

Field Notes on Fluid Illness

Jillian Moore

Received: 26 May 2024; Accepted: 9 September 2024; Published: 15 June 2025

Abstract

Illness is fluid. It can cross bodily boundaries, across space and time, and permeate entire families and communities. This is especially apparent in places where people have come to rely on one another in order to withstand austerity and state disregard. Here I share a creative revision of field notes from home visits with a family living with debilitating illness in rural Guatemala. Through their experience, I contemplate how vulnerability and illness are not merely hardships to be endured but can also be conditions productive of collective action, resistance, and new forms of belonging.

Keywords

Illness, Care, Violence, Precarity, Guatemala.

They say she has a hole in her heart, a hollow between two chambers where the blood can slip through. She was born with this hole, as many are. It was harmless at first. When she was a little girl, maybe someone heard a murmur, or maybe not. She grew up in a Maya farming village in the highlands of Guatemala. I wonder if anyone had ever listened to her heart closely enough to hear it.

She and her family once farmed their own land. They grew *milpa* and lettuce, to eat and to sell. She endured a civil war in which indigenous communities like hers were disappeared, murdered, unsung, buried in dirt. After the war her family could not afford to keep their land and sold it to an agricultural company. Her husband found a job watering flowers on an estate in the capital. She also sought work in the city: washing clothes, cleaning houses, selling tortillas. In the afternoons she rode the bus home to tend to her young children. For years she used her body to care for others and to gather wages from transient and unreliable work. No matter how much, it never felt enough. But she always found a way.

Pierre Bourdieu describes a 'conservation of violence' in which the total violence of society remains constant over time (1998, 40). Like energy, violence does not dissipate but is transformed. Just as the potential energy of position becomes the kinetic energy of motion, the massacres of war reshape into structural adjustment policies and their resulting inequities, and into the normalised everyday violence of hunger, illness, and despair (Scheper-Hughes 1992). All violence, the body carries and stores like a conduit.

She had a cough for years before she found out why. At first she would visit the local pharmacist who would give her injections of B vitamins. He told her that she had a cough because her lungs were tired from so much work. The understaffed public clinic gave her antibiotics for the cough, more than once. Friends brought peppermint tea and herbal ointments. Nothing helped. With time, she could no longer climb the path to her house. Her woven skirts and blouses no longer fit, her slight figure lost in their folds.

Informal workers and their daily scrambles to survive; anonymous and expendable, at the periphery, yet also at the centre; whose bodies have been exhausted by constant labour; bodies weathered to the bone, worn down, worn out by the very

act of living; bodies made ill, made injured, in long slow deaths at the hands of a violence nearly imperceptible, a violence obscured (Berlant 2007).

When she could no longer breathe, her family turned to their community for help. A local midwife told them of a visiting clinic run by a non-governmental organisation. There, an American doctor heard the murmur and sent her to the city for imaging. This is how they found the hole in her heart, but it was too late to fix it. Blood now flowed through the hole in the reverse direction, causing high pressures in her lungs. He told her maybe her cough was from this, or maybe her lungs were scarred from smoke. Maybe both. Regardless, her body could not extract enough oxygen from the air of her breath. He told her family she would only worsen. He told her nothing, to keep her spirits high.

I skim the diagnoses in her chart: idiopathic pulmonary fibrosis, atrial septal defect, pulmonary hypertension, cor pulmonale. The doctors seem uncertain which of these have caused her condition. Even her diagnosis, as precarious as her life. I note the word idiopathic, defined as 'without known cause, of spontaneous origin'. Spontaneous: 'without apparent cause'. Cause of death. Proximal causes, so often unknowable. Upstream causes, palpable and clear, yet left unspoken murmurs in our minds.

Each week the clinic sends a nurse to her home with medication: morphine to calm the constant feeling of drowning, water pills to relieve the swelling, and another to lessen the pressures in her lungs. None of these seem to help. Her family takes on debt to buy her an oxygen concentrator.

Illness is a world. It is a performance and an entanglement. Illness is fluid. It ripples like water, seeps like honey, through time and space, through bodies and across bodily boundaries. Illness spreads through families and communities like wildfire, not the flame itself but the entire forest aflame.

Her youngest daughter leaves work to care for her. She bathes her, braids her hair. Three times a day she crushes the medicines in cooked apple and feeds it to her with a spoon while her young son plays at their feet. Other family members

take on extra jobs to gather money for the oxygen concentrator and electricity. Her church collects money for this too. She tells me she feels like a little baby.

Illness is a lens. It illuminates which kinds of care matter in a society, and by whom: not state or government, but churches and nonprofits, but women, unpaid and paying (Livingston 2005; Stevenson 2014). Illness is a catalyst. It unearths networks of obligation, seeds moral economies of gifts and favors, offered not because someone has a surplus to give but because another needs it more, and that is reason enough (García 2010; Han 2012). Sam Dubal describes how 'violence is not exclusively something destructive that must be coped with or survived, but can also be creative, producing new forms of mutual belonging' (2018, 177). Illness may similarly bring people together in unprecedented ways.

When I visit, I hike from the paved road up a steep muddy hill to her cinderblock house. The road and path are lined with weeds, trash, dead animals. But inside her gate, the ground is neatly swept. Geese scuttle around plastic bottles of water that her daughter hauls from a neighborhood pump. Next to these are metal coffee canisters holding roses and hibiscus, each carefully watered and pruned.

The town where I live prepares for a fair. I never liked the fair because I did not understand it. I did not understand how a place with so few resources could spend so much to construct ferris wheels and rows of wooden booths selling sweets and toys. I could not understand how people could be so easily mobilised to prepare for a fair but not to staff and supply the clinics and hospitals. I never liked the fair until I understood delight: that in order to endure suffering, people need delight. They need sweetness and brightness. They need flowers whose only purpose is to be beautiful.

The last time I visit her, I find her perched on her bed. Her long dark hair is wet and clean, gathered in a braid down her back. Her face is gaunt, her skin like leather, eyes weary with years of illness and hard labour. She is encircled by women from her church, each draped in bright colored cloth. They have brought herbs and oils. They anoint her forehead and rest their hands on her arms and shoulders as they murmur prayers. The leader begins to sing, others clap. But she is somewhere else.

As the women sing, she breathes slow and deep, lifts her chin, presses eyelids closed like half-moons, as if struggling to hold on to each air molecule that passes through the cannula in her nose. She turns towards the window, towards mountains and sky, as if basking in a glow we could not see, as if floating on a wind we could not feel. What world surrounded her in this moment? Is that where she is now?

Free falling through the abyss: embrace others to augment your air resistance, to not plummet to the ground. Wandering through darkness: embrace others to know you exist, to not disappear.

As Judith Butler describes, ‘loss and vulnerability seem to follow from our being socially constituted bodies, attached to others, at risk of losing these attachments, exposed to others, at risk of violence by virtue of that exposure’ (2004, 20). All are vulnerable, but bodily vulnerability is not evenly distributed. Certain lives are made more exposed, more susceptible to violence. This may lead to a deepened relationality, as if sometimes the only buffer is to weave oneself more tightly into the social fabric. Interdependence. Indeed, vulnerability can be an active state, prompting tactic, collective action and resistance (Butler, Gambetti and Sabsay 2016).

I walk home past the cemetery. It is autumn, and soon it will be *Día de todos los Santos*. The concrete headstones and tombs are painted coral and teal, adorned with marigolds, pine needles, candles. Outside the gate, men with carts sell syrupy fruits and sugared squashes to nourish living and dead. In the hills beyond, children fly kites. They race through grass fields to launch small triangles of coloured tissue paper and bamboo. The kites flutter in the wind, float amid billowy clouds, up above the corn fields and muddy roads, above mountains, soaring until they fall, tattered in the gusts.

She dies at dawn. Her daughter calls to tell me. ‘All night she was in so much pain, and she would beg me for more medicine. I would give it, but it no longer helped. Then she asked for water, so I gave her a sip of water. I lifted her up and embraced her, and then she went.’

At her funeral, there are so many children. They cling to the backs of their mothers, scurry about head stones, dart between our legs. The pastor reads a verse from the Book of Job. 'They spring up like flowers and wither away; like fleeting shadows, they do not endure.' Her daughters weep as men stack brick and mortar to seal her tomb. I turn to the sky and see a kite, so high it seems it could escape the atmosphere. I imagine her at last untethered from the plastic nasal cannula and the whirr of the concentrator in that small damp room. I imagine her free.

To care is to tend to the vulnerability of another—to soften their experience of violence and to share it. When one offers care, they also make themselves more vulnerable, for these entanglements with others are channels along which malady can diffuse. Just as a fluid takes the shape of its container, illness extends beyond a body, flows through social relations and communities, even beyond death.

A year after she dies, I visit her daughter. She still works to pay the debt for the oxygen concentrator. It sits in the corner of their house, motionless and quiet like a stone. She asks if I might buy it from them, to give to someone else. I falter, unsure how to respond, unsure of my place in her world. She rubs her hands, sore from sewing and washing clothes. I imagine the body of her mother, sealed in a tomb, with her heart and the tiny hole. Yet her illness still pulses through this world, through the joints of sore fingers, through hungry bellies and stress-laden minds. How we linger.

I never purchased the oxygen concentrator. Years later, I still contemplate the boundary I drew between us and whether I had cared enough. Lisa Stevenson defines care as 'the way someone comes to matter and the corresponding ethics of attending to the other who matters' (2014, 3). Care is not always a positive gesture or sentiment and can even lead to harm despite good intentions (Stevenson 2014, Ticktin 2011). It can be particularly disempowering when offered out of compassion, a humanitarian impulse that 'presupposes a relation of inequality' (Fassin 2012, 4). I am not the first to wonder how to best show care within the asymmetric relationship between anthropologist and subject.

To care often means to protect from harm or to alleviate suffering. But to care can also mean to pay attention to, to be unsettled by. In this sense, to care can be to attend to another with deep presence in order to learn how to provide a structural response beyond what is simply felt to be ‘good’ (Dubal 2018, 222). To care can be to confront my own vulnerability—that I too rely on social and material structures to survive, structures perhaps implicated in the suffering of others (Butler, Gambetti and Sabsay 2016). I show care as I stay with the trouble (Haraway 2016), as I wade through the murk and come unhinged. I am not a filter but a vessel—one that carries and ferments. I allow myself to be changed. For to be haunted is to be inhabited, but it is also to embody. Life runs fluid between us.

Authorship statement

This article was conceived and written in its entirety by the author.

Ethics statement

This project received ethical approval by the Institutional Review Boards of Wuqu’ Kawoq | Maya Health Alliance and Mass General Brigham in Boston.

Acknowledgements

This piece is based on home visits and interviews in rural Guatemala between 2014 and 2018, in collaboration with the Wuqu’ Kawoq | Maya Health Alliance. I am grateful to the many people who welcomed me into their lives. The research was funded by the Doris Duke Charitable Foundation.

About the author

Jillian Moore currently works as a physician in rural New Mexico.

References

Berlant, Lauren. 2007. ‘Slow Death (Sovereignty, Obesity, Lateral Agency).’ *Critical*

- Inquiry* 33 (4): 754–80. <https://doi.org/10.1086/521568>.
- Bourdieu, Pierre. 1998. *Acts of Resistance: Against the Tyranny of the Market*, translated by Richard Nice. New York, NY: The New Press.
- Butler, Judith. 2004. *Precarious Life: The Powers of Mourning and Violence*. New York, NY: Verso.
- Butler, Judith, Zeynep Gambetti, and Leticia Sabsay, ed. 2016. *Vulnerability in Resistance*. Durham, NC: Duke University Press.
- Dubal, Sam. 2018. *Against Humanity: Lessons from the Lord's Resistance Army*. Berkeley, CA: University of California Press.
- Fassin, Didier. 2012. *Humanitarian Reason: A Moral History of the Present*, translated by Rachel Gomme. Berkeley, CA: University of California Press.
- García, Angela. 2010. *The Pastoral Clinic: Addiction and Dispossession Along the Río Grande*. Berkeley, CA: University of California Press.
- Han, Clara. 2012. *Life in Debt: Times of Care and Violence in Neoliberal Chile*. Berkeley, CA: University of California Press.
- Haraway, Donna. 2016. *Staying with the Trouble: Making Kin in the Chthulucene*. Durham, NC: Duke University Press.
- Livingston, Julie. 2005. *Debility and the Moral Imagination in Botswana*. Bloomington, IN: Indiana University Press.
- Scheper-Hughes, Nancy. 1992. *Death Without Weeping: The Violence of Everyday Life in Brazil*. Berkeley, CA: University of California Press.
- Stevenson, Lisa. 2014. *Life Beside Itself: Imagining Care in the Canadian Arctic*. Berkeley, CA: University of California Press.
- Ticktin, Miriam. 2011. *Casualties of Care: Immigration and the Politics of Humanitarianism in France*. Berkeley, CA: University of California Press.