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Love in the Time of Sickness: On Disability, Race, and Intimate Partner Violence

August 2019

Two weeks before the deadline of this submission, I am thinking about bowing out. My editors have offered suggestions for possible topics, on subjects I know intimately: race, disability, and pedagogy. I have taught the *Open in Emergency* volume in my own courses, thought about the hacked *DSM* as a genre of refusal and revisioning, written on the politics of anti-work and anti-productivity in the arena of mental health.

But my summer has been relentless. Over the winter, I made arrangements to spend the summer of 2019 in my hometown. My best friend of seventeen years, another queer woman of color, is in the final stages of aggressive brain cancer. The diagnosis, given in September 2018, is glioblastoma. The five-year survival rate is about five percent. At the end of April, the cancer metastasized to her spine. At the time of this writing, doctors found additional tumors in her brain.

Yet during what seems to be her final weeks on earth, she is somehow utterly consumed by pacifying the erratic moods of her primary caregiver, who is also her romantic partner. Over the past few months, he has convinced her that her friends and family have abandoned her, even though our desperate attempts to connect with her were met with constant refusal. He has convinced her that her life prior to cancer was meaningless, comparing it unfavorably to his own life of public service. He has claimed that he is entirely without assistance, yet most attempts to extend our support labor—emotional, domestic, or otherwise—have been bypassed.

I am a young professor of race, gender, and disability, and I am witnessing my terminally ill friend entangled in intimate partner violence at the end of her life. Her abuser is another queer person of color—an Asian American immigrant, an activist within queer communities. I recognized him, at first, as a comrade, someone whose life, values, and experiences reflected my own. I have spent the past ten years studying feminist, anti-racist, queer, and disability politics, organized my life around writing and teaching on these topics, and surrounded myself with people dedicated to the same projects. I am learning, however, that this knowledge has its limits. It cannot help me protect her.

At first, he appears to be a saint. Following diagnosis, he resigned from his job to care for her full-time, devoting all his energies to researching treatments and finding the best professional care. We shower him in our praise—his devotion appears undeniable, and we view him as the best and most capable caregiver. There is a growing rift between him and her parents, sure, and he complains about their lack of support and their “flakiness,” but we assume that, ok, maybe they did retreat in the face of this unbearable news, and yes, we’re disappointed, and yes, we’re sad, but we trust him, and of course he wouldn’t lie, just look at all he has sacrificed for the survival of our closest friend.

But as the cancer progresses, his narrative begins to fray. I arrive in my hometown at the end of May, seven months into her illness. Three days into my summer stay, she is whisked to the

emergency room to treat a blood clot in her lungs—a condition common to cancer patients of the brain and spine. She is placed on a blood thinner and taken to a rehabilitation hospital to ensure that the clots do not re-form. Three weeks later (all of which my friend spent in the hospital), I and two of her closest friends suddenly receive a barrage of panicked phone calls and texts. He must end the relationship, he announces, because he is overwhelmed by the demands for her survival and unsure of his capacity to meet them. Further, she has failed to adequately appreciate his caregiving and has “lied to him about her past.” We ask him to be gentle with her; he retaliates by announcing that we are suddenly responsible for all aspects of her care: medication, food, hygiene, appointments, treatments. We attempt to address this abrupt void; he is back by her side two days later and quick to point out our failures. “No one can take care of me like X does,” my friend tells us. “Not even all of you combined.” The breakup, we are informed, was a “test” and a “lesson” conducted by her partner to prove that he is her one true advocate, and the only one on whom she can truly depend.

At this point, the contours of the situation begin to come into focus. The possible path of action, however, seems less clear. Shortly after her discharge from the rehabilitation hospital, her mother reaches out to me, desperate for updates on her daughter—contact between the two has been increasingly limited. I call her, and she informs me that she did not willingly withdraw her support, but was in fact repeatedly denied the ability to provide care, and further, was subjected to relentless verbal abuse while trying to do so. Frantic, I contact the Domestic Violence Hotline, and they inform me that unless there is documentable evidence of physical violence or care neglect, there can be no intervention. I look at the report submission form, and it does not even allow you to input anything other than physical or sexual assault. Only isolated incidents are accommodated by its format. And as a scholar invested in feminist critiques of the state, I am wary of state intervention anyway.

I fantasize about nailing the power and control wheel to their front door like Martin Luther and his 95 theses. I fantasize about a direct confrontation in which he is forcibly removed from their house and stripped of his medical power of attorney (which she granted him). This all remains in the realm of fantasy. We must placate his ego in order for her to continue receiving care. Placation, unfortunately, also involves receiving and tolerating his abuse. Following a recent visit to the hospital, where I brought them food, a phone charger, and eight hours of emotional support, he posts on Facebook that my friend has been abandoned by all her close friends and family. It is clear, by this point, that he holds all the cards. We know he is her abuser; he has humiliated us publicly, and yet we cannot confront him or enforce any kind of change. We cannot risk another emotional meltdown that leads to a sudden withdrawal of support.

Like always, during times of intense distress, I turn to books. I am reading *The Revolution Starts at Home: Confronting Intimate Violence Within Activist Communities*. This is the primer I need. An anthology of personal testimonies, manifestos, grit, and rage, it discusses the necessity for better practices of recognition and accountability regarding abuse in leftist and queer communities. Even just recognizing abuse, it tells me, can be difficult in these circles, given that so many of us joined these communities in hopes of creating homes free of white supremacy and

the tyranny of hetero domesticity. So invested are we in these new homes, we are often less attuned to how such dynamics might be replicated by those who inhabit them—those we have willingly invited into our home space. But home, as I know from my own childhood, is not always a place of safety, and safety, too, is an ongoing process—maybe an illusion at best—and never a destination.

I come across a chapter that provokes in me the horror of recognition: Peggy Munson's "femora and fury: on IPV and disability." At first I cannot even finish reading because it feels too intimate, as if someone had seen my raw evidence of experience and turned the mirror inward on me. Most directly, this chapter helps me recognize the situation as abuse. "Coercion and threats to a disabled partner," Munson writes, "could involve threatening to withdraw basic support, an act that can be more dangerous to a person with a disability than a violent beating" (50). Less directly, it helps me crystallize some of the questions that had begun forming in my own mind, and to think through how disability complicates existing frameworks for understanding intimate partner violence:

In a culture that denigrates human vulnerability and provides nothing but a shoddy caregiving net, people with disabilities often rely on their abusers for food, bathing, toileting, transportation, and other survival needs. Leaving can be imminently life-threatening because victims might lose sustaining care, and replacing this can be next to impossible unless there are non-abusive family members willing to provide it (Munson 48).

What happens, the chapter asks, when your abuser and your caregiver are one and the same? How do we contend with abuse when removing the abusive agent could, very directly, cost someone their own life? And what do we do when abuse is not only contained to the actions of an individual abuser, but is thoroughly embedded within cultural ideologies that cast disability and caretaking as a burden?

It becomes clear to me that the ideology of ableism, like the ideology of rape culture, is both the guiding architecture of and condition of possibility for their relationship's dynamic. As good feminists, many of us know that it is not just individual acts of physical and sexual assault that constitute rape culture, but also a victim-blaming mindset and sense of entitlement to the bodies of others. Fewer of us know that ableism—which involves both active discrimination against disabled people *and also* a shared cultural contempt for vulnerability, care labor, and people's physical/emotional needs—also enables certain forms of abuse to flourish, allowing care to become its own form of violence.

Ableism taught my friend that her cancer made her a burden to others, a sense of indebtedness thoroughly exploited by her abuser/caregiver. It allowed her partner to punish her repeatedly for the sacrifices he made to ensure her continued survival, and to normalize and even justify his behavior. Ableism, too, made it initially difficult for me to identify the situation as abusive. In the first days of her partner's meltdown, I was admittedly slow to criticize him, chalking his actions up to his inability to handle grief and the immense stress of caregiving. If this is an isolated incident, I thought to myself, I can forgive it and move on. But Munson points out that "disabled victims are more likely to be blamed for their abuse, because they are perceived as difficult to be around or care for, and 'caregiver stress' is considered a legitimate excuse for bad

behavior” (49). These myths, Munson writes, “are no different from abuser jargon that habitually accuses the victim of provoking the abuse” (49).

But it is not only ableism that gives me pause. The intersecting forces of racism, U.S. militarism, and (neo)colonialism—systems of domination that have shaped both my and her partner’s life—further complicate my response. He and I, truthfully, are not so different. We are both the products of the Cold War turning hot in socialist Asia, the generation raised in the afterlife of the so-called wars of containment. We are both the children of nations beset by centuries of colonial rule. And while he was born abroad and I in the U.S., we both came up in families undoubtedly impacted by the traumas of war and diaspora, and all the psychic, emotional, and interpersonal wounding bound up in these processes. As erin Khuê Ninh (*pace* Tricia Rose) puts it, the “intimate harm” of structural racism does indeed find us “where we live,” turning our bodies and minds into haunted houses (169). After all, what does it mean to be “sane” in the context of coerced migration, racial injustice, and cultural estrangement? How does colonial domination condition how we, as colonized subjects, understand love and care, and what these practices look like in our day-to-day lives? Can intergenerational trauma provide any explanation for the abusive dynamic that has unmoored my world?

The first edition of *Open in Emergency* seems invested in similar questions. The opening epigraph of the hacked *DSM I: Asian American Edition*, from Lisa Park’s “A Letter to My Sister,” asks its readers, “Why would you want to become a productive, well-adjusted citizen when the primary requisite of Americanness is racism? Isn’t our madness the only evidence we have at all to show for this civilizing terror?” (67) For communities of color, navigating the onslaught of whiteness often means operating in constant survival mode with little time to heal and little ability to recognize care as something you can (and deserve to) receive.¹ I know that my own family of origin modeled love as a relation of control, and that I am still in the process of unlearning this. I know that my understanding of love cannot be separated from the ideology of colonial domination internalized by my family for generations. I know all of these things. But what happens when trauma—be it from war, colonization, or migration—then becomes abuse inflicted upon queer women of color? What frameworks exist for parsing the relationship of intergenerational wounding to intimate harm in the context of global white supremacy? And does the presence of our shared trauma, on both intimate and global scales, mean that I can ever forgive him?

It becomes clear that addressing this abusive dynamic, either in terms of healing or intervention, requires more imagination than dominant models of “wellness” will allow. As Kai Cheng Thom observes in her essay “Belief in Mental Health,” the first entry in the hacked *DSM I: Asian American Edition*, the psychological-industrial complex conceives of mental health as “something we can possess,” and its achievement as an individual, not structural, pursuit (9). And as Lisa Park points out, our criteria for “a well-adjusted citizen” are completely conditioned by the mandates of white supremacy (among other systems of domination). Mental health, under the terms of mainstream psychology, is yet another instrument for reproducing what already

¹ I use the term “heal” in the spirit of the healing justice collectives and organizations, centered on the experiences of BIPOC, who are working to address legacies of trauma (and ongoing injury), and who teach us how to access and accept joy, rest, and respite. For more on healing and joy as necessary modalities for BIPOC, see *Pleasure Activism: The Politics of Feeling Good*, edited by Adrienne Maree Brown.

exists, the violence of the present that so many of us find unbearable. And yet, even with all these warranted critiques, I still want an outside to this dynamic of harm.

October 2019

The day after I began writing this piece, I received what was to be my last text from my friend: “I got bad news.” A week later, she died. During that week, her partner/caregiver weaponized his medical power of attorney against her parents, granting her father and extended family only two minutes in the hospital room to say goodbye. The night of her passing, I was the one to call her mother, as she had been denied further updates on her daughter’s condition. My friend, to be clear, enjoyed a close relationship with her parents, so I do not interpret her partner’s end-of-life choices as gestures of protection on her behalf. I view them as attempts to control a situation that was ultimately beyond all control, but that also did not have to unfold in the way that it did. Her death was tragic, but the conditions surrounding her death were unjust. Even in the fresh debris of her passing, this much is clear.

I dream of elsewhere where my friend’s most viable option is not an abusive caregiver with whom she is romantically entangled, but expansive networks of care support that could gift her with a feeling of abundance rather than the fear of scarcity. I dream of support webs that would have rendered her less vulnerable to a sudden withdrawal of care from her romantic partner, and that would have mitigated, if not eliminated outright, the gross imbalance of power that characterized the final months of her life. I want a system of decision-making that doesn’t rest entirely on the person named medical power of attorney and an infrastructure of care that isn’t the preconditional machinery for abuse.

This, however, would require a complete revisioning of our available systems used to distribute and access care, as well as our existing ideologies around care itself. Individual solutions around abuse, such as removing the abuser/caregiver, can only begin to address that which requires structural transformation. We cannot, for instance, separate my friend’s experience from the context of a post-welfare United States, in which escalating healthcare costs and eviscerated public support systems render abusive care from one’s romantic partner one of the few viable options in a threadbare world. We cannot separate it from the context of an administrative regime bent on killing sick and disabled people through its persistent attacks on Medicaid, the Affordable Care Act, and the Americans with Disabilities Act. We cannot separate it from the inflating numbers of the uninsured, or from the ruthless profit motives of the pharmaceutical industry. Turning to our belief-systems around care, we cannot separate her situation from cultural expectations that place the onus of caregiving—especially when terminally ill—solely on one’s partner, spouse, or family unit. As the title of a Caleb Luna essay puts it, “romantic love is killing us,” or more specifically, an ideology of caregiving that tells us to invest our care labor primarily, if not exclusively, in people we have sought out for romantic partnership.

How then, do we move away from understandings of care labor as scarce and begrudgingly given, and away from individual, privatized models of caregiving (largely gatekept by the institution of romantic love)? As Luna writes, “I want to give my love and care generously, and I want it returned in kind—regardless of a romantic obligation to each other.” How might we

organize care labor differently in order to manifest this vision of generosity? And what do these “economies of care,” as Luna puts it, look like? ²

In the groundbreaking essay collection *Care Work: Dreaming Disability Justice*, poet, performer, and activist Leah Lakshmi Piepzna-Samarasinha details some of the alternate configurations of caregiving envisioned and enacted by disability justice activists in the face of state neglect. Here, she tells us about “care webs,” a mutual aid-oriented caregiving model grounded in collective resource-sharing. Care webs can take a number of forms (depending, always, on access needs, available resources, and labor capacity)—they don’t have to look any particular way. Departing from the model of paid attendant support, care webs refuse to operate under the mandates of charity, which imagines disabled people as passive recipients of care, thus evacuating them of agency and decision-making power. Instead, they uphold the principle of solidarity, of “showing up for each other in mutual aid and respect,” in order to unsettle paternalistic dynamics in which the caregiver wields all the power (41). As such, care webs are directed by “the needs and desires of the disabled people running them” (41). This model of care, as Piepzna-Samarasinha demonstrates, prompts more than just a re-arrangement of caring relations. It demands a complete paradigm shift around caregiving itself, “[shifting] our ideas of access and care... from an individual chore, an unfortunate cost of having an unfortunate body, to a collective responsibility that’s maybe even deeply joyful” (33). Care as joyful, as a site of pleasure, as a means of building and strengthening community—these are the principles that would make generosity possible and that could have upended the power dynamics that structured my friend’s own end-of-life care.

I know, also, that community is not “a magic unicorn, a one-stop shop that always helps us do the laundry and be held in need,” and that community care and mutual aid, too, have their pitfalls (Piepzna-Samarasinha 35). Community cannot fill all the gaps left by decimated state systems, in part because one’s popularity and ability to maintain friendships should not determine one’s level of access to care, and in part because people are people and inevitably cause harm, even with the best of intentions. I dream, too, of a robust, well-funded welfare and state health/care system that can fully support the access needs of sick and disabled people, minus the paternalism, charity, and excessive paperwork. I dream of care infrastructures that do not view sick and disabled people as burdens, do not believe we should be grateful for crumbs, and understand disabled people as inherently valuable. I believe that we deserve all of these systems of care, with all of their resources, and that my friend deserved to be supported in all of these ways. I wanted her life to have ended differently, as an extension and intensification of all the love she held in this world. Because she was not a burden, but someone whose weight we would have borne with delight—all of us, all of us. Because I wanted her to die as she lived—with joy and abundance.

² Other examples of re-visioning care include the concept of pods and podmapping as articulated by the Bay Area Transformative Justice Collective, the Big Door Brigade and the “health” section of the Mutual Aid Toolbox, which describes instances of self-organized health care in the face of state neglect, and the free community health clinics organized by the Black Panthers in the face of state terror. For more on pods and podmapping, see <https://batjc.wordpress.com/pods-and-pod-mapping-worksheet/>. For more on the Big Door Brigade, see <https://bigdoorbrigade.com/>. And for more on the health activism of the Black Panthers, see Alondra Nelson’s *Body and Soul: The Black Panther Party and the Fight Against Medical Discrimination* (Minneapolis: University of Minnesota Press, 2013).

This essay is an offering and gesture toward an alternate ending. It is also a means of bearing witness to the unjust conditions that shaped the end of my friend's life—to try to make some sense of these final months in the only way I know how.

But the decision to bear witness is not an easy one. It is freighted with worry. Even as I commit to writing, I am tempted daily to withdraw my submission, in no small part due to the rawness of the situation. My hesitation, too, comes from the thorniness of witnessing itself. I am not an ethnographer by training, but I know I do not have my friend's informed consent to write this story, and that getting her consent is impossible at this point. What, then, does it mean to bear witness when no one is asking you to do so? When the subject of your story might have actively resisted putting this narrative into print? When witnessing might, in fact, intensify the wounds of the people who survive her? I know the family is grieving, and I do not wish to further complicate their process. And while I unequivocally identify his behavior as abusive, I nonetheless do not wish to further complicate her partner's grief, nor do I wish to torpedo his reputation, even as I have detailed some of his abuse. Admittedly, I also fear the possibility of retaliation if he ever comes across this essay. For my own wellbeing, I have enforced a policy of no contact with this person, even though I hope for his healing, and I hope for his peace.

Why, then, do I still choose to bear witness under these circumstances? When witnessing could, in fact, generate further fallout in the aftermath of her passing? I admit that this decision risks worsening the grieving process for her family and committing violence to her memory. But I also recognize that this kind of abuse is much more common than we care to admit, and that few resources exist to address it. When I was in the thick of the summer—and navigating an onslaught of abusive behavior—it became evident to me that we do not yet have the resources or infrastructure to contend with the abuse, power, and control that so often emerges under the name of care.³ My choice to bear witness, then, emerges from this scarcity and silence, and with a hope for something else to exist. Because even as this essay sifts through the recent past, I also write it with an eye toward the future.

I wanted her life to end another way. In the haze of grief, I re-write the ending again and again. But I know this is impossible, and so I also bear witness in service of what comes after death—of all that lives and survives with her imprint still on it. Because ultimately, bearing witness can also be an act of love, and of love as “lifeforce,” as June Jordan so aptly puts it (11). Love for my friend, of course, but also love for myself and for everyone moved by her presence and spirit. And not love as an abstraction or cliché, but love as transformation, as revolution, as the “essential nature of all that supports life” (Jordan 11). Love as “opposed to the death of the dream,” and love as “a serious and tender concern to respect the nature, and the spontaneous order of other things, other people” (Jordan 11). Love as a means of refusing control, as an

³ Of course, this is not to discount all the testimonies by disabled people that detail the violence enabled under state-run or institutional care, or all the alternate care infrastructures created by disabled people under the principles of mutual aid. This is not to discount the many theories, strategies, and skills generated under the banner of healing justice. I lift up all of these practices, systems, and strategies and hope this essay can also be a part of this transformative work.

insistence on abundance in the face of scarcity, and as a practice that renews us even in my friend's absence.

Since I began writing, I have built an altar for my friend in my home, and am guided daily by the force of the transformative love I was so lucky to have once savored. Here, I remember the first person who ever knew and saw me fully, and in whom I found the intimacy for which I had long been searching. She is the home I return to always, the one who gives me the “on-going fascination and sustenance of life” (Rich 652). Only in her passing do I understand how she made it possible for me to live.

My friend. My dearest, oldest soul friend. The love of my life, an “eruption of the divine” on this earth, who remained fearless—so, so fearless—in spite of repeated and brutal attempts to diminish her (Rodríguez 24). In her spirit, I offer this essay as testimony, as memorial, and finally, as prayer. A prayer for what endures between us, and what will always endure between us: a persistent love that fear, abuse, and death cannot extinguish; a shared admiration both sacred and familiar; a constellation and bridge that forever joins my world to hers.

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