnutrition—precisely the conditions in which Bessire's informants live. We usually associate the term “medicalization” with explanatory frameworks that use medicine and science to make normal things seem specialized and abnormal. Hence the pejorative accusation of “medicalizing” disability. But in Bessire's article the opposite seems to be true. By totally withholding the medical explanation, by insisting that *only* social and cultural features can explain brick-eating, he makes that practice more extreme, more disgusting and alienating than it need be.

Now, I'm not usually one to endorse a *symptomatic* reading. By this I mean that I like to read texts gently, listen to what they are telling me softly, and not seek about for what they might be holding back. In this case, however, I am sorely tempted to talk about the *loud* absence of medical engagement in recent ethnography. In these texts medical explanations are either totally sidelined

or put under the onerous weight of scare quotes. Rather than merely decentering medical or scientific knowledge, they seem to present it as non-knowledge, a false consciousness.

This vivid absence feels new to me. It certainly reads differently than “classics” of southern cone medical anthropology that I’m familiar with. Take Nancy Scheper-Hughes’ treatment of the condition *nervosa* in *Death Without Weeping* (1989). Scheper-Hughes’ informants understand themselves to be suffering from “nervosa,” a chronic medical condition characterized by anxiety and physical weakness, one that is best treated with injections and pills. Scheper-Hughes looks at the same symptoms and uses her medical training to attribute them to plain old hunger (*fome*). Being an anthropologist, however, she must negotiate between these two situated diagnoses without letting one truth override the other. Ironically, Scheper-Hughes here pushes against her informants’ “medicalization” of their symptoms, while also taking seriously the scientific perspective that might reattribute those symptoms to chronic undernutrition.

In *Vita: Life in a Zone of Social Abandonment* (2005), medicalization is built into the very structure of the text. João Biehl creates a story arc in which the discovery of a rare genetic condition becomes a kind of absolution that makes his chief informant not lazy or crazy but merely sick. Here the “truth” of medical knowledge is used as a weapon against a cruel system of marginalization. While I don’t totally endorse this argument, I do appreciate the way that medical knowledge here acts as the grounds for a stirring critique of structural violence.

Medicine should not totalize, but it can explain. In the cases I’ve outlined above, potential diagnoses of disorder are based, in part, on affect: do these behaviors cause distress? The behavior of Bessire’s informants distresses others: it angers husbands, it disgusts friends. But it pleases the women themselves. In this way, Bessire recovers brick-eating as a practice of self-making, what he calls “negative immanence.” The same is not quite true for another recent article, “Unruly Affects,” by Jessica Cooper (2018). Cooper, like Bessire, writes about the self-making temporal practices of her informant Harriet—though her hearty endorsement of the “resistant” quality of those practices reads somewhat differently in white, middle-class California than it does among Bessire’s indigenous informants. In painting the state as Harriet’s nemesis, by turns threatening and incompetent, Cooper also throws suspicion on the Harriet’s state-endorsed diagnosis of mental illness. Yet that suspicion is predicated on a minimization of the intense distress Harriet, herself, reports. One might ask what is gained for the writer—and what might be lost for the subject—by describing her affect as merely “unruly,” and not something more negative, more demanding.

The question looms large: can critiques of “medicalization” fully account for negative affect, especially distress? If we all adopt the attitude of my students—*you do you*—I’m afraid we’ll end up reproducing a kind of ethical blindness in which where every difference is value neutral. But some differences arise from structures of oppression, some cause distress, and some require action, not merely critique.

