Mask Magazine

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Sick Woman Theory

Johanna Hedva lives with chronic illness and her Sick Woman Theory is for those who were never meant to survive but did.

Johanna Hedva Tue, Jan 19 2016

1.

In late 2014, I was sick with a chronic condition that, about every 12 to 18 months, gets bad enough to render me, for about five months each time, unable to walk, drive, do my job, sometimes speak or understand language, take a bath without assistance, and leave the bed. This particular flare coincided with the Black Lives Matter protests, which I would have attended unremittingly, had I been able to. I live one block away from MacArthur Park in Los Angeles, a predominantly Latino neighborhood and one colloquially understood to be the place where many immigrants begin their American lives. The park, then, is not surprisingly one of the most active places of protest in the city.

I listened to the sounds of the marches as they drifted up to my window. Attached to the bed, I rose up my sick woman fist, in solidarity.

I started to think about what modes of protest are afforded to sick people – it seemed to me that many for whom Black Lives Matter is especially in service, might not be able to be present for the marches because they were imprisoned by a job, the threat of being fired from their job if they marched, or literal incarceration, and of course the threat of violence and police brutality – but also because of illness or disability, or because they were caring for someone with an illness or disability.

I thought of all the other invisible bodies, with their fists up, tucked away and out of sight.

If we take Hannah Arendt's definition of the political – which is still one of the most dominant in mainstream discourse – as being any action that is performed in public, we must contend with the implications of what that excludes. If being present in public is what is required to be political, then whole swathes of the population can be deemed *a*-political – simply because they are not physically able to get their bodies into the street.

In my graduate program, Arendt was a kind of god, and so I was trained to think that her definition of the political was radically liberating. Of course, I can see that it was, in its own way, in its time (the late 1950s): in one fell swoop she got rid of the need for infrastructures of law, the democratic process of voting, the reliance on individuals who've accumulated the power to affect policy – she got rid of the need for policy at all. All of these had been required for an action to be considered political and visible as such. No, Arendt said, just get your body into the street, and *bam*: political.

There are two failures here, though. The first is her reliance on a "public" – which requires a private, a binary between visible and invisible space. This meant that whatever takes place in private is *not* political. So, you can beat your wife in private and it doesn't matter, for instance. You can send private emails containing racial slurs, but since they weren't "meant for the public," you are somehow not racist. Arendt was worried that if everything can be considered political, then nothing will be, which is why she divided the space into one that is political and one that is not. But for the sake of this anxiety, she chose to sacrifice whole groups of people, to continue to banish them to invisibility and political irrelevance. She chose to keep them out of the public sphere. I'm not the first to take Arendt to task for this. The failure of Arendt's political was immediately exposed in the civil rights activism and feminism of the 1960s and 70s. "The personal is political" can also be read as saying "the private is political." Because of course, *everything* you do in private is political: who you have sex with, how long your showers are, if you have access to clean water for a shower at all, and so on.

There is another problem too. As Judith Butler put it in her 2015 lecture, "Vulnerability and Resistance," Arendt failed to account for who is allowed in to the public space, of *who's in charge* of the public. Or, more specifically, *who's in charge of who gets in*. Butler says that there is always one thing true about a public demonstration: the police are already there, or they are coming. This resonates with frightening force when considering the context of Black Lives Matter. The inevitability of violence at a demonstration – especially a demonstration that emerged to insist upon the importance of bodies who've been violently un-cared for – ensures that a certain amount of people won't, because they can't, show up. Couple this with physical and mental illnesses and disabilities that keep people in bed and at home, and we must contend with the fact that many whom these protests are for, are not able to participate in them – which means they are not able to be visible as political activists.

There was a Tumblr post that came across my dash during these weeks of protest, that said something to the effect of: "shout out to all the disabled people, sick people, people with PTSD, anxiety, etc., who can't protest in the streets with us tonight. Your voices are heard and valued, and with us." Heart. Reblog.

So, as I lay there, unable to march, hold up a sign, shout a slogan that would be heard, or be visible in any traditional capacity as a political being, the central question of Sick Woman Theory formed: How do you throw a brick through the window of a bank if you can't get out of bed?

2.

I have chronic illness. For those who don't know what chronic illness means, let me help: the word "chronic" comes from the Latin *chronos*, which means "of time" (think of "chronology"), and it specifically means "a lifetime." So, a chronic illness is an illness that lasts a lifetime. In other words, it does not get better. There is no cure.

And think about the weight of time: yes, that means you feel it every day. On very rare occasions, I get caught in a moment, as if something's plucked me out of the world, where I realize that I haven't thought about my illnesses for a few minutes, maybe a few precious hours. These blissful moments of oblivion are the closest thing to a miracle that I know. When you have chronic illness, life is reduced to a relentless rationing of energy. It costs you to do anything: to get out of bed, to cook for yourself, to get dressed, to answer an email. For those without chronic illness, you can spend and spend without consequence: the cost is not a problem. For those of us with limited funds, we have to ration, we have a limited supply: we often run out before lunch.

I've come to think about chronic illness in other ways.

Ann Cvetkovich writes: "What if depression, in the Americas, at least, could be traced to histories of colonialism, genocide, slavery, legal exclusion, and everyday segregation and isolation that haunt all of our lives, rather than to be biochemical imbalances?" I'd like to change the word "depression" here to be all mental illnesses. Cvetkovich continues: "Most medical literature tends to presume a white and middle-class subject for whom feeling bad is frequently a mystery because it doesn't fit a life in which privilege and comfort make things seem fine on the surface." In other words, wellness as it is talked about in America today, is a white and wealthy idea.

Let me quote Starhawk, in the preface to the new edition of her 1982 book *Dreaming the Dark*: "Psychologists have constructed a myth – that somewhere there exists some state of health which is the norm, meaning that most people presumably are in that state, and those who are anxious, depressed, neurotic, distressed, or generally unhappy are deviant." I'd here supplant the word "psychologists" with "white supremacy," "doctors," "your boss," "neoliberalism," "heteronormativity," and "America."

There has been a slew of writing in recent years about how “female” pain is treated – or rather, not treated as seriously as men’s in emergency rooms and clinics, by doctors, specialists, insurance companies, families, husbands, friends, the culture at large. In a recent article in *The Atlantic*, called “How Doctors Take Women’s Pain Less Seriously,” a husband writes about the experience of his wife Rachel’s long wait in the ER before receiving the medical attention her condition warranted (which was an ovarian torsion, where an ovarian cyst grows so large it falls, twisting the fallopian tube). “Nationwide, men wait an average of 49 minutes before receiving an analgesic for acute abdominal pain. Women wait an average of 65 minutes for the same thing. Rachel waited somewhere between 90 minutes and two hours,” he writes. At the end of the ordeal, Rachel had waited nearly fifteen hours before going into the surgery she should have received upon arrival. The article concludes with her physical scars healing, but that “she’s still grappling with the psychic toll – what she calls ‘the trauma of not being seen.’”

What the article does not mention is race – which leads me to believe that the writer and his wife are white. Whiteness is what allows for such oblivious neutrality: it is the premise of blankness, the presumption of the universal. (Studies have shown that white people will listen to other white people when talking about race, far more openly than they will to a person of color. As someone who is white-passing, let me address white people directly: look at my white face and listen up.)

The *trauma of not being seen*. Again – *who is allowed in* to the public sphere? Who is allowed to be visible? I don’t mean to diminish Rachel’s horrible experience – I myself once had to wait ten hours in an ER to be diagnosed with a burst ovarian cyst – I only wish to point out the presumptions upon which her horror relies: that our vulnerability should be seen and honored, and that we should all receive care, quickly and in a way that “respects the autonomy of the patient,” as the Four Principles of Biomedical Ethics puts it. Of course, these presumptions are what we all should have. But we must ask the question of who is allowed to have them. In whom does society substantiate such beliefs? And in whom does society enforce the opposite?

Compare Rachel’s experience at the hands of the medical establishment with that of Kam Brock’s. In September 2014, Brock, a 32-year-old black woman, born in Jamaica and living in New York City, was driving a BMW when she was pulled over by the police. They accused her of driving under the influence of marijuana, and though her behavior and their search of her car yielded nothing to support this, they nevertheless impounded her car. According to a lawsuit brought against the City of New York and Harlem Hospital by Brock, when Brock appeared the next day to retrieve her car she was arrested by the police for behaving in a way that she calls “emotional,” and involuntarily hospitalized in the Harlem Hospital psych ward. (As someone who has also been involuntarily hospitalized for behaving “too” emotionally, this story feels like a rip of recognition through my brain.) The doctors thought she was “delusional” and suffering from bipolar disorder, because she claimed that Obama followed her on twitter – *which was true*, but which the medical staff failed to confirm. She was then held for eight days, forcibly injected with sedatives, made to ingest psychiatric medication, attend group therapy, and stripped. The medical records of the hospital – obtained by her lawyers – bear this out: the “master treatment plan” for Brock’s stay reads, “Objective: Patient will verbalize the importance of education for employment and will state that Obama is not following her on Twitter.” It notes her “inability to test reality.” Upon her release, she was given a bill for $13,637.10.

The question of why the hospital’s doctors thought Brock “delusional” because of her Obama-follow claim is easily answered: Because, according to this society, a young black woman can’t possibly be that important – and for her to insist that she is must mean she’s “sick.”

3.

Before I can speak of the “sick woman” in all of her many guises, I must first speak as an individual, and address you from my particular location.

I am antagonistic to the notion that the Western medical-insurance industrial complex understands me in my entirety, though they seem to think they do. They have attached many words to me over the years, and though some of these have provided articulation that was useful – after all, no matter how much we are working to change the world, we must still find ways of coping with the reality at hand – first I want to suggest some other ways of understanding my “illness.”

Perhaps it can all be explained by the fact that my Moon’s in Cancer in the 8th House, the House of Death, or that my Mars is in the 12th House, the House of Illness, Secrets, Sorrow, and Self-Undoing. Or, that my father’s mother escaped from North Korea in her childhood and hid this fact from the family until a few years ago, when she accidentally let it slip out, and then swiftly, revealingly, denied it. Or, that my mother suffers from undiagnosed mental illness that was actively denied by her family, and was then exasperated by a 40-year-long drug addiction, sexual trauma, and hepatitis from a dirty needle, and to this day remains untreated, as she makes her way in and out of jails, squats, and homelessness. Or, that I was physically and emotionally abused as a child, raised in an environment of poverty, addiction, and violence, and have been estranged from my parents for 13 years. Perhaps it’s because I’m poor – according to the IRS, in 2014, my adjusted gross income was $5,730 (a result of not being well enough to work full-time) – which means that my health insurance is provided by the state of California (Medi-Cal), that my "primary care doctor" is a group of physician's assistants and nurses in a clinic on the second floor of a strip mall, and that I rely on food stamps to eat. Perhaps it can be encapsulated in the word "trauma." Perhaps I've just got thin skin, and have had some bad luck.

It's important that I also share the Western medical terminology that's been attached to me – whether I like it or not, it can provide a common vocabulary: "This is the oppressor's language," Adrienne Rich wrote in 1971, "yet I need it to talk to you." But let me offer another language, too. In the Native American Cree language, the possessive noun and verb of a sentence are structured differently than in English. In Cree, one does not say, "I am sick." Instead, one says, "The sickness has come to me." I love that and want to honor it.

So, here is what has come to me:

Endometriosis, which is a disease of the uterus where the uterine lining grows where it shouldn't – in the pelvic area mostly, but also anywhere, the legs, abdomen, even the head. It causes chronic pain; gastrointestinal chaos; epic, monstrous bleeding; in some cases, cancer; and means that I have miscarried, can't have children, and have several surgeries to look forward to. When I explained the disease to a friend who didn't know about it, she exclaimed: "So your whole body is a uterus!" That's one way of looking at it, yes. (Imagine what the Ancient Greek doctors – the fathers of the theory of the "wandering womb" – would say about that.) It means that every month, those rogue uterine cells that have implanted themselves throughout my body, "obey their nature and bleed," to quote fellow endo warrior Hilary Mantel. This causes cysts, which eventually burst, leaving behind bundles of dead tissue like the debris of little bombs.

Bipolar disorder, panic disorder, and depersonalization disorder have also come to me. This means that I live between this world and another one, one created by my own brain that has ceased to be contained by a discrete concept of "self." Because of these "disorders," I have access to incredibly vivid emotions, flights of thought, and dreamscapes, to the feeling that my mind has been obliterated into stars, to the sensation that I have become nothingness, as well as to intense ecstasies, raptures, sorrows, and nightmarish hallucinations. I have been hospitalized, voluntarily and involuntarily, because of it, and one of the medications I was prescribed once nearly killed me – it produces a rare side effect where one's skin falls off. Another cost $800 a month – I only took it because my doctor slipped me free samples. If I want to be able to hold a job – which this world has decided I ought to be able to do – I must take an anti-psychotic medication daily that causes short-term memory loss and drooling, among other sexy side effects. These visitors have also brought their friends: nervous breakdowns, mental collapses, or whatever you want to call them, three times in my life. I'm certain they will be guests in my house again. They have motivated attempts at suicide (most of them while dissociated) more than a dozen times, the first one when I was nine years old. That first attempt didn't work, only because after taking a mouthful of sleeping pills, I somehow woke up the next day and went to school, like nothing had happened. I told no one about it, until my first psychiatric evaluation in my mid 20s.

Finally, an autoimmune disease that continues to baffle all the doctors I've seen, has come to me and refuses still to be named. As Carolyn Lazard has written about her experiences with autoimmune diseases: "Autoimmune disorders are difficult to diagnose. For ankylosing spondylitis, the average time between the onset of symptoms and diagnosis is eight to twelve years. I was lucky; I only had to wait one year." Names like "MS," "fibromyalgia," and others that I can't remember have fallen from the mouths of my doctors – but my insurance won't cover the tests, nor is there a specialist in my insurance plan within one hundred miles of my home. I don't have enough space here – will I ever? – to describe what living with an autoimmune disease is like. I can say it brings unimaginable fatigue, pain all over all the time, susceptibility to illnesses, a body that performs its "normal" functions monstrously abnormally. The worst symptom that mine brings is chronic shingles. For ten years I've gotten shingles in the same place on my back, so that I now have nerve damage there, which results in a ceaseless, searing pain on the skin and a dull, burning ache in the bones. Despite taking daily medication that is supposed to "suppress" the shingles virus, I still get them – they are my canaries in the coalmine, the harbingers of at least three weeks to be spent in bed.

My acupuncturist described it as a little demon steaming black smoke, frothing around, nestling into my bones.

4.

With all of these visitors, I started writing Sick Woman Theory as a way to survive in a reality that I find unbearable, and as a way to bear witness to a self that does not feel like it can possibly be "mine."

The early instigation for the project of "Sick Woman Theory," and how it inherited its name, came from a few sources. One was in response to Audrey Wollen's "Sad Girl Theory," which proposes a way of redefining historically feminized pathologies into modes of political protest for girls: I was mainly concerned with the question of what happens to the sad girl when, if, she grows up. Another was incited by reading Kate Zambreno's fantastic *Heroines*, and feeling an itch to fuck with the concept of “heroism” at all, and so I wanted to propose a figure with traditionally anti-heroic qualities – namely illness, idleness, and inaction – as capable of being the symbol of a grand Theory. Another was from the 1973 feminist book *Complaints and Disorders*, which differentiates between the “sick woman” of the white upper class, and the “sickening women” of the non-white working class.

Sick Woman Theory is for those who are faced with their vulnerability and unbearable fragility, every day, and so have to fight for their experience to be not only honored, but first made visible. For those who, in Audre Lorde’s words, were never meant to survive: because this world was built against their survival. It’s for my fellow spoonies. You know who you are, even if you’ve not been attached to a diagnosis: one of the aims of Sick Woman Theory is to resist the notion that one needs to be legitimated by an institution, so that they can try to fix you. You don’t need to be fixed, my queens – it’s the world that needs the fixing.

I offer this as a call to arms and a testimony of recognition. I hope that my thoughts can provide articulation and resonance, as well as tools of survival and resilience.

And for those of you who are not chronically ill or disabled, Sick Woman Theory asks you to stretch your empathy this way. To face us, to listen, to see.


LORDE
SISTER OUTSIDER
KAFER
FEMINIST QUEER CRIP

5.

Sick Woman Theory is an insistence that most modes of political protest are internalized, lived, embodied, suffering, and no doubt invisible. Sick Woman Theory redefines existence in a body as something that is primarily and always vulnerable, following from Judith Butler's work on precarity and resistance. Because the premise insists that a body is defined by its vulnerability, not temporarily affected by it, the implication is that it is continuously reliant on infrastructures of support in order to endure, and so we need to re-shape the world around this fact. Sick Woman Theory maintains that the body and mind are sensitive and reactive to regimes of oppression – particularly our current regime of neoliberal, white-supremacist, imperial-capitalist, cis-hetero-patriarchy. It is that all of our bodies and minds carry the historical trauma of this, that it is *the world itself* that is making and keeping us sick.

To take the term "woman" as the subject-position of this work is a strategic, all-encompassing embrace and dedication to the particular, rather than the universal. Though the identity of "woman" has erased and excluded many (especially women of color and trans and genderfluid people), I choose to use it because it still represents the un-cared for, the secondary, the oppressed, the non-, the un-, the less-than. The problematics of this term will always require critique, and I hope that Sick Woman Theory can help undo those in its own way. But more than anything, I'm inspired to use the word "woman" because I saw this year how it can still be radical to be a woman in the 21st century. I use it to honor a dear friend of mine who came out as genderfluid last year. For her, what mattered the most was to be able to call herself a "woman," to use the pronouns "she/her." She didn't want surgery or hormones; she loved her body and her big dick and didn't want to change it – she only wanted the word. That the word itself can be an empowerment is the spirit in which Sick Woman Theory is named.

The Sick Woman is an identity and body that can belong to anyone denied the privileged existence – or the cruelly optimistic *promise* of such an existence – of the white, straight, healthy, neurotypical, upper and middle-class, cis- and able-bodied man who makes his home in a wealthy country, has never not had health insurance, and whose importance to society is everywhere recognized and made explicit by that society; whose importance and care *dominates* that society, at the expense of everyone else.

The Sick Woman is anyone who does not have this guarantee of care.

The Sick Woman is told that, to this society, her care, even her survival, does not matter.

The Sick Woman is all of the "dysfunctional," "dangerous" and "in danger," "badly behaved," "crazy," "incurable," "traumatized," "disordered," "diseased," "chronic," "uninsurable," "wretched," "undesirable" and altogether "dysfunctional" bodies belonging to women, people of color, poor, ill, neuro-atypical, differently abled, queer, trans, and genderfluid people, who have been historically pathologized, hospitalized, institutionalized, brutalized, rendered "unmanageable," and therefore made culturally illegitimate and politically invisible.

The Sick Woman is a black trans woman having panic attacks while using a public restroom, in fear of the violence awaiting her.

The Sick Woman is the child of parents whose indigenous histories have been erased, who suffers from the trauma of generations of colonization and violence.

The Sick Woman is a homeless person, especially one with any kind of disease and no access to treatment, and whose only access to mental-health care is a 72-hour hold in the county hospital.

The Sick Woman is a mentally ill black woman whose family called the police for help because she was suffering an episode, and who was murdered in police custody, and whose story was denied by everyone operating under white supremacy. Her name is Tanesha Anderson.

The Sick Woman is a 50-year-old gay man who was raped as a teenager and has remained silent and shamed, believing that men can't be raped.

The Sick Woman is a disabled person who couldn't go to the lecture on disability rights because it was held in a venue without accessibility.

The Sick Woman is a white woman with chronic illness rooted in sexual trauma who must take painkillers in order to get out of bed.

The Sick Woman is a straight man with depression who's been medicated (managed) since early adolescence and now struggles to work the 60 hours per week that his job demands.

The Sick Woman is someone diagnosed with a chronic illness, whose family and friends continually tell them they should exercise more.

The Sick Woman is a queer woman of color whose activism, intellect, rage, and depression are seen by white society as unlikeable attributes of her personality.

The Sick Woman is a black man killed in police custody, and officially said to have severed his own spine. His name is Freddie Gray.

The Sick Woman is a veteran suffering from PTSD on the months-long waiting list to see a doctor at the VA.

The Sick Woman is a single mother, illegally emigrated to the "land of the free," shuffling between three jobs in order to feed her family, and finding it harder and harder to breathe.

The Sick Woman is the refugee.
The Sick Woman is the abused child.
The Sick Woman is the person with autism whom the world is trying to “cure.”
The Sick Woman is the starving.
The Sick Woman is the dying.
And, crucially: The Sick Woman is who capitalism needs to perpetuate itself.
Why?
Because to stay alive, capitalism cannot be responsible for our care – its logic of exploitation requires that some of us die.
“Sickness” as we speak of it today is a capitalist construct, as is its perceived binary opposite, “wellness.” The “well” person is the person well enough to go to work. The “sick” person is the one who can’t. What is so destructive about conceiving of wellness as the default, as the standard mode of existence, is that it *invents illness as temporary*. When being sick is an abhorrence to the norm, it *allows us to conceive of care and support in the same way.*
Care, in this configuration, is only required sometimes. When sickness is temporary, care is not normal.
Here’s an exercise: go to the mirror, look yourself in the face, and say out loud: “To take care of you is not normal. I can only do it temporarily.”
Saying this to yourself will merely be an echo of what the world repeats all the time.

6.
I used to think that the most anti-capitalist gestures left had to do with love, particularly love poetry:

to write a love poem and give it to the one you desired, seemed to me a radical resistance. But now I see I was wrong.

The most anti-capitalist protest is to care for another and to care for yourself. To take on the historically feminized and therefore invisible practice of nursing, nurturing, caring. To take seriously each other's vulnerability and fragility and precarity, and to support it, honor it, empower it. To protect each other, to enact and practice community. A radical kinship, an interdependent sociality, a politics of care.

Because, once we are all ill and confined to the bed, sharing our stories of therapies and comforts, forming support groups, bearing witness to each other's tales of trauma, prioritizing the care and love of our sick, pained, expensive, sensitive, fantastic bodies, and there is no one left to go to work, perhaps then, finally, capitalism will screech to its much-needed, long-overdue, and motherfucking glorious halt.

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This text is adapted from the lecture, "My Body Is a Prison of Pain so I Want to Leave It Like a Mystic But I Also Love It & Want It to Matter Politically," delivered at Human Resources, sponsored by the Women's Center for Creative Work, in Los Angeles, on October 7, 2015. The video is here.

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