

Taking Center Stage in the Face of Shame and Scars

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Mainstream media is ultimately a stage. Over the past thirty-one years of my life, I have been on a journey learning how to claim my stages. From birth with a rare craniofacial disability to my baptism, from a would-be actress in front of the camera, to a health communication scholar and a network television subject, I have had to contend for full participation in a range of spaces—some affirming and supportive, and others that seem to justify my exclusion at every turn. As a subject in a docuseries on commercial television, I became the main character in a dramatized version of my own story without control over my narrative, profit from my participation, or an ownership stake in the intellectual property produced by the efforts of me and my family. All of this while leading up to and following my 44th surgery, a 12-hour procedure to replace half of the disfigured jawbone I have used my entire life to speak with a section of the fibula in my right leg.

Media participation has become a central concern in what disability media scholar Elizabeth Ellcessor calls the “politics of disability representation” (2017, p. 2). The media representation of disability centers a concern for the presence of disabled characters in mainstream entertainment narratives. Media participation demands particular attention to the lack of opportunities for disabled people to ultimately acquire equal access to resources needed to produce media independent of, and particularly within, the mainstream media industry. Such access can directly influence our capacity to overcome stigmatization and acquire the cultural, social, and material capital needed to become fully liberated. By telling the story of these different stages I have occupied in my life, centered around my recent experience as a main subject in a reality TV show, I hope to flesh out the stakes of an important debate within the disability justice community.

Logline: What happens when a would-be child actress with a craniofacial condition turned entertainment-industry professional turned health communication academic is transformed into an accidental disability-rights activist through a baptism by fire?

Light

Setting: Graduate Student Housing in Chapel Hill, North Carolina
Time: Spring, 2019

The half of my face that is not paralyzed turned upward into a smile as the two blondes, one with a few grays and the other with a ponytail, spoke to me through the screen of my laptop; they thought I was “awe-inspiring.” At thirty years old, a graduate student at UNC Chapel Hill, I had finally learned my love language—words of affirmation. A television producer telling me that I inspire amazement felt very close to love. I thought it was divine intervention. What were the chances that a production company from London would come across an article I’d published in a nonprofit newsletter, just as I had finally grown vulnerable enough to voice out loud my journey to emotional healing from medical trauma and body shame? What were the odds that they would be casting the final subject in a network docuseries called *Medical Marvel* right as I prepared to fly home for my father to drive us from Memphis, Tennessee, to Little Rock, Arkansas, for my 44th medical procedure?

After two media degrees with one on the way, I was far from naïve about the television industry. I knew everything that glitters is not gold. However, the prospect of this particular role seemed dazzling. The producers of this major reality television series, focused on people with craniofacial conditions before and after a major procedure, nodded encouragingly from the other side of my computer screen. They had recruited six others to be a part of the docuseries, four white men, one white woman, and now me; we would each have an hour-long episode dedicated to our individual story. They said that I could rest assured that the crew would be small, warm, and friendly, and that the footage would be “beautifully shot.” Their aspirations sounded honorable: documenting the physical, practical, and emotional changes that medical treatment can bring a person.

Now is the perfect time, they suggested, to record a “kind of mini casting tape.” As I tried to make the mental switch from what had been essentially an off-the-record, casual Skype conversation to what would now be an on-camera, recorded interview, Codie and Molly explained that they would ask me some pre-planned questions and then cut together clips to send to the series director and network liaison. These entertainment executives would have the final say about my participation. They asked me to scoot closer to the camera. A little closer still, and then could I also turn my swollen right cheek toward them? As I did, I could see a little red light flashing.

Water

Setting: Parkway Village Church of Christ in Memphis, Tennessee
Time: Fall, 1998

This particular Sunday morning, November of 1998, autumn in Memphis is fading fast, and winter is on the horizon. Inside a red brick building with a hunter green roof and white church steeple, behind the burgundy curtain of a baptistry, the water is lukewarm. I place my bare toes on the first step. Before I can move any further, my momma’s strong hands calmly gather my hair and tie it down with a white turban wrapped tightly. The white cotton gown I wear hangs off my shoulders and long over a chest that isn’t quite there yet, and then billows at my knees. In the water, I can see Daddy coming. He stops halfway. The water reaches his belly area and ripples in waves toward me.

Over the 45 surgeries I go on to have after this day, my dad will use his last vacation day, or even go without pay, to be at every single one and to be my primary caretaker for weeks afterward. From dressing open wounds on my face, emptying oozing drains from my neck, and washing out saliva suction machines to concocting the best homemade Ensure smoothies a foodie could ask for three times a day—he will see and do it all. He smiles at me now. And I float. Down into the blue-gray painted pool. As the curtain creaks open revealing the auditorium, I put my hands over my mouth and nose in anticipation. When I arise from the water, through clogged ears, I can still hear the cheering faintly.

I felt different coming up out of that water. Relieved but something more. My baptism was not the biggest stage I would ever

be on, but it was the most important. I had willingly allowed the Most High co-authorship of my story and decision-making authority over my life. I knew exactly how Christ had died. How, at thirty-something years young, he had willingly decided to suffer—to carry his own cross, to be spit on, beat up, to have his garments sold off for profit piece by piece, to have stakes, burnt orange with rust, driven through his hands and feet—so that I could have life that would never truly end and a connection to a purpose beyond myself. And yet, even then, after this kind of rebirth, even for Jesus himself, the call on my life—to persevere in the midst of the suffering and stigmatization I was about to endure—would prove more than I could bear without family and faith to help me fight for the future I saw for myself.

In the months following this day, I would be underdiagnosed with a port wine stain and misdiagnosed with a hemangioma before being correctly diagnosed with diffuse arteriovenous malformations throughout the right side of my cheek, jawbone, mandible, tongue, and lip—arteries connect to veins without capillaries invading healthy tissues and organs (Kelly, 2015). My aim from early in life was to represent myself with authenticity and the courage of my convictions. As my health deteriorated, I would build upon this spiritual practice by honoring each opportunity to show up as my full self—to live, learn, work creatively, and persevere with a disabling, chronic condition. People like me, with visible differences and invisible illnesses, who want desperately to simply be treated fairly within the entertainment industry, we do not always have the physical and emotional bandwidth to weather the doubly disabling combination of industry exploitation *and* illness. However, in the words of vulnerability researcher Brené Brown, “You either walk inside your story and own it or you stand outside your story and hustle for your worthiness” (Brown, 2018).

Fire

Setting: Holiday Inn ballroom in Memphis, Tennessee

Time: Summer, 1999

The summer before sixth grade, I feel like I am really hitting my stride. I am working my way up on the local arts “scene” as they said in the biz. After booking a few plays at community theaters and my

first modeling gig, I convinced my mom to take me to an audition for a children's modeling agency, excitedly proclaiming, "It could be my big break, Momma!" Yet, as I sit in a gold banquet chair with a crown back and gray foam cushions in the ballroom of the Holiday Inn, I am willing myself not to burst into tears, or into flames, as I stare bewildered at the stage. So-called talent agents, behind a long table with the white tablecloth and half empty water glasses, gaze smugly at the line of kids in front of them whose images they have deemed capable of making money representing various products. And I noticed something—they are all beautiful, various ages and ethnicities, the epitome of diversity and inclusion except everyone's face is perfectly symmetrical, everyone's body is complete.

By this time, I have endured two surgeries by a local plastic surgeon who told my parents he could definitely decrease the size of my growing bottom lip with no problem. He had no experience treating vascular conditions. And he had failed. And my lip had grown back twice the size it was before. And there is now a keloid down the center, a pink and protruding scar. I am hurt because the lady in the black slacks with the clipboard had smiled in my face, had given me encouraging nods as I strutted my stuff on the makeshift catwalk, yet she had not called my name. I can feel something rising up in me—an epiphany. "Girl, duh," I think to myself. "They not going to choose you with this big lip and stupid scar." I look intently across the ballroom until I make eye contact with my mom standing in the entrance, looking right at me. She knew. And I knew that she knew that I knew. Things would never be the same.

This was my first inkling that the arc of the moral universe in the entertainment industry bent toward exploitation. Twenty years later, I would receive further sociopolitical education through the cognitive dissonance of taking doctoral classes on media production and community empowerment while experiencing increasing powerlessness during my participation in the filming of a version of my story for TV. Communication researcher Vicki Mayer (2011) explains that the combination of creative arts and commerce illuminates a key tension between the two for those who hold power within these roles, particularly in nonfiction TV programming. The aim is simple—mandated from network executives and advertisers through production companies and to these creative professionals interacting with us as subjects—exhume as much as possible (or "get what we need") from the subjects toward producing the content

while keeping expenditures as low as possible. For the identities, like mine, at the center of this entertainment content, these actions can lead to a lack of agency that must be counteracted. As a TV show subject having what would become a traumatic procedure with a long recovery, a lack of critical awareness tied one arm tightly behind my back while a lack of physical and emotional health tied the other squarely across my heart. I felt unable to fight.

Fears

Setting: Childhood home in Memphis, Tennessee

Time: Spring, 2019

The filming for *Medical Marvels* was punishing. It took place as I prepared for and recuperated from my 12-hour jaw replacement surgery. By the end of the process, my family and I had filmed off and on with the production team over a total of 7 months. During the shoots, certain days are marked for interviews at our family home in Memphis. I am asked to shoot and then reshoot a master interview 2 hours long. Each time, I am asked to be vulnerable, to share and then reshare my memories of the traumas I have overcome so far. The second time, the emotional intensity drains me in a way it does not the first time. My parents and younger sister are also interviewed in our living room for several hours and asked to relive moments of their journeys with my illness. My dad bursts into tears when he is asked to describe how he felt having to change out my wound packing after a surgery complication left me with a hole where my cheek should have been. I have the urge to stop the filming, to tell my Daddy not to cry. I start to cry myself, so I get up and leave the room. By June, when I'm asked by my mother's sorority to speak to a group of high schoolers, Momma will tell me afterward that I held back and did not tell my full story. I agree, although I don't yet understand why I gave them the abbreviated version.

An "iatrogenic" disease is one that is caused by medical treatment itself. The film crew, I began to realize, was not merely recording pain and suffering; they were themselves inflicting it. During the filming process, I did not yet have the critical knowledge to understand what can happen when people with disabilities and illnesses—and I would contribute our family members as well—are subjected to what

Arthur Frank calls “multiple tellings” of our stories in a rhetorically appropriate manner in order to appease the interest of a listening audience (2013, p. 71). My family and I were being “written on from the outside” as we listened to our own speech; although we were doing lots of talking, prompted by the crew, we had essentially lost our voices (Frank, 2013, p. 71).

In what I originally think is collaboration with the crew, I become a de facto coordinating producer, a role I have held on independent projects but have never been credited for on a commercial production. I arranged a scene at an upscale African-inspired lifestyle boutique to shoot my sister and me on a “spontaneous” (read: staged) shopping trip to “catch up from college.” I arrange another shoot at a quaint, quiet massage parlor called Spa Therapies, where I receive soothing treatment under the banner of “self-care.” I also arranged an in-depth interview with my surgeon Dr. Suen in Little Rock, which I listened to from outside the closed door of an empty office turned makeshift set, complete with a backdrop and lights.

The crew arranges to film me walking around downtown Memphis. Although I’ve only been downtown a handful of times in the past 10 years—“the trolleys and people make for great shots,” says the director who is also the cameraman. He and the producer strap a Go-Pro on my chest and ask me to walk back and forth down a long stretch of sidewalk in the middle of crowds of people. They say they need to get footage from my perspective of how people react to my presence, to my face. By the end of the day’s shoot, my legs are hurting, and they still have not gotten the perfect sequence they have been working me all afternoon to capture. I have not yet had the bone in my right leg removed, but the tissue from my left leg has been used to reconstruct my chin. It’s left a long, pink scar, a dead weight on my thigh, and sharp shooting pains when I’m on my feet too long. I have to keep reminding the production team—both on the ground and in London—of this pain throughout the production process. Still, the team is so desperate to get this particular shot that they try to put it back on the schedule for another shoot months later. By then, I’ve started to push back, finally.

Soon, my family and I would lose the façade of collaboration we had with the production team; the false notion that we had equal decision-making control over what parts of our lives would be shot and included in “my” TV episode. I realize that, even if I insist on the crew filming a particular scene that I deem crucial to my journey with

disability, they could very well appease me but then leave the footage on the cutting room floor. Nonetheless, I keep trying to participate in the staging of my story.

During all of this, my mom jokes that I need a producer credit. I tell my mom that I have actually done the production work, and the least they can do is give me a coordinator credit for my professional production resume. We decide I should ask. I approach the producer outside in the driveway as the director is setting his camera up to film the introductory montage scene with my family. He agrees that I've done the work but argues that the production will push back. "Why?" I ask, my eyes narrowed and brows furrowed. "Well," he says with that half smile that is becoming less cute each time he whips it out, "Because the viewers may think the show is staged if you get a credit." My throat goes dry. The viewers watching my trials while eating dinner from the comfort of their living room are more important than crediting me for my work. I smile back before responding as calmly as I can, "I doubt the viewers will notice my name is in the credits, but I will know." He says, "Of course," and promises he will ask. Perhaps he did: but I never did hear anything back from London.

In *Justice and the Politics of Difference*, Iris Marion Young and Danielle S. Allen conceptualize exploitation as the ways in which "the labor and energy of one group benefits another" (2011, p. 50). By the end of the fall of 2019, my family and I were officially overworked and drained of energy. At this point, I understood all this work was to serve a company creating a product I had little actual control over. My family, friends, and doctor were all trying their best to accommodate me. But I had not truly enjoyed shooting "my story" since the first day of filming.

Power

Setting: Home, Memphis, Tennessee

Time: Fall, 2019

Sitting up in my bed, texting back and forth about additional days that the production team wants to film, my fingers get those shakes that have become familiar yet remain exasperating. Peering over the white wooden banister of our family's living room, I could see my

mother downstairs getting ready for work. I decided to confide in her about what's been happening with me—the anxiety and stress over all this work, all this back and forth on top of school and in the midst of trying to heal. I no longer had the energy to lie to myself by saying, “Well, at least my story will get out there.” Yet, I had not been allowed to view any of the footage, make any editing suggestions, or even know what footage they planned to include. At least, awareness would be gained for those with craniofacial conditions. Yes, but at our own expense, figuratively and literally. At least, I was being paid. Except I was not. There is no “at least” anymore. It was just no longer worth it for me unless something were to change.

When I told my mother how I felt, I think she heard the guilt in my tone. She reminded me that this network and production company have sent a two-person crew back and forth to Chapel Hill, Memphis, Little Rock, and Nashville several times now—from London. That's thousands of dollars spent, plus them being paid for their hard work. “These people are employees,” she said. “We are not.” She reminds me that, on top of the medical bills for my last few surgeries, we were still paying for a \$10K dental procedure not covered by insurance. Meanwhile, the production crew was excited to film my next dental appointment for “interesting” footage. She asked me how much I was being compensated for me, my family, friends, and doctors “doing all this stuff.” I admit that I was not, and we are not, getting paid. I told her I got \$1,000 to cover what they called “loss of earnings.” I told her there is a law in the UK that apparently prohibits television productions from compensating people who participate in medical documentary content even for shows making a commercial profit. She suggested we both review my contract.

As I read through the contract again, the same words have new meaning. I had agreed that I would not sue them if I did not like the “exploitation” of my portrayal for commercial use. I had agreed to release them from all liability and obligations for “emotional distress/pain and suffering” that arose from my participation. I had agreed that I would not, at any time, assert that any representation of identity violated any of my rights. I had agreed that I may “discover facts or incur or suffer claims” that I did not suspect when I signed the agreement that may have affected my decision to participate in the show. “Ya think?!” I say under my breath. I assumed any and all risk. I think, “How in the world could I have allowed this to happen?” The contract seemed to be a standard form.

A question flew into my mind: how had the fine print of this contract spoken so precisely to my actual experience—“emotional distress/pain and suffering”? My exhausted mind started to clear like a fog lifting. And there was light: they *knew* that the filming would be distressing, draining, debilitating. *Every person with a disability or health condition who had participated in producing commercial content and pushed back, their stories were in this fine print.* And now mine was too. Momma looks at me, a sigh in her eyes. “A lawyer should have looked this over,” she says. “I don’t think it would have mattered,” I think but refuse to say out loud. Back in May, delighted by the prospect of telling my story of disability, I did not have the context to anticipate what the words in my contract would truly mean. But the executives did, they knew.

In writing about powerlessness, empowerment, and health, Professor Nina Wallerstein explains that empowerment and powerlessness are two sides of a coin that, when tossed up in the midst of our lives, can have significant health consequences. While powerlessness breeds sickness and disease, empowerment is a “health-enhancing strategy” (1992, p. 192). Wallerstein asserts, “Empowerment becomes the avenue for people to challenge their internalized powerlessness while also developing real opportunities to gain control in their lives and transform their various settings.” Through literal blood, sweat, and tears, my experiences over the past 7 months had shown me a visceral truth. While there are available stages for disabled, disfigured, and different bodies in creative commerce, we will need more than our dreams and our drive to finally and definitively take our places on them.

Nothing about us without us. Nothing—not the image of our likeness, not the inspiration of our stories, nothing—without relinquishing control, without investing resources, and without imparting critical understanding (Zimmerman, 2012). For far too long, people with disabilities and chronic illnesses have been kept as mere charitable beneficiaries (at best) to a behemoth of a media industry that has a historic track record of exploiting our stories while withholding the support we need for entrance into spaces we should have been in all along and an equitable seat at the table. In 1810, the “freak show” that toured Sarah Baartman, a now infamous Black woman trapped in an atypically shaped body that other people thought inspiring, interesting, and entertaining, claimed that Sarah

had gone willingly onto stages and into cages for them—she had, after all, signed a contract (Holmes, 2007).

Through agreeing to share my lived experiences, I exposed my personal darkness to public light willingly—I, too, signed a contract. But Sarah died at 26, overworked, diseased, and alone. By God’s grace, that is not my story. Throughout my life, I have been tested by trials and refined like gold. And in the middle of each fiery furnace, under submission to immense heat, I have gained clarity. And what is left of me now, as impurities melt away, glows. I take my bruises, blue and purple on this brown skin, as lessons learned, put them up for public display, and live to tell my side. In between redressing the lingering wounds on my chin and on my heart, I have found healing through voicing a transparent, empowering version of my story through this writing. And in the process, I believe I have spoken truth to power.

Discussion Questions

1. What is the difference between media representation and media participation? What role could each play in redefining disability?
2. What is exploitation? Explore the relationship between exploitation and illness and/or disability.
3. How can powerlessness and empowerment impact health?
4. What does the phrase, “Nothing about us without us” mean? Explore some examples from the chapter as well as any from your personal experiences.

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