

## Ode to Leah

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I met Leah in the summer of 2020, when the rhododendrons were blooming in Boston, and *Anthropology and Medicine* asked me to review an article she had submitted for inclusion in this special issue on clinical iatrogenesis. I was stunned by her essay. Some 25 years earlier I had endured a life-negating, near-death experience of misdiagnosis followed by iatrogenic illness at the hands of an over-zealous physician. Leah knew only too well that the club of (self-aware) fellow sufferers from serious iatrogenic harm was tiny. ‘This sort of experience disables one profoundly’, she wrote knowingly in some notes, ‘and in ways that are probably not immediately apparent even to the most sensitive, sympathetic reader’. I too sought to make my suffering coherent – to give it larger meaning and social purpose – by crafting a critical, theoretically informed auto-ethnography (Greenhalgh 2001). Driven by the need to *do something*, I hoped to reclaim my voice and use it to right a terrible wrong by drawing attention to the neglected reality and effects of iatrogenesis, and opening new lines of thinking and political action that would solidify its place in the medical order of things. And so we had an intimate bond, Leah and I, though we knew not each other’s name or identity.

Over the next few months, as the blooms fell to the ground and the leaves turned brilliant, Leah and I communicated extensively, although indirectly and namelessly through the journal. Leah, hungry for interlocutors, crafted long, thoughtful responses to the reviewers’ queries, adding extensive elaborations, illustrations, and conversations, ending up with a 13-page, single-spaced commentary. I was so looking forward to turning the paper friendship into an in-the-flesh friendship. Leah, too, ended those back-and-forths on a hopeful note: ‘Thank you... for this wondering [how I’m doing]’, she wrote. ‘[B]ecause there’s ‘too much’ to answer here with even the tiniest bit of coherency and satisfaction... I prefer to leave that either for ‘conversation’ – where and when and how, who knows, but I hope it might come to pass – or for another writing’.

She wrote that on August 24. By the time the autumn leaves had fallen, Leah was no longer, leaving those who cared for her in states of confusion and anguish. All that suffering, for what? Why? How? How could we have not known? What could we have done? To which there are no answers. All that is left is to honor her life and work, not just by not forgetting but by carrying it forward. In doing that here, I draw from her long commentary, as it gives us a more complex and spontaneous Leah than the person we know from her article.

## Iatrogenic and nosocomial harm

To begin, I want to honor Leah's courage, her stamina, and her fortitude in persisting with this writing project in the face of the long-term injury her body sustained during that hospital experience. Her case of nosocomial injury was so extreme that it lies beyond the capacity of the English language to capture it. After 311 days of hospital treatment that produced starvation, infection, necrotic ulceration, cardiac arrest and temporary death, as well as more everyday effects like physical deconditioning and pressure ulcers, her body must surely have suffered some irreversible damage. And the body was but the beginning. The before-self was dead, the before-world smashed to smithereens; all that existed were the long-term consequences of her ordeal. 'Yes, there are (untellable numbers of) long-term consequences', she wrote in response to my timidly put question. 'Or I should say: There are *only* long-term consequences... [and] they constitute and limit my total... experience-in-the-world'.

One set of long-term consequences rarely talked about is the battering of one's professional capabilities. Asked why so few write about medically induced harm, Leah responds: '[In brutal terms]: Most people who have something like this happen to them are [if not] dead, vegetables, [or] unemployed, [then] too sick, disabled, or socio-professionally excommunicated to even think about trying to publish.' That she both survived and published is a testament to Leah's extra-human strength and will to live.

Even more profound is the moral wound forced open by the awful realization that the world of medicine is brimful of badness. 'We, livers in the great Western world so advanced not only technically but also *morally*, understand – *know* – doctors... to be *good*. This is a major part of what makes this story so unintelligible: How could it be that evil sometimes lurks beneath the white coat, and how could it be that it goes unnoticed or unreported or un-cared about?' Leah wrote of the personal Watcher in the psychiatric internment center who sat next to her bed hour after hour making sure she did not move. Leah was forced to listen to her crunching snacks and talking to her partner on the phone about their evening meal. 'It struck me as (cruelly) absurd that this person, who evidently had a family life... a 'human' life to which she would return in just a few hours, could, depending on the day, either/both (1) participate in my torture (ie, by subjecting [restraining] me while they forced that tortuous tube and its liquids into me) or (2) 'just stand by' and watch while others did it. Was there evil [here]? Yes, absolutely – despite the lack of bad intention, *bystanding was evil*. How does one even respond? Leah answers: 'In the moment(s) of its enactment, [the] torture [of force-feeding] takes away language; and, afterwards, 'what it was like' is simply not... communicable to a world that has no cognitive tools for conceptualizing it. I'm left with what Amery called perpetual 'astonishment' (with the experience itself, and with the person-denuding realization of the badness of the world and of the fellow-men who did it and who allowed it and who stood by and watched it...). *That's it, it's a state of perpetual astonishment*' (emphasis added).

In the face of this horror, writing was not just an act of inspired analysis, but an act of self-restoration, of claiming, naming, and creating a self in the face of this massive despoliation of her previous personhood. It was also a cry of moral anguish, an act of exposing a wrong that cannot be made right, but can only be protested and insistently critiqued in hopes that it may happen less often. This is why Leah's text has such urgency to it, an urgency we feel in the bold punctuation, the narrative tension, and the carefully omitted pieces of

the story that were so horrific they might incite disbelief or disgust. Given the ubiquity of iatrogenic and nosocomial harm in medicine today, Leah's project of revealing and protesting remains urgent for her readers, some of whom may be unknowingly practicing that very medicine, but all of whom may someday be the victim of such misdiagnosis and maltreatment. There but for fortune go you and me.

### The power of critical medical auto-ethnography

Leah's work amply demonstrates the potency of medical auto-ethnography. The use of auto-ethnography in medical writing is especially powerful, because such interventions in the body tend to produce cascades of (corporeal, psychic, emotional, and other) effects that can be perceived only by the object, the intervened-upon. Her descriptions of her bodily experiences (of confinement, physical restraint, refusal of physical therapy, force feeding, and much more) put flesh on her abstract concepts – discursive escape valve, epistemic vice, cruelty, (re)inscription, corruption – making them real, visceral, and feel-able in a way that could not be achieved if the ethnographer were merely an observer.

The power of 'technic-obsessed' biomedicine in our lives makes writing critical auto-ethnography of medicine's workings – and its harmful yet hidden effects – all the more important. Leah takes the critical auto-ethnographic form in new directions, bringing the insights of philosophy, medical anthropology, and ethics together in productive ways. Her extensive footnotes reveal the extraordinary breadth of her imagination and scope of her ambition, which she had to constantly restrain on account of 'the tyranny of the 8000-word article.' From 'nosocomial snowballs' to 'explanatory pliability of the everywhere-useful narrative,' in Leah's hands, words and phrasings are everything. Her word choice is original, brilliant, sometimes truculent, and always evocative, often in ways she cannot elaborate. In her marginal back-and-forths with her copy-editor about the word 'excisions,' for example, Leah writes exuberantly:

I don't think it's good to 'clarify' here; this might be a good example of the 'usefulness' of unclarity... See!, it's intuitively understandable – Ex + Scissors .... well, it'll get most readers most of the way there. And I like the way it sounds. Let's keep it.

The essay is an extraordinary accomplishment, all the more so when we realize that Leah must have been in a great deal of pain when she wrote it. Among the tragedies here is that Leah could not write the book that would have given her the space to say everything she wanted to say, in the way she passionately wanted to say it.

May all of us honor Leah's life and give wing to her ideas. We can share her work, assign it in our classes, and include it in medical school curriculums. More broadly, we can make her critique of hospital-induced harm an enduring part of our critical appreciation of the capacity of biomedicine to remake lives and deaths.

### Reference

Greenhalgh, S. 2001. *Under the Medical Gaze: Facts and Fictions of Chronic Pain*. Berkeley, CA: University of California Press.

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