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**On Survival and Education: An Academic's Perspective on Disability**

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When illness and disability strike, it can seem as though one's very being is threatened. We tend to consider illness a temporary situation, a phase, a phase that will be done with, sooner or later, and the victim of the attack will be rectified, and will survive it. But in chronic illness, there is a gap, a missing piece that cannot be found, despite all attempts. This is not necessarily a loss, as to claim that there is a loss falls into dangerous territory of positing a once complete or whole body and/or self. The losses are not due to a changing body, but rather discriminatory disablement by society's understandings of disability. When bodies begin to falter, painful experiences of embodiment and how we experience the world begin to emerge. But to survive is to live through, live with, or live without something. To survive is to also be resilient to any losses. To be a survivor is to have been on the threshold of non-surviving, to have considered giving up, letting go – to allow for a break, a rupture from resilience. In order to survive in a world that is sexist, racist, and ableist, academic scholarship and education yields itself as a necessary constituent of making sense of living in a different body, as part of communities that tend to marginalize and discriminate against individuals who are marked as different (whether by a disability, sexual orientation, etc). Different bodies are marked as deviant and are often excluded from communities. My lived experience of disability and an academic identity have gone hand in hand as I have attempted to survive, question, and shape a new understanding of life.

As a Disability Studies scholar, but also, more importantly, an academic struggling with Multiple Sclerosis, my definition of selfhood and illness has benefited from other voices, other scholars who have helped me navigate a not-quite-safe-zone: that of acquired disability, a progression of a disease that has made itself my life partner, one I had to adjust to. The question that demands an answer is who is responsible for the other, and if it is a relationship between myself and this life partner, is it a toxic relationship? Science has always informed us that MS invades the body, in a quite literal way, attacking the immune system, being overprotective of one's body that it mistakes "good" cells for "bad cells" and as such attacks its own home. This used to feel like a war to me, a constant war, except that I am unable to decide whether the mind or the body (limbs, flesh, and muscles) is to blame? My dichotomies just won't do: mind/body, self/other, abled/disabled. My self is no longer entirely mine, and I must adapt to this other, who has moved into my territory. No dichotomous way of thinking about my lived experience will do; and science reiterating the invasion against my body yields a war image. War imagery will reproduce negative connotations about disability. When individuals with disabilities are informed, as I was, that my body would not survive a war, this further oppresses and places the blame of failing to survive against an alien intruder on the individual. I refused to see the attack against my body as a full-blown attack, as a split between my body and self; and I wanted to survive the ableist reductions of what my body was experiencing on a daily basis. Physical pain, crushing mental and physical fatigue that hinders my ability to walk, talk, lift objects, recall words, and survive the new symptoms that emerge presented daily obstacles. With Multiple Sclerosis, age is not a determining factor. I have felt older than most people my age. Diagnosed at eighteen, people surrounding me refused to acknowledge the disease as a part of my life. "You're too young to be sick" was a statement I heard continuously. I had to defend myself constantly, explaining to

people that this was not my fault, that I had not somehow transgressed into the territory of illness and disability – that it was the other way around, my life had been interrupted. Society's judgement was part of my struggle, and I was instructed by my mother to be resilient in the face of illness and society: both were the enemy. There was no way around the stigma that society perpetuated. Society was disabling and the first introduction to how interacting with others who are not afflicted by disability came from my social circle: my family, friends, and peers. Being surrounded by 'able-bodied' individuals renders one as constantly facing a hardship, a struggle, while others are able to navigate the world more freely, with better accessibility to resources such as jobs, living accommodations, health, etc. My relationship with significant others was affected as I began to feel isolated and lonely and not understood. My lived experience was too different and I did not fall into any category of either 'able-bodied' or 'disabled' as my symptoms alternated between being physically functional, mobile, and at times immobile and crushed by physical and mental fatigue.

In my case, an academic revolution was born. I learned to adapt to loss, to limitations, to time that was always running out, chasing me into a panic-stricken state, wondering how many more hours I had until the chronic fatigue would have me sprawled across the bed, unable to lift my head, let alone read, mark my students' papers, or produce substantial work. Individuals living with disability or illness negotiate time differently. The view of time, energy conservation, minimizing pain and also confronting one's own mortality –these are all adjustments one has to make. Resilience is worrying, at times, because it is difficult to ascertain just how much farther you can push. Push. Keep going. Do not falter. These are just a few of the words that became part of my everyday life. Whether these words were my mother's or society's definition of resilience –I am not sure.

Nearly twelve years after the diagnosis, and struggling to live with MS, I am able to say that my mother was one of the subscribers to the belief that resilience and perseverance will get you places. There was no tragedy that could befall you, unless you died, that meant life was over. It was only "on pause" as she would say; hence, an interruption. My mother used the words "pause" and "on hold" to reaffirm that my life's narrative was not necessarily over, as much as I desired it to be. Living with pain and a fear of the unknown, the unpredictability of the disease's progression, a sense of social isolation, lack of a support system or a community, all of these factors were not ingredients for survival. And yet, she insisted, quoting from the Syrian poet Nizar Qabbani, "Revolution is born from the womb of tragedy." Quite political, perhaps, but in a sense, I felt like a combatant. My disability was not tragic, and yet, society's discrimination had made me feel isolated and helpless. I had to rise up against the stigma and my own self-stigmatizing views, in which I thought I was to be held accountable for what was happening, that I had to keep fighting otherwise I would lose the imaginary war. The war was imaginary, fueled by my sense of isolation and frustrations. I was fighting my body and society up until I was introduced to Disability Studies and scholars who helped decode the hieroglyphics of disability. It was in fact society that was disabling and not my MS.

One philosopher whose work I have benefited from while attempting to find a new understanding of this partnership between myself and the "failing" body is Havi Carel, a philosopher who looked at her own illness and the phenomenology behind it. Havi Carel in *Illness* (2008, 81) considers adaptability to be critical in one's journey through illness: "Adaptability takes place on physical, psychological, social, and temporal levels...it is not a smooth process but a series of dialectic encounters of a body with an environment, of a demand with failure, and of failure with the need for modification" (81). Carel, dealing with her own

illness, has found ways to approach, to accommodate, and to survive this attack. If this relationship between body and self is to be understood in non-abelist terms and accommodated as a non-toxic relationship, then the language we use to communicate must be adapted. A new lexicon is to be created. Negotiations are to be made. How can we adapt?

The very definition of what constitutes a good life has to be called into question. What is a good life and how can we even begin to define it? We experience the world every day through the same bodies, and yet, there are times when our bodies suddenly change. How will this affect our understanding of our lives and how happy and safe we feel? The material body is redefined. This body, this house of mine, is now shared by an alien intruder. And the intruder is not going anywhere. The narrative of one's life, then, is hijacked, interrupted. Carel, like many scholars, holds the view of illness as interruption of one's life.

The view of illness as biographical disruption is illuminating...Becoming ill creates a need to find meaning for a new narrative...Changes to a person's sense of self and identity are common and both patients and researchers use concepts such as enduring, struggling and disruption to describe the experience of illness. (83)

My life was interrupted and I needed to recreate a new life narrative. We create our own stories and what works for the majority might not work for me. I began to see the world through different eyes, that it was society that had pushed me to believe I was failing, faltering, that society's ideals of health were not what I had to live up to anymore. I was to survive the world and be resilience in the face of change, lack of access, and create new definitions of a good life, a life that made me happy, and a body in which I felt safe, not attacked. As much as resilience became a part of breathing, so did my desire for education and academia. I did not want much from life. The everyday struggles of living with limited energy supply, mobility and

concentration difficulties meant I had to stay resilient and not fall into a self-victimization role. To be resilient and survive simply to have access to the things I loved, such as teaching, meant I had to keep reminding myself that I was still alive, breathing, and still myself—that nothing was completely taken away from me, that I only had to make alterations and adjustments to my life's expectations, desires, and what I expected my body to be able to perform. I simply wanted to survive in order to teach. I wanted to be inside the classroom with students. My mother's voice, always in my head: "Get up Shahd. You are a survivor." These words, branded forever in my memory, the water I need when I feel like giving up (and there are many, many days where I do). My mother's voice is sometimes invasive, but like MS, it is not a war against me, it urges me to reconsider the things that matter, what I know is a good and safe place, that life is not simply experienced through the body, that the world needs to be accommodating, but that we also need to find our own tools of survival.

An academic revolution was born when I found my way into Disability Studies and Women's Studies. These academic fields offered tools to make sense of the interruption, of a sense of identity that I felt robbed of. Survival involves reinstating personal changes, new laws, new disciplinary measures, and new communicative relations with and through one's bodily being. Redefining material boundaries and temporalities is part of this process, which involves multiple and discontinuous changes, adaptations and accommodations. I began to view life as a constant state of alterations, changes, and of survival. I started searching for ways to deal with societal exclusions and found that I belonged not simply in my body (which was changing and deteriorating) but that I also belonged in academia and I had as much to offer academic scholarship than ever. I learned to reinstate new laws by negotiating different definitions of happiness and satisfaction, that life was as temporary and transitory as my own embodied

experience, that it was in fact the small things that I cherished, that happiness was not winning any imaginary war, but rather it was coming to terms with a different life and a different body, that it was not about coming out of the pain but rather living with it through a different perspective. I had to accommodate the pain and my new body as much as I demanded that society was to be accommodating.

To survive is not to come out of pain with a badge of heroism. More often than not, survival constitutes agonizing experiences. It is not agonizing in the sense that the agony must be overcome or defeated. Feminist Disability Studies theorist Susan Wendell (1996) asserts that "disabled heroes" may be comforting for non-disabled individuals. Not everyone is able to survive or resist the progression of a disease, more often than not "disabled heroes have extraordinary social, economic, and physical resources that are not available to most people with disabilities." I am aware that my access to higher education was one of the defining forces in my life and dealing with the disability. But it was more than access, there was a burning desire to redefine what a good life meant to me. I wanted to find meaning and a sense of purpose; I wanted to understand my own struggles and consider the societal factors that influenced my understanding of disability.

Disability Studies and Women's Studies have been invaluable for my psychological survival. I have been able to survive the real world only by the tools granted to me through theoretical readings and academic work. Academic work is not altogether separate from the real world; it is not an elusive place, but rather, it helped me find a sense of purpose, answers to my confusions, my frustrations with the real world. We experience our bodies and embodiment through the real world, but academic scholarship helps to bridge the gap between how we feel and our understanding of the various factors at hand. Feminist killjoy Sara Ahmed provided me



with tools to survive in a world that is racist, sexist, ableist. Sara Ahmed's *Living a Feminist Life* (2017) reiterates the importance of survival and resilience. She reminds us that Audre Lorde also considered self-care an act of survival, "as not about self-indulgence but self-preservation" (239). So we must care. We must love ourselves in times of war. We must preserve parts of us. Even the parts that have been raided, shell-shocked, and threatened. We must come out alive. Part of the experience lingers, but it is these very experiences that become our reference points. Ahmed, speaking of painful experiences, states: "The experiences we have are not just of being worn down; these experiences also give us resources...Survival can also be about keeping one's hopes alive; holding on to the projects insofar as they have yet to be realized" (235). Like Ahmed, I too believe that survival is about keeping one's hopes alive. Survival is not about being alive, but more importantly, about pursuing a sense of purpose, holding on to yet unrealized projects, and engaging with our imagined others, MS, my mother's voice, significant others, theorists that attempt to explain the lived experiences, students who need the same survival tools. Each time I teach a course, I publish a paper, I write a story, I feel a sense of life bursting through me. My work, I hope, will survive beyond me. This hope defines survival.

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