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Living with Herbert: Mediating Survival and Resilience

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In my second year of my doctoral program I was struck by a debilitating bout of vertigo. Not certain of what was happening or why my body suddenly seemed to be in a spinning room that no one else was experiencing, I consulted trusted family and friends in the medical field for an explanation. Most of my friends dismissed my concern as the stress of a new school year or just the circumstances that befall someone who has always been clumsy. I, however, was not swayed in my concern and paying attention to the material realities of my body, I went to the doctor. Over the next several weeks I went from specialist to specialist until an MRI was ordered and a cause was identified. A large benign brain tumor was found, growing off of my hearing and balance nerves and pushing against my brain stem. I was told that though the tumor was benign, it had grown larger than the space available to it, that I was losing my hearing and balance and without treatment I would most certainly die in a few years because of the way the tumor was growing in the space my brainstem required.

I remember those weeks of my life clearly, the way everyone peppered my everyday with certain platitudes that I would survive, overcome, thrive, and become stronger than I had been before. I remember people letting me know that I was resilient. I endured ten brain surgeries over the next four years. I was hospitalized for about half of each academic year and I suffered from chronic pain. I lost the hearing in my right ear and was plagued by spinal fluid leaks. I was constantly assured that I still looked normal and it would not be long before I overcame this surgery, pain, or whatever else I was suffering with. I was comforted after each surgery that I had done it before, and I could do it again. I was lost in a space of assurances that there must be a reason for this, that I would learn whatever mythical lessons pain stood to teach me, and I would see myself through. As each surgery opened the door to the next I grew weary of the assurances that I would be as strong or stronger than I was before and my inability to meet the enthusiastic cries for resilience from people around me only made me feel like a failure. So, I went online to mediate my experience, to seek out others who were suffering, to make new meaning from what I was suffering from, and to mediate my experiences, and to try and find an accepting space to be comfortable with my new body.

I took advantage of the affordances of the flexible, negotiable, as-if space of digital media to articulate that I didn’t want to return to normal. I was trying to find a space to negotiate what it meant that there was no return to normal and that I didn’t want to be fixed. And yet, I so desperately wanted to be fixed. I wanted the world to take me as I was, but I did not want to suffer. I wanted to live, I wanted to continue my life, but I didn’t want to feel obligated to fix my single-sided deafness, I didn’t want to rise out of the ashes of brain surgery stronger than I had been, and I didn’t want to feel like I’d failed somehow if I didn’t emerge from this experience as some kind of super hero. All of this was happening as my graduate program had me deeply steeped in the literature of Feminist Disability Studies. I was studying crip theory, queer theory, and authors such as Garland-Thompson (2002) and McRuer (2004) who told me that so much of what I was feeling was constructed for me. I was encountering first-hand the way the burden of my disability was on my own shoulders. I had to explain it away, apologize to people when I did not hear them, find easy ways to learn without burdening instructors, pass as normal or come out as disabled with all the self-deprecation that seemed to require. I wanted to keep my disability invisible and I wanted to name it, to illuminate to the world that they could make space for it to exist and that I didn’t have to work so hard to make others comfortable. This prospect seemed powerful to me. I wanted to buck the language of disability, so infused with ableist discourses about who could participate in the world. That process involved a constant debate about whether to hide my disability, to own it, name it, or to embody the language of resilience and overcome it. The battle between myself and my social world was exhausting, frightening, and disabling.

At the time of diagnosis, I wrote a blog about my experiences and I mediated my identity negotiation. Under the guise of "health updates" I interrogated ideas about my survival. I wrote about what I was feeling, what I was afraid of, and what it meant to live, in the academic world, in a body that didn't work the way it was supposed to, but substantially looked no different from other normative, able bodies. This paper traces material from that blog briefly identifying how using my blog I both inhabited and created ruptures in the language of disability, health, mental health, and trauma. I also provide a conceptual framework for how feminist disability studies, feminist poststructuralism, trauma studies, and media studies come together to enable me to give a powerful account of my mediation, what that means for scholarship around mediation, and what that means for disabled bodies attempting to negotiate how they hail themselves with how they are hailed by the structures that speak them. In order to interrogate my blog and my experience with the social, constructed, and imposed meanings given to disease, disability and trauma, I first provide a brief overview of key literature. In the following section I outline the theories from media studies I use, as well as relevant literature from other fields, including work on resilience, in order to position myself and the media artifacts I produced vis-à-vis the literature.

Bridging the fields: Feminist Disability Studies and Media Studies

Garland-Thomson (2002) states that feminist disability theory calls attention to the multiple and unstable nature of human identity by recognizing ways that gender and disability, among other markers of identity, signify complex power relations (p. 6). A critical politics from the perspective of feminist disability studies operates from the premise that "disability, like femaleness, is not a natural state of corporeal inferiority, inadequacy, excess, or a stroke of misfortune. Rather, disability is culturally fabricated narrative of the body, similar to what we understand as the fictions of race and gender" (p. 5). The disability system, the medical system, and other systems of social control mark unruly bodies and encourage them to fix, change, or adapt themselves to the discourses of normal. This constructs a "normate body" that Garland-Thomson describes as "the corporeal incarnation of culture's collective, unmarked, normative characteristics" (p. 10). This construction is held up by the medical language of resilience. Aranda, Zeeman, Scholes, and Morales (2012) define resilience as "the capacity to negotiate ordinary developmental tasks in the face of mounting adversity" (p. 550). Resilience, like recovery, is medicalized in order to identify "the capacity of people who are faced with adversity, to adapt, cope, rebound, withstand, grow, survive, and define a new sense of self through situations of adversity" (Deegan, 2005, p. 29). This resilience maintains an atomized focus on the individual and views the non-resilient subject as "deficient or lacking in one or more of the 'normal' or 'natural' attributes" (p. 551).

This medicalized understanding of resilience must be complicated by the fact that subjects, according to a feminist poststructural positioning, are "ambiguously conceived, being imbued with agency, but equally constrained, subjected to broader discourses or forces from elsewhere" (Aranda et al., 2012, p. 554). Bodies, particularly non-conforming bodies, are standardized by medical and disability discourses, as well as discourses around resilience in the way that individuals are urged to ply themselves to conform to a set of standards that make up the "normal" (Garland-Thomson, 2002, p. 12). Deegan (2005) notes that concepts of resilience can “shift clinicians’ attention away from disease processes and onto the whole person in the life context” but also identifies resilience as an “innate self-righting potential” (p. 30). Aranda et al. (2012) advocate for a resilience they term “unfinished” that allows individuals to position themselves politically according to social structures and discourses and their personal biographies. An unfinished resilience is “always in a process of remaking or becoming” (Aranda et al., 2012, p. 555) thus allowing resilience to be about process more than outcome, and look and be resistive, to account for social interests and values, and for it to capture the way individuals misrecognize themselves in relations to systems while still expressing themselves authentically and positioning themselves against those same systems.

Bringing together feminist disability studies and a feminist poststructuralist understanding of resilience that accounts for complex subject positions, I can more adeptly take into account the symbolic and material realities that converged to position me as a subject that both rejected and embraced resilience as a category for coping with my health trauma. Deciding how to navigate the physical challenges of my brain tumor and the symbolic challenges of my tumor was complicated by simultaneous pressures to pass as normal and come out as disabled or sick. I felt a pressure from my community to lessen their interaction with my illness, and any discomfort that it may cause people, by passing as able-bodied, or overcoming my disability in service of the comfort of others. This pressure was often noticed in the way, in response to my single-sided deafness, I would move closer to those who I could not hear and the way I would apologize to them when I didn’t hear what they were saying. Given that my disability, in many ways, is invisible, I also felt a pressure to come out as disabled, to name my disability in order to both provide people a reason why I was requiring them to modify their behavior and to medicalize my condition in order for it to be treated. I had to hide my body’s material realities yet display them as grotesque in for them to be fixed. Linton (1998) describes this as a "demand that you be plucky and resolute, and not let the obstacles get in your way" (p. 18) In our "culture of fixing" disabled bodies are medicalized and diagnosed in order to be cured, "the ideology of cure directed at disabled people focuses on changing bodies imagined as abnormal and dysfunctional rather than on exclusionary attitudinal, environmental, and economic barriers" (Garland-Thomson, 2002, 14).

The language of resilience is used in everyday language and representations outside of the medical field. When individuals suffer from any kind of trauma there is a discourse of resilience that comes from a multitude of voices including mainstream media. Within this message of resilience is the familiar separation of the body from its social constraints and factors, placing the burden of healing on the individual and stripping any role society might possibly play in ameliorating people's suffering. Within this discourse individuals are pushed never to give up, to power through, and to triumph over their circumstance. Indeed, media have long shown sufferers that "in order to overcome traumatizing experiences and transform weak victims into heroic survivors, the traumatic memories must be narrated" (Rothe, 2011, p. 4). This popular understanding of resilience discourse is akin to what disability scholars term the "super-crip," in which disabled bodies are stigmatized by being made to represent "our culture's deepest fears about any potential loss of moral, sexual, or physical control" (Cohen-Rottenberg, 2012, p. 1). A resilient body, in popular culture, can be translated to a body that overcomes or hides disability and persists despite it, in other words "the wondrous elicits admiration or astonishment by framing a disabled person's activity as extraordinary" thus setting disabled bodies up as "super-crips" (Cohen-Rottenberg, 2012, p. 7). For bodies to either avoid or resist dominant ideas of resilience, or to subvert them in the ways of focusing resilience on non-normative challenges to structures and expectations, people need to be able to articulate themselves in ways that express voice.

Couldry (2010) in his book, Why Voice Matters, argues that "human beings can give an account of themselves and of their place in the world" and that "treating people as if they lack that capacity is to treat them as if they were not human" (p. 1).[1] The language of resilience positions an individual who is suffering as a disembodied psychological subject that is independent, rational, acts in their own best interest, and able to succeed (Aranda et al., 2012, p. 551). This positioning, as it causes erasures of structural inequality that might limit those actions and the multiplex of identities involved in true recovery, diminishes people's ability to give account of themselves. To speak with, to, and against this ideal of resilience, individuals need to be able to give account of themselves, in other words to express their voice. Couldry (2010) sees voice as process and value, and as something that operates both "within and beyond politics" (p. 3). The process of giving account of one's life and its conditions "from a distinctive embodied position" (Couldry, 2010, p. 3) can have great power when told from a feminist poststructuralist position. For voice to have power it cannot be erased by complex social relations. Feminist disability studies seeks to identify, illuminate, and problematize the dual process of erasing disabled bodies and non-conforming female bodies through normative constructs (Garland-Thomson, 2002, p. 14).The process of voice "is undermined when societies become organized on the basis that individual, collective and distributed voice need not be taken into account, because a higher value or rationality trumps them" (Couldry, 2010, p. 10). A voice inflected with feminist disability studies allows gendered and disabled bodies to speak in digital media in ways that

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[1] While Couldry argues that there is a crisis of voice due to neoliberal cooptation of voice, I am invested in finding and highlighting ways of recuperating voice in digital space. Couldry argues, and in fact cautions, that current expressions of voice may normalize values of neoliberalism, but he does not deny the possibility for alternative media infrastructures to allow for new conditions for voice to be expressed (Couldry, 2010, p. 73).

counter normative frames. I argue that voice is a useful companion to feminist theories that seek to bridge the material body with social, symbolic forces that police the boundaries of those bodies in normative ways.

Media is an important part of understanding the way discourses around illness, disability, trauma, suffering, and resilience get made, are perpetuated, and become commonplace. In my case digital technology imbued every part of my experience with the health system, and digital mediation was a central tool in understanding myself in relation to other medicalized bodies. Couldry and Hepp (2016) indicate the importance of the media in making social worlds and constructing reality. They argue, media "comprise platforms which, for many humans, literally are the spaces where, through communication, they enact the social" (Couldry & Hepp, 2016, p. 2). When people suffer from illness or become disabled they often turn to media to help them make meaning from their experiences and to understand how their identities, those that are normative and those that are not, fit in with, subvert, are disavowed, or erased by social structures. Janoff-Bulman (1989) argues that when individuals are confronted with trauma such as disease, victimization, accidents, or natural disasters they face a "cognitive dilemma: they must integrate the data of their dramatic, negative experience and their prior assumptions, which cannot readily assimilate the new information" (p. 121). Media spaces are possible spaces through which individuals who suffer can negotiate this new information and make meaning from it. Digital spaces specifically allow media users to capitalize on the affordances of the technologies to make meaning.

Much of this article has grappled with the way the language of resilience positions people in-between material realities and the symbolic aspects of everyday practice and culture that may impact those realities. Media are not just symbolic tools, nor are they just technology. Returning to Couldry and Hepp (2016), they argue that "it is not a matter of positioning the material against the symbolic, but of grasping both in their interrelatedness, as part of a proper analysis of how media and communication contribute to the construction of the social world. We need, in other words, to consider media both as technologies including infrastructures and as processes of sense-making" (p. 5). The way this sense-making functions practically is based on the affordances of media platforms. Memes are one form of participatory media that enable people to easily make meaning using digital platforms. Memetics are about "processes of transformative reappropriation" (Milner, 2012, p. 38). Multimodal, multisensory internet memes are intertextual, they constantly refer to previous texts to convey new messages and remediate previous ideas (Piekot, 2012, p. 188). Memes are a useful meaning making tool and their logic is helpful to consider here.

Memes, as an online phenomena, are based on a concept first developed by evolutionary biologist Richard Dawkins "to describe the natural human spreading, replication, and modification of ideas and culture within his Darwinian hypothesis for cultural evolution" (Chen, 2012, p. 7). Dawkin's model of cultural development was based on the notion that ideas and knowledge would spread through imitation and transfer. Memes have an incredible power in creating meaning online and offline and in fostering a sense of connection, particularly as a part of cultural production (Knobel & Lankshear, 2007, p. 3). Milner (2012) notes that "participants are connected as texts are shared" (p. 33). More than just a sense of connection, memes can "acknowledge the autonomous decisions of social agents while also appreciating how those decisions compound into collective significance through creation, circulation, and transformation" (Milner, 2012, p. 21). In today's polymediatic environment, or an environment where "users exploit [these] affordances in order to manage their emotions and their relationships" (Madianou & Miller, 2013, p. 172), the acts of mediation in memes, meme culture, and digital spaces such as blogs are tactical gestures. Both the media platform that individuals choose to mediate through, and the format they choose to mediate with can become tactical in the way that they interrupt status quo constructions of narratives around the body, identity, illness, wellness, and more.

De Certeau (1984) identifies that "many everyday practices (talking, reading, moving about, shopping, cooking, etc) are tactical in character" (n.p.). These spaces are tactical because though they seem ordinary they "seize on the wing of possibilities that offer themselves at any given moment" (De Certeau, 1984, n.p.). In digital media, the tactical user is one that deploys the ordinary to convey the extraordinary. While these users operate within structures of power, their media artifacts say, "*see how I try to manage the ties that bind and produce me"* (emphasis from Raley, 2009, p. 2). In opening up the space for every day tactics to take place online, the memetic nature of digital space and the possibility inherent in media's power to construct social reality enable possibilities for "unfinished resilience" to be cultivated. The meanings produced in these liminal spaces are meanings that can interrupt disability discourses and discourses of compulsory heterosexuality that define and place parameters on *normal*, placing non-normative bodies on the outside of categories of legibility, or simply erasing them altogether. In interrupting these discourses suffering bodies create space for their own existence and to negotiate the complexity of illness, impairment, and identity and to make new meanings that account for their material and symbolic existence. Since being diagnosed with a brain tumor in 2012, I engaged with a negotiation of my own identity, ability, and place in the world as a material and symbolic subject. Through tactical blogs, images, memes, hashtags and social media, I attempted to find a place for my body to exist, a liminal place for me to make sense of my suffering, and to mediate my reality in ways that resisted what I felt the world was telling me to be. The following section takes material from my blog and social media in a kind of auto-ethnography that explores how media can be a place to make a new myth of resilience that subverts normative frameworks and makes space for my non-normate body.

Mediating Resilience

Between August of 2012 to March of 2017, I blogged 123 times on wordpress.com with an average of 4800 views on the blog each year. Many of the posts on the blog started as updates to friends and family but grew to serve two other primary purposes. One central purpose was for me to negotiate this new aspect of myself that didn't make sense with the life I had previously led. I had to make new meanings for the world and myself so that my narrative would fit into the world I existed in. When I discovered, mediated, and thus made those new meanings, I recognized that there was not always a ready acceptance of them in my surrounding support group and community. This led me to the second purpose of many of my blog posts, to articulate my suffering to my community and the community of digital users that would read my blog and engage my social media, as well as make my new meanings legible to them. In other words, my secondary goal was to resist the ways my trauma, disease, and disability were being constructed for me and gently, even in small ways, subvert them.

The excerpts from the blog that follow highlight the ways I was attending to the dual purpose of negotiating and making meaning while attempting to subvert categories of suffering and disability with my mediation. In these excerpts I engage in a resilience that is situated between the medicalized resilience that dictates a self-propelled strength and ability to manage recovery and the "resilience unfinished" that Aranda et al. (2012) discuss. In situating myself in this resilience I argue that my resilience is a political act that recognizes my relationship with structures of power and justice and highlights my positionality as both subverting and colluding with the system. My digital negotiations of meaning against the power structure fit within Foucault's concept of assujettissement in which, "a subject is produced and results from subjection to disciplinary power, but equally, this at the same time produces or constitutes a becoming" (Aranda et al., 2012, p. 555). As a disabled, gendered subject I am produced as such by systems of power, but I can act to resist the very systems of subjection that hail me in specific ways.

My blog is called "Living with Herbert," Herbert being the tongue-in-cheek name I gave to my brain tumor. The blog name was meant to convey the realities of living with such a life changing circumstance. The blog has four pages one of which, "Who the heck is Herbert" simply identifies who I was at the time of the writing, includes images of me, MRI images of my tumor, and an invitation to anyone who has a similar story to feel welcome to share with me. The first post of the blog narrativizes the long health history that was explained by the revelation of a tumor. It also includes an invitation for followers to "walk alongside me" (Author, 2012). That initial post is full of anxiety and optimism, and a palpable sense that I believe this circumstance to be temporary. Several surgeries later and after learning about the realities of my changing material abilities, the tone of the blog shifts. In January of 2015, I was preparing for my second tumor resection and my third brain surgery. I had flown from my home in Denver, Colorado to a hospital in Phoenix, Arizona for the procedure. I learned in my pre-operative visit that the doctor was going to remove the entirety of my brain tumor, a task he had previously expressed to me as "too dangerous." I returned to my hotel and I took to my laptop where I began to write furiously, in a raw and real attempt to make sense of my situation.

In the post, I struggle with the lack of control I have in my situation and I rage against my subject position, and an internalized gender role that silences my needs to appease and please others. I write, "When you spend long enough silencing yourself in favor of others, you stop listening to that little voice in you that screams to be heard. Over time those screams start to feel like whispers and even though they are there, you learn to look past them, your coping strategies transform into habits and you forget slowly who you are and who you want to be" (Author, 2012). In naming that inability to advocate for myself, for my sick body's needs, I felt as though I had made space for myself to exist, however flawed. In naming much of what I name in that post, however, I inhabit the complex language of popular resilience, willing myself to overcome my fear and anxiety. I become complicit in the very language that so often frustrated me, I state in one sentence that "I know I have a brain tumor, I know I am okay with that" and yet I admonish myself and push myself to overcome that circumstance. I even post a meme I find online that urges in big white block letters to "never let your fear decide your fate" (Author, 2012). I am not arguing that those in need of medical treatment shouldn't pursue recovery, nor am I saying that patients should not push for good outcomes, rather, I argue that regardless of the medical outcome, normative social frameworks can make space for more types of bodies to exist. Then, regardless of the outcomes of medical treatments, patients have space to articulate themselves and their unique needs.

In the same post I discuss the material reality of what the doctor had told me and I contend with and try to make meaning from the reality that my marked body will be changing in possibly substantial ways:

> I know that I have been posting pics on social media with the hashtag #operationexterminateherbert, but I didn't know that this would be the final mission in

> that operation. I suppose it should be heartening, this ordeal might end, and for all intents and purposes that can be really great. But, it may also mean a longer, riskier surgery, more side effects, more possibility for negative outcomes. And Herbert, even before I knew what and who he was to me, he was with me. How do you let go of a part of yourself, even if it is a part of yourself you feel pure scorn for? Will I still be a brain tumor warrior when he's gone? Will I be a survivor? Will he cease to be a part of my narrative? Will I still fear him? Will I lose my connection to the #btsm community? Will I be alone? Will I have to pave my way without the protective excuse of a brain tumor? He wants to take the whole damn thing out. I was suddenly very protective of Herbert. Of myself. Of my body. Of my story. What will happen when we're more "aggressive?" What will I be when this thing that has played a central role is so much of my life just disappears. Will he ever disappear? And if he does, will I go with him? Who will I be, if/when this isn't a part of me? Who am I now? Who will I be? Will I still inspire? Will I still matter without Herbert? (Author, 2012)[2]

In this excerpt I indicate a few things. First, I had so fully inhabited the language of the "super-crip." I had made myself significant based on my ability to survive and thrive *with* a tumor, thus leaving me unsure what I would do without it. Instead of recognizing agentic bodies, sick or disabled bodies are hailed into "a story of heroic overcoming of the odds" (Swartz, 2013, p. 157).[3] I firmly cemented myself in that space. I simultaneously planted myself in a place of acceptance of my lack of ability, I had remade my meaning making schema to account for my

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[2] #btsm is the hashtag used by the brain tumor community on Twitter, it stands for "Brain Tumor Social Media" and is a space for survivors, sufferers and caregivers to discuss their health.

[3] Hailed here refers to the theory of interpellation from Althusser (1971) in which he argues individuals are hailed as subjects and produced as such by and through ideology, but that people can see through the ideologies that hail them (p. 173).

body in a way that almost disallowed the existence of an unmarked body. I saw my body in binary, dichotomous terms, I was either going to be sick or well and there was no in between.

While there are several other areas in the blog where I make meaning as a person with physical disabilities, particularly my hearing loss, this passage strikes me as particularly interesting when confronting resilience. In my resilience I am not able to right myself or overcome but I am able to reject, embrace and challenge the multitude of ways my unruly body is hailed. This is a micro-political act of tactical resistance to the moral imperative to be resilient and for that resilience to be located in only my body, devoid of values, power, and social control. In March of 2015, I adapted one of my blog posts to appear on the University of Colorado's Center for Media, Religion and Culture's research blog, *Third Spaces*. In this post titled "My brain tumor deserves as hashtag" I articulate the way the mediated rituals I engaged in helped me cope with my lack of control in my offline world and helped me negotiate my identity as part of a group of people with unruly bodies.

> It was as though I needed to post. The ritual act of getting something off my chest was comforting. Beyond that the interactions from others was gratifying, empowering and hopeful. Plus, the pictures and the hashtags, they fit the aesthetic markers of the social groups I inhabit. It felt normalizing in a way to post. In a realm of illness and trauma, where normalcy is all but lost, the act of choosing a filter on Instagram felt straightforward and helpful. Plus each filter, each vignette helped me mediate my story and put it in interaction with all the other stories that were out there. (Author, 2015)

I go on:

> Each story matters, but together, they have their power. Carolyn Guertin, in her book *Digital Prohibition* notes that authorship online can function as a site of resistance and

> renegotiation, she notes that new media works are “fluid, deterritorialized systems.” The community I found online from my illness, in many ways is disparate, we have nothing in common except that something, at some point, went wrong inside our skulls. Some of us float in and out of the community as our needs for support and fellowship become more or less pressing. Some of us lurk, not posting much. Some of us comment on everything. Some of us just like and retweet. Whatever each user’s role in the community, when put altogether it forms a constantly changing identity of a group, one which is always negotiating and renegotiating the rules for participation, but always fostering the production of meaning. (Author, 2015)

Conclusions

On my way to a recent follow up doctor’s appointment at the hospital run by the University of Colorado Health system I noticed a new ad campaign that overtook the lobby full of elevators. On each elevator door there were large close-ups of patient’s faces, detailed and beautiful, with words over the faces. The aesthetic features were familiar, it was like seeing an Internet meme, with all of the logics of memes, in physical form. Most of the images were powerful but unremarkable in what they conveyed. They articulated what any hospital ad must seemingly articulate, that the patient and the medicine will join forces to somehow overcome adversity, trauma, and disability. While these message, as highlighted in this article, are problematic, they are commonplace in hospitals. There was one image, or in other words one media artifact, that was particularly striking in its language. Over the image of a fairly young woman, written in white block letters, were the words “every time her heart quit she refused to” (Sauer, 2017).

I stood in front of the elevator doors puzzling over this image, my head cocked to one side, curious if anyone else waiting in the crowded lobby was feeling as anxious about it as I was. I stood there until the elevator doors opened, her face parting and disappearing as a throng of busy patients and doctors pushed past me. The image rattled me, and I couldn't shake the feeling that it was unfair. "Unfair how?" my partner asked me as we walked back to the car after the appointment. I tried to convey the power dynamics involved in who has access to medical treatment and resources, as well as the constructedness of the idea that everyone who gets sick must triumph over their sickness and that triumph is somehow a reflection of their strength, mental fortitude, and desire to live. "So then people who don't survive, are they quitters?!" I exclaimed breathlessly. That advertisement, or "patient story," as it is termed by the hospital, captured the fraught language of resilience, disability, illness and the ways that language interacts with subjectivities. Aranda et al. (2012) argue that resilience unfinished is "always in the process of remaking or becoming…The resilient subject becomes someone who at any given time, across their biography or lifespan identifies, or misidentifies in complex ways, with demands to be resilient…This is a resilient subject who in turn can comply or collude, subvert or resist discourses of resilience governing and disciplining arenas like health and social care" (p. 555). The woman in the image was a shining example of the resilient subject, and what her image told other patients is that they should aspire to her strength in overcoming their circumstances, and what the advertisement told us, is that the hospital would facilitate that strength. I recognized in her an erasure of systems of control, replaced with her agency and determination. I saw that this woman's story was being hailed in order to cause patients to misrecognize themselves as perhaps the most powerful agents in their own health, thus absolving hospitals and social institutions of the responsibility of providing lifesaving care every time. The burden of surviving and overcoming was on the individual, and their ability to be resilient.

It has been fourteen months since I’ve had a brain surgery. In many respects that would put me in a place of recovery. I live each day with the abilities I have and I negotiate my existence on and offline. The mediated resistance to the identity categories that limited the legibility of my testimonies of trauma was and continues to be subtle. I am not, in my resistance, shifting or overturning the systems of power that seek to discipline my body, but I am pushing against them even as I collude with them. The space between liberation and oppression in self-expression online is murky at best but in everyday acts of resistance there is power. De Certeau (1984) names a tactic as “an art of the weak” (n.p.) and it is an art that can create fissures, dismantle oppressive symbolic structures over time, and make space for more bodies to exist. Garland-Thomson (2002) argues that feminist disability studies is not just about discourse, it is about the lived body (p. 10), so I humbly stake my body and represent it, to allow it to collide with the discourse, to see what kind of meaning is made.

References

Althusser, L. (1971). Ideology and ideological state apparatuses (notes towards an investigation). Lenin and Philosophy and other essays. New York, Monthly Review Press**:** 127-186.

Aranda, K., Zeeman, L., Scholes, J., & Morales, A. S.-M. (2012). The resilient subject: Exploring subjectivity, identity and the body in narratives of resilience. *Health:, 16*(5), 548-563.

Author (2015). My Brain Tumor Deserves a Hashtag: the third spaces of online coping. Retrieved September 28, 2017, from https://thirdspacesblog.wordpress.com/2015/02/22/my-brain-tumor-deserves-a-hashtag-the-third-spaces-of-online-coping/

Author (2012). Livingwithherbert. Retrieved September 20, 2017, from https://livingwithherbert.com/

Chen, C. (2012). The Creation and Meaning of Internet Memes in 4chan: Popular Internet Culture in the Age of Online Digital Reproduction. *ABITUS*, 6.

Cohen-Rottenberg, R. (2012). Caught Inside a Paradox: How Cultural Representations Perpetuate Disability Stigma.

Couldry, N. (2010). *Why voice matters: Culture and politics after neoliberalism*: Sage Publications.

Couldry, N., & Hepp, A. (2016). *The mediated construction of reality*: John Wiley & Sons.

De Certeau, M. (1984). *The practice of everyday life* (S. F. Rendall, Trans. Kindle ed.). Berkeley and Los Angeles, California: University of California Press.

Deegan, P. E. (2005). The importance of personal medicine: A qualitative study of resilience in people with psychiatric disabilities. *Scandinavian Journal of Public Health, 33*(66_suppl), 29-35.

Garland-Thomson, R. (2002). Integrating disability, transforming feminist theory. *NWSA journal, 14*(3), 1-32.

Janoff-Bulman, R. (1989). Assumptive worlds and the stress of traumatic events: Applications of the schema construct. *Social cognition, 7*(2), 113-136.

Knobel, M. and C. Lankshear (2007). "Online memes, affinities, and cultural production." A new literacies sampler: 199-227.

Linton, S. (1998). *Claiming disability: Knowledge and identity*: NYU Press.

Madianou, M., & Miller, D. (2013). Polymedia: Towards a new theory of digital media in interpersonal communication. *International Journal of Cultural Studies, 16*(2), 169-187.

Milner, R. M. (2012). *The world made meme: Discourse and identity in participatory media.* University of Kansas,

Piekot, T. (2012). Pictorial representation of idioms in Internet humour. *Estonia and Poland: Creativity and Tradition in Cultural Communication, 1*, 187-203.

Raley, R. (2009). *Tactical media* (Vol. 28): U of Minnesota Press.

Rothe, A. (2011). *Popular trauma culture: Selling the pain of others in the mass media*: Rutgers University Press.

Sauer, A. (2017). Patient Storytelling: 5 Questions With Colorado's UCHealth System. Retrieved September 27, 2017, from http://www.brandchannel.com/2017/03/06/5-questions-uchealth-030617/

Swartz, L. (2013). Oscar Pistorius and the melancholy of intersectionality. *Disability & Society, 28*(8), 1157-1161.