

Constructing Identity, Disability, and Agency through Systemic Lupus Erythematosus

Starting from the late 20th century in the medical world, significant research has focused on exploring a biosocial approach, where “dynamic, bidirectional interactions between biological phenomena and social relationships and contexts” are highlighted as deep and central towards understanding illness, healing, and medicine (Harris and McDade). In addition, research across sociolinguistics, linguistic anthropology and discourse analysis have shown identity being produced at the intersection between agency and structure; structure in the social, cultural, and ideological constructs that shape our social worlds, and agency as the property of social actors who exert a degree of control over their situation (Birnie-Smith 1). In an effort to further explore the significance of these bidirectional interactions between the biological and the social, I aim to examine the central role that social identity plays in how society confers disability upon impaired individuals, and how impaired individuals accordingly respond and resist against societal constructions of disability. This point will be examined alongside the experience of Jason, a then-20-year-old Brown University student diagnosed with Systemic Lupus Erythematosus, abbreviated as SLE, who I interviewed and whose experience will be presented alongside these points to support my arguments. These points will be explored through three sections: through discussion on how impairment conflicts with societal expectations surrounding youth, fitness, and student life, through faith-based recovery for the

religious, and through acts of defiance and resistance against the label of disability that societal constructions confer upon the impaired.

Internalized Suffering: Stigma, Identity, and Cultural Constructions of Disability

Kleinman frames illness stigma as rooted in group dynamics, where the stigmatized person is transformed into “an alien other, upon whose persona are projected the attributes the group regards as opposite to the ones it values” (159). For the stigmatized person, this ‘othering’ manifests in an internalized change of their identity as “inferior, degraded, deviant, and shamefully different,” burdened with a “moral connotation of weakness and dishonor” (Kleinman 159). Jason’s suffering with SLE was similarly constructed through his impairment conflicting with social expectations surrounding his status as a young, physically active college student, playing into Birnie-Smith’s idea of structure sparking change in Jason’s identity. Jason’s SLE appeared in his sophomore spring semester, as he started noticing unpredictable pain across his wrists, elbows, knees, and ankles, while Raynaud’s phenomenon concurrently manifested in the extreme restriction of circulation in his hands and feet, often turning his fingers “white and blue.” Over these first few months where his symptoms developed, Jason felt a growing sense of alienation and frustration, with his symptoms conflicting with the societal expectations he felt surrounding 20-year-olds like himself:

“Like most 20-year-olds that are healthy, they can play sports, they can run around, they can brush their teeth and wash their hair and you don’t have to walk around like a crippled old man...I felt like an old man, and it hurt.”

“I’m a very fit, athletic person at the time, and I couldn’t do a push up because my wrists were too swollen and painful...I love playing sports. I love being active, and not being able to do that at such a young age was terrifying.”

Jason's frustrations were further rooted in his difficulties surrounding routine, daily tasks:

"The hardest thing for me was the frustration I would get...even very mundane, simple tasks, I couldn't do. Think about how often we brush our teeth, and how often we don't think about brushing our teeth, or how often we wash our hair...I remember having to hold my toothbrush. I would bend my arm as much as I could, twist my wrist around, hold my toothbrush, and then I would move my head in order to brush my teeth...but that really sucked. Sometimes I just couldn't wash my hair, so I just rinsed it."

Jason's experience demonstrates Kleinman's idea of socially defined stigma, with Jason's

internal sense of inferiority and shame with SLE stemming from the expectations conferred to him by his identity. In "Culture as Disability," McDermott and Varenne frame disability first and foremost as a cultural construct; referring to inadequate performances only on tasks arbitrarily circumscribed from daily life (324). They outline how this cultural construction of disability creates an unfortunate outcome when one's behavior, often arbitrarily, differs from social expectation, with that difference then being used by others for degradation (330).

This outcome is seen in Jason's story, where culturally constructed differences are used to enact symbolic violence against and degrade impaired individuals. To this end, it is critical to acknowledge society's role in constructing Jason's feelings of frustration. Firstly, much of Jason's suffering centered around his difficulty to adequately complete daily tasks by himself. This is rooted in how present society simply does not normalize the care of impaired individuals going through suffering; allowing structural conditions to limit what impaired individuals can or can't do, while paradoxically holding impaired individuals responsible for their own individual outcomes. Johnson argues that, regarding the treatment of impaired individuals, "we [society] should pay workers to provide that care, in the home. In some places, it's been done that way for years," highlighting that such care is possible, yet unrealized. Just as Açıksöz's work

highlights the confluence of nationalism and masculinity as important components to the construction of the Turkish disabled veteran identity (1), political and cultural values similarly play into Jason's construction of his identity as a disabled individual. For young college students like Jason, receiving care to assist with so-called 'mundane, simple tasks' is encumbered by both the stigma of accepting help in a deeply ableist society that prioritizes independence, and the difficulty to organize or afford such care privately. Secondly, Jason's comments surrounding physical activity and walking also demonstrate Kleinman's idea of society alienating impaired individuals by projecting upon them attributes society regards as opposite to the ones it values. Jason is a young, physically fit 20-year-old, yet he has difficulty walking and playing sports. In U.S. society, functional losses are "considered inevitable" with age (Becker and Kaufman 3), then functional losses for youth are thus seen as avoidable, escapable, needless, marking the struggles and difficulties for those like Jason as less valid than that of the elderly arthritic. In short, Jason's identity as a young person does not allow him to struggle as he does with SLE.

Jason's capacity during these first few months was further burdened by his structural reality surrounding him as a student at an elite university filled with pressures and commitments. Jason noted the semester he got diagnosed as his definitively most challenging one, with Jason taking five classes, having an on-campus job, and being involved in a lot of clubs. Jason remarks: "I just didn't really have a lot of time. I feel like I was stressed all the time." This structural environment of stress and commitment, especially common in elite colleges such as Brown, fueled Jason's avoidance in seeking medical care for several months: "I didn't go to the doctor a single time. I just ignored it...it only got worse." Jason only ended up

seeking medical care while visiting home during winter break, where his parents urged him to visit a rheumatologist who provided him with an official diagnosis of SLE.

McDermott and Varenne state that “disability may be a better display board for the weaknesses of a cultural system than it is an account of real persons” (327). Despite the societal construction of disability fueling Jason’s suffering, after several months of SLE, Jason said:

“This disease has brought me down, it has made me feel my worst. It has made me feel weak, in pain, and suffering, and it’s preventing me from doing things.” Jason’s addressing of his frustrations internally to “this disease” in his body rather than externally demonstrates how the weaknesses of our cultural system often mutate into how impaired individuals construe these weaknesses upon their own identities. Regarding this time, Jason states that what bothered him the most was that “no one was around to see” his suffering when he needed assistance the most. These two needs of assistance and visibility, themselves politically and socially constructed, therefore remain open to change.

Agency, Faith, and Recovery

Alongside structure, Birnie-Smith describes individual agency as a critical component to the production of identity. Despite Jason’s identity being heavily affected by society’s construction of him as disabled, Jason’s experience with SLE also highlights Jason’s use of faith and his religious identity to exert a degree of control to his management of SLE. While traditionally defined through its physical presentation, Askanase et al. highlights the deeply mental nature of SLE, where many patients “simply lose a battle of faith” against SLE to become absorbed in the vicious cycle of disability, depression, and distress. To this, faith was critical in how Jason managed the psychological instability and struggle that came with his SLE:

“My faith really mattered to me...That was very core and central to my experience, was I really relied on God. I really put all my faith in God that I would be healed, that I would get better, and that I could really do what I set my mind to...and that’s really how I built my foundation. I wanted to share that foundation with other people as well.”

Jason also remarked how his faith extended to his family and the broader Christian community:

“I remember my parents were praying a lot for me. They would bring me to all these different churches with all these different people to pray for me. And I prayed for myself too. And I really had faith. I had faith that there was a reason for what I was experiencing and that I would feel from it and I would grow from it.”

During our discussion, Jason also acknowledged the importance of prayer as an important outlet for the difficult feelings of frustration and anger he experienced with managing lupus:

“I think prayer is a really interesting and powerful tool...because it’s a very powerful tool to the process and to be interested. I think prayer really, really helped me spend time with myself and actually sit with my emotions and sit with what I was experiencing. I can be able to have someone to talk to and just get all my frustrations out and to plead my case and to ask for healing.”

While Jason was also prescribed medicine which he felt helped his condition, I argue that Jason’s identity as a Christian, heavily linked with his acts of prayer and faith, played a critical role in both his recovery of SLE and in Jason’s own agency to regain control over his identity. Researchers such as Sherman and Simonton have discussed how, in the case of cancer patients, there exists “ties between religiousness and greater active-cognitive coping and reduced emotional distress” (170). For Jason, his routine of prayer provided a corollary to Sherman and Simonton’s example, allowing Jason to emotionally process his feelings of frustration and anger towards SLE. While lupus is incurable, its symptoms can be managed with medication and significant lifestyle changes. After his official diagnosis, Jason spent significant effort towards making “some pretty drastic lifestyle changes,” including sleeping 9 hours a day, exercising three or four times a week, and reducing stress wherever possible through reducing classwork

and extracurricular commitments. Over time, Jason's routine of taking greater self-care of his body fueled a process of "very, very gradual change" where over time Jason's flare ups stopped hurting as much and subsided quicker. For reference, Jason was diagnosed in the summer of 2017, but as of December 2022, Jason has remarked that he has not experienced any flare ups of lupus for the entirety of 2022. As Jason discusses his faith as critical to allowing him to "do what I set my mind to doing," I argue that Jason's practice of faith and prayer demonstrated and reinforced his own agency to define his own identity. This, in turn, played a critical role in managing the psychological sequelae of SLE, integral to Jason's recovery.

Narrative, charity, and producing purpose

Jason's experiences from his first few months of SLE have demonstrated how living with SLE significantly fueled internal characterizations on how Jason saw himself as "weak, in pain, and suffering," demonstrating the role that structure, in the form of cultural and social constructions of disability, plays in defining social identity for the impaired. Significantly, a critical part of Jason's recovery and management of SLE centered upon his agency in responding to and resisting the degrading nature that being disabled confers upon the impaired, as seen through the internal characterizations Jason described with the onset of his SLE. As Johnson recounts, a common trope about disability centers around "a negative correlation between disability and happiness," where disability simply makes someone unequivocally "worse off" compared to a perfectly healthy individual. Johnson counters this sentiment by describing how disability prompts individuals to "take constraints that no one

would choose and build rich and satisfying lives within them” and “enjoy pleasures other people enjoy, and pleasures peculiarly our [their] own.” As a corollary to Johnson’s experience, Jason’s experience with lupus demonstrated a dynamic interplay between the constraints that his symptoms applied, and how those constraints fueled positive personal developments beyond conventional expectations. Jason recalled the story of two upperclassmen in high school who climbed Mt. Kilimanjaro for a senior project. On this, Jason remarked:

“I remember thinking at the time: ‘Holy shit that’s so cool’...there was no way in hell I could do that. It was so far from the experience I had growing up.”

Then in November 2017, 9 months after his lupus symptoms started with lupus still affecting much of his daily life, Jason saw a Facebook ad from Choose a Challenge, an NGO recruiting interested applicants to hike Mt. Kilimanjaro, the world’s tallest free-standing mountain, to raise funds for a charity of their choice. On that moment, Jason remarked:

“It was so far removed...and I think because of that I felt even more so compelled to do it. I remember this feeling of defiance overcoming me in the minute, and it was defiance against my illness. I remember feeling very compelled. This disease has brought me down, it has made me feel my worst. It has made me feel weak, in pain, and suffering, and it’s preventing me from doing things...I’m not going to let this disease prevent me from doing what I want to do in my life.”

Jason’s remarks demonstrate the extent to which the societal constructions surrounding his SLE had come to internally define his identity, which had reached a boiling point of frustration. In response, Jason applied for the position, putting in motion a journey where Jason ended up recruiting a team of students to hike Mt. Kilimanjaro to raise funds for Pencils of Promise, an international children’s education NGO, by the summer of 2018. Jason saw this campaign as an opportunity to share his own narrative of experiencing SLE, motivate himself, and grow; over

the next 9 months, Jason spent significant time sharing his story online and raising funds by, for instance, letting donors vote on what word to shave into his head. Jason's journey brought him to eventually hike Mt. Kilimanjaro in August of 2018, which he remarks to this day was both by far the most physically and mentally challenging, and beautiful, memory of his life. Throughout his summit attempt, Jason went through excruciating physical and mental challenges. He and his team would painstakingly take one step up, take "five, ten deep breaths," take another step, then repeat, with him remembering tears "coming out of [his] eyes" to then see them "fall to the ground." Exacerbating this, the extreme cold temperature and fatigue caused his Raynaud's Syndrome and SLE to flare up: "circulation was entirely cut off on [his] hands and feet," creating fears of frostbite and losing all sensation wherever he stepped. After experiencing awe at the summit, he spent 10 hours "being dragged, almost like skiing" back down by his group's guide.

I argue Jason's "feeling of defiance" against his debilitating experience of SLE, and the journey it led him towards, acted as resistance against the sense of reduction and degradation that his experience with SLE had conferred. On this, McDermott and Varenne further illustrate: "Careful work with those locked in "special" identifications always reveals the ingenuity of the ways that they resist the constraints that they cannot ignore...the ways that they resist being made into less than they could be, or less than they are...their resistance to what they cannot ignore also reveals the hegemony of all the institutions that originally constructed their problems" (344).

Internally, Jason's fundraising efforts centered on a drive to transform his suffering into purpose:

"I think there are ways to look at your situation and see only the negative things, right? Only the pain and the suffering, and how it's unfair and how someone like my age shouldn't be experiencing what I'm experiencing. But what I learned was, again, I was really focused on like, how can I make this have a purpose? What is the purpose here? And I think what I eventually was able to grasp onto and hold onto was this experience is teaching me about what it means to experience physical suffering."

Jason's fundraising demonstrates the ways where impaired individuals are uniquely informed and positioned within our society to produce purpose through disability. As Johnson puts it, "we [the disabled] have something the world needs." While Jason noted that his experience doesn't "come close to the variety of physical and mental illnesses that people go through," it provided him an understanding of the invisible struggles of those suffering from chronic pain and lupus. This understanding, born from lived experience and suffering, fueled his efforts to share his illness narrative publicly on social media to increase public awareness on disability. Jason's efforts to publicize his story were also linked with his identity rooted in faith: as faith had been his foundation for much of his time living with lupus, he expressed that his outreach was a way to share that foundation with others as well as for others suffering; made possible through his experience, while raising significant, tangible funds for a cause he felt strongly about.

Now in December of 2022, Jason's health has changed dramatically from where he was in 2017. Jason still takes significant effort to take care of his sleep, to exercise, and manage stress while visiting his rheumatologist regularly to check on his lupus. However, he is off his medicine and describes himself as feeling the healthiest he has ever been:

“I feel fit, I feel strong, I’m proud of where I’ve gone in terms of my physical health...I think I, in many ways, am thankful for my experience with lupus because I’m so much stronger now than I was before. Now that I know that I was able to do what I did, come back from an illness like that and a year later complete the most physically and mentally challenging thing I’ve ever done in my life, I know that if I set my mind to something, I can do it,” while also acknowledging that lupus “affects everyone very, very differently” and that he was fortunate it did not progress further.

Jason’s experience plays into Johnson’s view that disability allows individuals to “take constraints that no one would choose, and build rich and satisfying lives within them.” Lupus gave Jason the conditions for him to start “listening to my body, respecting my body” alongside “stress and the effect that it had on me”; much of which he had wished for before lupus’s onset.

Jason’s act of defiance against his experience of SLE demonstrates the potential of individual agency to produce purpose and reassert some control of the disabled identity away from existing social, cultural, and ideological constructions surrounding disability. Jason’s actions showcase the ingenious ways in which impaired individuals are often uniquely empowered to respond against the often reductionary and degrading labels society confers alongside the disabled identity, further proving McDermott and Varenne’s statement that cultural constructions of disability focus on tasks “arbitrarily circumscribed” from life (330).

Jason’s experience, through his suffering and eventual near-complete recovery of SLE, all demonstrate the central role that social identity can play in society’s conferring of disability upon impaired individuals, alongside all the suffering this brings, and in the agency that impaired individuals employ to assert control over their identity as impaired individuals within an ableist society. Through the impact of his age, student status, and peers on internalized stigma and suffering, the importance of faith and religion as a foundation in the mental battle

with SLE, and the transformation of impairment into a force for growth and purpose in his life, these events all highlight the nuanced ways in which disability, identity, and agency weave together.

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