The Medical Humanities Journal of Boston College seeks to: • Initiate and engage in conversation in the Boston College community and beyond about the emergent field of Medical Humanities, Health and Culture. • Provide students at Boston College with the opportunity to publish original work. • Feature a variety of work from several disciplines. • Examine critically and represent creatively ideas of health, illness, caregiving, and medicine. • Connect students with alumni, professionals, and other Medical Humanities programs to extend and to engage in conversation beyond Boston College.
EDITOR’S NOTE

Boston College is home to ~15,000 students from all over the world with many different identities, experiences, and values. We all enter college with the hopes to learn and grow -- to become leaders and experts in our fields of interest. We are driven by our personal passions and goals, eager to explore and develop our infinite potentials. In navigating the sea of our individual possibility, we often forget what it is that truly brings us together: humanity.

The Medical Humanities Journal of Boston College seeks to unite all of our experiences in an effort to communicate the breadth of the medical humanities field. Through pieces like Justin Schnebelen’s reflections on the resilience of the members of the Pine Ridge Indian Reservation, Neil Cochrane’s poems about cancer and grief, and Emma Blackwell’s narrative on mental health, we hope that our journal elucidates that despite our differences, we are connected through what makes us human: loss, our desires for support and love, internal struggles, and celebrating life, especially in the wake of this past year.

2020 was a distressing, confusing, and difficult time for all 15,000 of us. In the midst of a pandemic, “unprecedented” was the word of the year: schools were shut down, jobs were lost, and many lives were taken. Following the emergence of a public health crisis, a summer of violence and unrest ensued after the unjust murders of several Black Americans including Breonna Taylor, Ahmaud Arbery, and George Floyd (to name a few). The recent deaths of eight Asian American women in Atlanta only further highlight the senseless racism and injustice against people of color in this country.

The past year has been marked by many losses -- whether that be of life, social interactions, and in many cases, hope. One of the things all 15,000 of us have in common, however, is resilience. We may have altered lifestyles and lost many things, but we have not lost our senses of possibility. These pages are filled with glimpses of possibility from the talented authors and artists who have contributed to our journal. It is my hope that this journal serves as an outlet for our emotions and makes the experience of loss less isolating. We seek to expand the meaning of health, demonstrating that it is on a continuum characterized by setbacks and personal progress, including not only physical, but mental, emotional, spiritual, and social well-being. Through reflection and conversation, we can make sense of the fact that what separates us is not nearly as big as what brings us together.

I want to extend profound gratitude to everyone who has contributed to our journal, a thousand thank you’s to members of our board for compiling a publication in the midst of a difficult year, and a final thank you to our readers for sharing these experiences with us. We hope this journal can act as a platform for solidarity, possibility, and hope, amplifying the voices of those who have yet to be heard.

Katherine Montas
Editor in Chief
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Horses wear blinders so they can focus on what is ahead. They are easily spooked and distracted by what is next to or behind them, which can be costly and dangerous. They trot along the single path ahead of them, unaware of any surrounding mayhem or chaos.

Dad always loved horses. He was a simple man of few words. He worked treacherous long hours outdoors in Central Park with his horses seven days a week, so we were only in each other's company at night or on days of tumultuous weather.

Yet, Dad and I were buddies. I found him hilarious. While Mom was occupied with my younger brother Kevin, and my older and younger sisters were too mature and immature to match my frequency, Dad and I were always on the same wavelength. He acted like an elementary schooler — like me. I felt comfort in hearing him come home from work when I was in bed. My siblings and I shared a room right next to the cold fridge he frequented. I liked to think that when he made his trip from his couch to grab a Heineken, he would peek his head into my room to check on me.

Dad and I had a different relationship compared to my friends. He did not go to my softball games or even know I was on a softball team. But he would bring me to Sissy's on some weekends to watch a boxing match or football game. I would get free Coca-Cola, and the bartender would allow me to spray it out of the soda gun myself. People would give me dollar bills to play Big Buck Hunter, where I quickly learned the difference between a doe and buck. I even got the code to hack the jukebox and play whatever Matchbox 20 song I wanted.

His silly energy diffused out of Sissy's and into everyday occasions. He rarely drove, but the ride to Elmhurst Hospital to see Mom and my new baby sister was an exhilarating experience that was way too similar to bumper cars. I shared his love for horses, and on many nights, he asked me which horse did I think might win at Saratoga or Aqueduct or Belmont. One time, at a playdate, he grabbed my friend's pizza to take a fat chomp out of it, leaving us roaring. Any time Mom would scold me, I would run to Dad to protect me.

After one Thanksgiving trip, I came home and saw that Dad's beer mug was still in the sink from a few days ago. I felt uneasy. When Crazy Uncle Tom rang our doorbell, I knew something was wrong.

Months went by without him. Very quiet, clean, and boring months.

So much time passed that my eyes glazed over him when he finally returned. I did a double-take before realizing that the person in front of me was, in fact, Dad. His once-strudel belly had inverted, exposing his ribs through his new blue, pressed V-neck sweater. His big blue moon eyes reminded me of a doe, scared and trapped. His old shiny, red, patchy skin had transformed into a greyscale, cracked coating. Worst of all, he did not speak. I felt rather confused at what happened to Dad. He not only seemed sad but robotic. He was physically barely there, but spiritually had disappeared.

His silence penetrated my ears. No more blaring music at night coming from work. No more Wednesday night shenanigans when the Giants played. No more shooting does just for giggles. Thinking of Dad and our good times made my lip quiver. I lost a friend.

Being from Ireland, Dad was a huge Gaelic football fan. I perked up one day while working on
my Social Studies homework when he asked if I would want to watch the Finals at Sissy’s. Of course, I did.

Because of the time difference, we had to be at the bar at around 8 a.m. — before anyone in the house was awake. It was the end of September, where the dying Sun’s beating heat wrestled the fresh, new looming chill of winter. Our walk was silent.

As usual, the smell of saturated sugary Cola and Brandy entered my lungs, wildly triggering nostalgia.

Within minutes, Dad ordered me my Cola, and for the first time, almost met my eyes. His dark blue moon eyes with draped eyelids scared me in their intensity. “Look,” he stuttered, his gaze dancing around, rest in one place. The crowd at the pub almost drowned out his voice as he continued, “Mom doesn’t have to know this, okay?” I nodded—not in agreement but understanding. The hiss of the open Heineken’s high octave vexed my eardrum

Within moments, my old Dad was back.

When we got back home, hours later, the tide had turned. Now, everyone else was silent; and it was him that was loud—loud in voice, appearance, and smell. He repelled my siblings and Mom. I held the rope, taut with tension between my father and the rest of our family. But he kept pulling the rope harder and harder. Soon, I knew it was going to snap, with him tumbling out of our lives. Words boomed and swirled through my ears. Yet my brain was too frazzled to make sense out of them. “Promise.” “Care.” “Selfish.” “Disease.” “Repulsive.” “Lonely.” I wanted to stand up for him, but my face burned dry and hot at the scene. Embarrassment and guilt exuded from me. I let this happen because I missed a friend, a man to whom I never got to say goodbye. But this silly man was not so funny to everyone else. There was a profound disconnect between my family and me. Was I, like the horse, wearing blinders? Who put them on me, and most importantly, what was I not seeing?
You probably didn't know what I was thinking when I was on my way to see you for the last time. I was remembering heading to your house after school had ended. Grandma would greet me while preparing dinner, and you would be watching television in your room while studying card games. When you saw me walk in, you would not hesitate to put all the cards aside and ask me what I wanted to do. I would bring out Korean chess from the shelf and ask you to teach me. You would always laugh and hum as we played. You never pretended to lose for my benefit, but instead challenged me to beat you. You would take away piece after piece, telling me to remember all the different ways they could move. It took me more than several games, but I eventually remembered.

When my family and I were at the airport heading to the States for the first time, you were there, sending us off. I was terrified of leaving and I cried. At that moment, you held my hands and told me there was nothing to cry about. I saw in your eyes how heartbroken you were, but you were able to hold your tears back. I don't remember if I stopped crying, but I could never forget your kind words.

Four years after we immigrated, you came to visit us in our new home. I had forgotten how much I enjoyed playing Korean chess, but you remembered. You brought the pieces with you and started teaching me again. I was older, and I was able to understand faster. You weren't the only one taking away pieces anymore and I would imitate your hums and laughs as I took yours. I could never beat you though. Maybe you were letting the games get close, but that was as far as I could go. Every day, I would come home from school, looking forward to playing with you again. Every day, I would hope that the next game will be my first win. But when you had to return home to Korea a month later, I still hadn't had that first win. You promised me that the next time I saw you, we would play again and I promised you that next time, I would win. After you left, I practiced with my dad, brother, and cousin and I tried to remember how your pieces moved. I won against everyone else and I was looking forward to our next match.

I found out that you were diagnosed with lung cancer and it felt like all the air left my own. I didn't know what to say. When I called you, you sounded hoarse but energetic, so I thought I had time. I thought I could worry about seeing you after I finished my college applications, after my fall semester of senior year. I didn't think your health would deteriorate so quickly. When I finished everything and was on the plane to Korea, you had less than weeks to live. I remembered our promise to play Korean chess on our next reunion and how I had been so confident that I would win. That's what I was thinking of when I was on my way to see you.

The first time I walked into the hospital to visit you, I felt very strange. I could not imagine you hospitalized. You used to always walk around the park near your house. You even used to take me along on your walks—even if I declined—telling me that I needed to stay active and be fit and healthy. I finally got to the room you were in. Your name
and five others were on the door. As I walked in, I looked around carefully to find you, but couldn't see you at first. Then I recognized Grandma and turned my head to the patient closest to her. Even then, it took me a moment to realize that it was you. I didn't think you would look so fragile and beaten. I didn't know how to respond to you, except to reassure you that I was there. I couldn't make sense of what you were saying without your dentures, but you didn't talk for long anyways. You held your chest tightly and started moaning in pain. My aunt took me out from the room and started explaining your condition to me. She told me how lung cancer is one of the most painful cancers, and that you also had difficulty breathing. The doctors were giving you a lot of narcotic medications to relieve your pain, but the side effect was that you weren't able to think straight.

I could not quite grasp the seriousness of this side effect at first. I didn't want to believe the cancer or the medications could take you away from me. You recognized me. You remembered me. You couldn't pronounce my name but I knew you were trying to mouth it. However, when I went to see you the next day, something was different. Grandma was translating what you were saying and you were looking for my mom. Not from the States, but from Korea. You couldn't remember that we had immigrated. Day after day, the drugs continued to take away pieces of your memory, pieces of us. My aunt would ask you what you knew, and you remembered me as a baby, where I used to live, when I was born. When your daughter asked you again, you couldn't remember me anymore.

Still, you were so strong. Your oldest daughter asked you which one of the four daughters is your favorite, just to have a laugh, and you answered with, “I love them all equally.” I want you to know that I admired you much more because of the answer. Your wife told me that you favored your youngest daughter when they were young, but you didn't want to hurt others' feelings. That's why you had to say that you love them equally. You still had the strength to care for others despite all the pain you were going through.

A day after you were admitted to the hospice, the rest of your daughters arrived from the States. Your second oldest daughter, my mom, held your hand tightly and told you that she was there now. Afterwards, she had to step out, and I followed. She was thinking about all the things she couldn't do to take care of you because she had chosen to immigrate. I have never seen her cry that much. However, I knew what to do. I quietly held her hands and told her that everything would be okay. I could feel that my eyes were becoming red, but I was able to hold back my tears.

I flew back to the States a day after, and the suspense during the flight was unbearable. Thirteen hours. Anything could have happened in those hours. The memory of me being unsettled during the entire flight is still vivid. Thankfully, nothing happened then and I was able to sleep after I arrived home. What I didn't consider was, anything could have happened while I was asleep. My dad came into my room to wake me up, and he softly told me that you had passed away a few hours ago. Upon hearing the news, I just sat on my bed. Surprisingly, I was calm. Few hours later, I picked up my phone and called my brother who just arrived at the hospice. He too missed your last moment by a few hours.

He told me all the things he regretted doing in front of you. He wished he could have spoken with you, one last time, and show you how much he has matured since the last time you've seen him. He wanted to apologize to you before you left.

We all imagined our final moments with you, but didn't quite get them our way. Your death came as a surprise to us all, and we didn't know how to react. Was there a right move we could have taken? Whenever I play chess, I think of that last game that we never got to play. It wouldn't have mattered to me who won or lost. What I miss and remember are the games we played together and the conversations we had, not the outcome. I think that no matter what move we took to prepare, we would still have this unsettled feeling; the game can't move on without the other player, without you.
8:00h
I had just returned to the clinic in Pifo when the initial excitement to my arrival quickly shifted to how I might be of use to the medical and nursing staff. In my still less than perfect Spanish, I expressed to the staff that I was only there that day to do my research, but Dr. Pati’s begging eyes conveyed that the clinic really could not afford to send another staff member up to Tablón. OK, ok – I agreed – pero necesito acabar mis encuestas cuando regresemos. The doctora confirmed that there would be no problem with finishing my work and that we would return from the campaña de vacunación before lunch time.

Five months earlier, I had first been integrated to the community of Pifo, a largely agrarian and rural parroquia pertaining to the far outreaches of Quito, Ecuador. That was back when I first arrived in Ecuador for my semester abroad, which allowed for my integration into a project already started by a fellow Boston College student and friend. My principal investigator on the project had explained to me his methodology behind public health investigation which bordered on ethnographic in its nature. I soon had integrated myself as a student with the escuela de medicina, wearing scrubs, contributing to a social outreach program for elderly folks, and shadowing medical students. Though I am still at least a year off from applying and entering medical school in the United States, the local staff and my professors overwhelmingly embraced my interests and participation. Our work centered on a research protocol dedicated to understanding how the public health system addressed the comprehensive needs of elderly care in this specific locality, and I further contributed to the staff’s needs, often through vaccination campaigns.

I struggled with my lack of experience and formal training. My expressed concerns over my administering of basic services like vaccinations were met only with confused faces. I still remember my first day of work when I initially refused to vaccinate a 5-year-old child who attended the local public school due to my preocupaciones de la ética. Nidia, the older Cuban nurse present there, quickly dismissed my ethical considerations. “We didn't have all day to get through these vaccines” – she said, “and the team could really use my help.” The medical students and nursing staff nodded in agreement, and without being able to think twice, I became an expert at loading needles, injecting the vaccine pa’ el gripe, and discarding them without second thought. Some months later, a nurse bragged to her patient about my manos suaves, especially for a man.

In those months, I grew in my Spanish fluency, especially in the local lenguaje pifeño that separated my pronunciation from many of my fellow international students. More importantly, I fostered authentic relationship with the local staff and the local members of the community. Through my weekly engagement with El Club de los Adultos Mayores, I enjoyed weekly activities of bailaterapia, yoga, and eventually gardening with the elderly folks. I spent my days at work interviewing the members of the club and collecting my data on my computer (thanks to my friend Don Carlos, la guardia, who shared the Health Clinic’s contraseña secreta de Wifi). Yet I still felt unsettled. While my experience was valuable for me, I often found myself questioning whether someone else – with better language, cultural, intellectual context – could do my work better. On days where I
would doubt my role or contributions, my boss or the clinic staff would embrace me—with an abracito, or sometimes with a smile or a chiste— that quelled my concerns and reaffirmed my presence.

I also worried about leaving. After building such relationships and dedicating serious time to community members, what was at stake in leaving? Was I just taking advantage of the community for my own educational and linguistic benefit? Towards the end of the semester I realized that I desired to stay and further contribute to our projects with a great sense that I could not abandon my new compañeros y compañeras.

8:45h
Hence my return to the clinic that Wednesday in June. Luis, a local of the parroquia and a hired driver for the Ministerio de Salud greeted me as always with a hug and a big smile, amused that I had returned to his barrio aleatorio. At age 42, Luis had lived his whole life in Pifo and his presence always brought me a great sense of comfort. He had as much if not more medical expertise than me (neither of us were expertos) and he was an invaluable member of the staff when visits to the communities lejanas were necessary. We made small talk with Don Carlos, joking about that one time that I had eaten a salchipapa from a local shop that left me hospitalized (my sensitive barriga gringa was always a go to conversation in moments of awkward silence).

Luis mentioned that the gringo – that is to say, me – was unprepared for the harsh conditions in Tablón. I reminded that Luis had clearly never seen an invierno like the ones in Boston. Luis shook his head in amusement, implying my ignorance, and we entered his camioneta. As there can be no time wasted in a trip such as this one, we also brought along frascos to administer tuberculosis samples. Luis navigated through the town’s center, scorching hot already at 9am. I smirked thinking on how sensitive ecuatorianos were to the cold weather. Passing through the small center of town, I admired the ordinary yet spectacular flow of daily life. Large bunches of plátanos, papayas, frutas desconocidas were piled upon one another in market displays – both along the street as well as inside shops. As we moved just outside of the center of town, a middle aged woman in traditional andina dress greeted her neighbor with a kiss, effortlessly keeping her child swaddled against her spine as if secured like a backpack. Moving just beyond central Piño, the vista of Quito to the west and the mountains to the east became apparent. The intense and varied greens of the landscape became more and more sparse as we began our climb in elevation up into the páramos.

9:30h
Unexpectedly, as we reached a more remote section of Piño, Luis pulled down the dirt road towards a small neighborhood of houses. He slowed to a stop in a driveway and proceeded – without explanation – to leave his car. A few minutes later he returned with his sister as well as a fleece. Luis -still maintaining his smile - handed me his chompa, he didn’t trust my Bostonian pride in bearing cold weather. We watched from the car as the doctor directed Luis’s sister to cough in a manner that would emit flema. The sister could not bring herself to do so and the doctor decidedly admitted that if she could not produce phlegm for the test, TB probably was not the reason for her body aches.

The doctor gave her a few painkillers for her aches, and we were now, officially, on our way to Tablón, where a roomful of school children awaited our arrival with vaccines. The car went silent as we slowly climbed the páramo trail, which slowly but the suddenly shifted from a cleanly paved road to a somewhat treacherous carretera. As we listened to the loud noises of the truck and felt our centers of gravity being pulled higher and higher in our abdomen, I imagined the scene that we might encounter. Small children – anywhere from 5-10 – in a multi room school building. They would look at us timidly at first – maybe with a few of them embracing us at the thought of class being interrupted. Within minutes, as always, they would be screaming at the realization that their classmate was receiving a pincha. While vaccines mean health and communal protection to health professionals, pain communicated a mistrust to their recipients, especially among a classroom full of fellow niños y niñas.
When we did arrive, and I exited the camioneta, a cold gust of air initially pushed me back into the car. My hands, within minutes of exposure to the outdoor air, turned stiff, and I hoped the exaggerated whiteness in my fingertips would not so quickly turn purple. We walked up to the school building with supplies (vaccine-filled coolers, clearly marked biohazard waste bags, and a vaccine disposal box) where the doctor greeted the school teachers with a beso. We all proceeded to saludar before beginning conversation.

This school building was not quite what had earlier filled my imagination. In fact, it was limited to one large classroom, unlike the schools that suited larger populations down in the center of Pifo. The room looked scarce, though some colorful student artwork covered the walls. As my attention wandered back into the conversation, I realized the school teacher’s confusion. They had not expected our visit and – as such – the students present did not have their health carnets. Even worse, only the younger half of the students attended school in the mornings, with their older counterparts attending in the afternoon.

And that was how we spent the next two hours driving house to house yelling through a blowhorn. We repeated instructions with such a ritmo that it nearly became a meditative chant: <<come outside with your children younger than 8 years old, without vaccinations they would not be allowed to attend school>>. We drove through the cold highlands area until we touched each house. 6 vaccines – only 2 of which I prepared and none of which I administered – was our total count. The beauty of the paisaje contrasted my internal landscape. So many difficulties despite the good will of everyone involved. Most clearly, miscommunication. Something had failed in the line of communication between the medical staff and the school administrators.

More concerning beyond today’s mishap was location. The Pifo public health center, often overwhelmed with patients, only very rarely interacted folks in Tablón. The law requires all children to have their basic immunizations in order to attend schools, which – in theory – should ensure health across children. In practice, a health disparity was created. The health clinic – for time-efficiency sake – often turned away patients when they did not arrive on time for their appointments. Realizing that – other than this visit on the health staff’s time – parents or guardians would be required to bajar la montaña down to the health clinic, I realized just how easy it might be to arrive late for such an appointment. When the health staff or school district came across an outdated vaccine card, criticisms of irresponsible parenting and consequences of exclusion would follow. The doctor with us commented that Tablón should have its own clinic, but the government could not afford to staff another clinic. As we continued
on our winding to each house, we encountered a woman who after speaking with the doctor for several minutes, refused to bring her daughter out for her required vaccination. How fair, though. *Imagínate*, when your only interactions with health professionals occur when they come to yell at you through a bullhorn... who would follow their bidding?

Yet the medical professionals were – are – not by any means *pecadores* in this process. While many professionals choose private practice, these *trabajadores* invested in the daily, hopeful, and thankless work that demonstrates community medicine as much more than technical; in this context, clearly *medicina es un arte*. Despite only 8 vaccinations out of the many more required, I could not help but appreciate the effort of these clinicians to work alongside each person in Tablón despite the difficulties of success. We began our descent when the doctor asked Luis to *<< dé la vuelta >>* so that we may visit one more family. Our trip could not be wasted. We arrived at a steep driveway and slowly lowered ourselves to a *casa desadecuada*. A corrugated roof and exposed concrete showed that the home owners had many other concerns before house maintenance. We honked the horn and a woman in her mid-thirties, wearing a grease covered purple t shirt, jeans, and flip flops exited the home. The doctor spoke with her privately for a moment and then she motioned us out of the truck as to be welcomed. We entered her home, which largely consisted of an unfurnished living room with a small kitchen and two bedrooms. Given the high altitude and harsh temperatures, the buzzing of flies inside surprised me. In the middle of the vacuous room without any light except that from outside, sat a child in a highly mechanized chair. While he appeared the size of a young boy, the nurse commented that he was much closer to my age, 15. Not understanding the full scope of his condition or what I could possibly contribute, I stood respectfully quiet other than a kind *saludo* with the woman who had welcomed us. I gathered that the appointments for this child only occurred when the health center staff could visit Tablón, a rare time like now.

1:30h
As we finally descended back to the center of town, arrival time now at 2:15h, I sat in disgust with the unproductivity of my day. Five hours and eight vaccinations later, my stomach growled in disappointment and for *un almuerzo*. Yet, I then thought on my own shame that I might call such a day unproductive. Five hours, by the metric of witness, had allowed me into the lives of Luis, his sister, school teachers, students and the homes of people carrying much more than deserved. I jotted scribbles in my notebook as we bounced down the windy path. Looking to across Andean landscape once again I thought to myself: how messy, how difficult and how human a morning's work, and how hopeful.
The Monster

Emma Blackwell

It is a monster; an ugly, dark green monster, with razor-sharp yellow fangs and twisted, knotted jet-black fur. Its voice is loud and harsh, it shakes you to the core and makes your ears and mind ache. You cannot escape, because this monster is different. This monster is not confined to under your bed or your closet, and he is not confined to the dark depths of the night.

Oh, no, this monster permeates your skin, blood, bones, and your very soul, which he makes sure is no longer just yours but is his, too. He works all hours, not stopped by a radiant sunrise, nor the light of twinkling stars.

This monster likes to make you think you are crazy. He watches you turn your straightener off because you always turn your straightener off, and you know you turned your straightener off, but then he convinces you that maybe you didn’t. Maybe you didn’t turn it off, and maybe your house will burn down, and maybe it will be all your fault. So he’ll make you turn your car around, even though you’re already late, and you have people in your car, and now they’ll think you’re crazy, and you know you’re crazy because he has made you crazy, so you turn your car around, and you check your straightener, because he says you should, and so you have to.

But he does not stop with the straightener. You hear his maniacal laughter in your head as he squeezes the rational part of your brain with his long, wiry, strong blackened fingers, and forces you to go back and make sure the doors are locked, the space heater is unplugged, the candles are blown out, the stove is off, the refrigerator is shut, the windows are locked, and everything is locked and everything is off. And then he makes you check it all again.

And he especially likes when some Very Bad Thing happens on the news, like a murder or a kidnapping. He snaps his fingers, and, just like that, you obsess over the Very Bad Thing. You find out everything about the Very Bad Thing, scaring yourself more with every word you read, but he makes sure your eyes are glued to the screen, scouring page after page of gruesome details. He’ll tell you that the more you learn, the more likely that the Very Bad Thing will not happen to you, so you’ll keep reading and terrify yourself. But then again, maybe you’re jinxing it, he tells you, and maybe your panic-spurred obsessing over the Very Bad Thing will happen to you anyway. He tells you that Very Bad Things have to happen to someone, why not you? And so you live in fear, and he is happy.

He loves when you see your friends. As soon as you start to feel comfortable, his strong, dark, oozing arms wrap themselves around the gears of your brain setting your nerves on fire. And then as your mind whirls, your hands shake. They shake so bad you cannot hold anything, and you’re surrounded by people, but you cannot let them see because they will not understand that your monster makes you crazy, that it isn’t you, and if they see your erratically quivering hands, they will just think you are crazy. Your heart follows your hands, pumping frantically, racing so fast, it’s almost as if it’s running from him, but it is not running from him, because nothing can get away from him. So then your arms go numb and you’ll think you’re having a heart attack, no, you’ll know you’re having a heart attack, but you know it’s him making you feel this way, and how can you explain your monster to 911? Maybe you are going crazy. Maybe it’s you. Your throat is tight and the breaths
can barely get in, and for one second, he makes you sickly jealous of people who die from anaphylactic shock because at least they have a medical condition explaining their symptoms, and what do you have? Just your monster and no one sees him except for you. And so you pant and you cry and you throw up and you shake and you wonder how it will stop because you cannot live with this, you can’t.

You’ve never gotten in an accident, and you’ve never gotten a ticket, and you drive safe, but what’s that to him? So he makes you think about the possibility that you might hit someone, and maybe you should just stop driving altogether because you’d rather let him take that freedom from you than endure his constant badgering you about what could go wrong in that huge, dangerous killing machine you used to call a car.

It’s exhausting, what he does to you. But no, sleep does not come easy. No matter how tired you are. He whispers in your ears at all hours. Did you study enough for your test? Do you think your mom is mad at you? Do you think maybe your teacher is mad at you, too? Did you laugh too loud at lunch? Did you drink too much at the bar? What more could you have done wrong, you’ll think, but then you’ll hear him laugh and he’ll leave the past alone for a few minutes and launch into the future. What if you accidentally sleep through your Psych class tomorrow? What if you run out of your hairspray before the dance on Friday and so your boyfriend thinks you’re not as pretty anymore and likes someone else? What if you have to miss your friend’s dinner party tomorrow because you feel sick, but won’t she be so furious?

And when you finally do fall asleep, he nudges you awake at 3 am whispering hushed, angry words into your ears describing a creaking floorboard, a noise in your house that should be quiet. He’ll grin widely, his ugly teeth glistening their rotten yellow, as you shoot out of bed in a panic, adrenaline coursing through your veins, no, not your veins anymore, his veins. He’ll watch you stack chairs and books by your window because you read that deters burglaries and he’s convinced you that if that noise you heard wasn’t a person in your house yet, someone else could be, no, will be, soon and you will be taken unless you lock everything and block everything. You’ll dive back under your big blankets, wishing they could protect you, but the real monster, your monster, is inside of you still, and no amount of locks can save you.

He makes you study weeks in advance for your exams, missing time with friends because if you do not start studying at least two weeks in advance you will fail your test, you will fail out of school, you will never get a job, you will never get married, you will never have kids, you will never be happy, or at least that is what he tells you. But then when you get the test, he will make you feel like no matter how much time you spent studying, it was not enough, and he will squeeze the tears out of the corners of your eyes as you look around you at everyone typing and writing and think of how you’re behind and you probably won’t finish the test and you’re not going to get an A but you need an A, or you will never be happy, right?

He especially loves when your friends are busy. Then, he can tell you that they’re not busy, they just haven’t answered their phones because they’re mad at you because you’re a stupid, annoying person, and they never wanted to be friends with you anyway. He’ll convince you to text your friend a long message asking what’s wrong, and asking if she’s mad, and what you can do to make her happy again, and then she’ll answer and say nothing’s wrong, but now it’s too late, your embarrassed because you were stupid and crazy and he won’t let go of you and he revels in your distress.

People will try to make your monster go away. You’ll see people who specialize in your monster, but the strategies they give you won’t work. Because you’ll know so well how irrational this monster makes you, and how you should not believe him. You’ll get it. But then he’ll speak again and there’s nothing you can do. So then they’ll give you pills in the morning to quiet him during the day, and pills in the evening to save you from his words while you sleep. But he’s too strong, for both their words and their pills, and you keep moving, the two of you, side by side, his mangled meaty hands with those spindly, crooked fingers clutched with a death grip around your throat, squeezing, squeezing, squeezing...
I have always volunteered for one more thing than I can handle. If a course load is five classes, I took six… and worked as a TA… and held down two jobs… and wrote one chapter of a book I’ll never finish… and… and…

I was this way before my transplant, but since then, now that there are no excuses, the little voice in my brain that says

“slow down”

is fainter and fainter. The jenga tower of my life was as wobbly as ever as I boarded a 9pm flight from Boston to Fort Lauderdale that cool May evening in 2019. I sat the whole flight, foot tapping, anxiously typing on the notes app of my phone. I knew I was delivering this speech for months. Answered a half dozen check-in emails with calm reassurance of the “great progress I had made” on my remarks. But if the weak airplane coffee and gentle glow of the screen I was furiously typing on proved anything… it was that I hadn’t written a single word.

I turned off airplane mode.

*buzz* *buzzzzzz* *buzzzzz*

“You are going to do amazing tomorrow, I am so proud of you!” -Mom

“I’m in the car by your gate, come quick, we have 11pm reservations” -Dad

“Is your speech done? Email me your draft ASAP. We will have your credentials ready at the entrance, let me know as soon as you arrive. Can’t wait to see you!” -Sokphal

I looked down at my cluttered screen, cautiously typed in the same 4-digit pin I’ve had since I was 13 and opened my notes. There it was, the speech I knew I had to deliver in front of a room of medical professionals later that day.

*First of all I would like to thank Patrick for that great introduction and the NPF for inviting me to speak to you all today. I would also like to thank all of you, both for taking the time to listen to my story.*

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1 This excerpt, and all excerpts to follow, were taken directly from the note in my phone titled “NPF Fellowship Conference Speech”, written on May 3, 2019 at 10:04pm.
Why had it taken me so long to start?

This is my life's story they want to hear. After years of fighting, screaming, kicking, pulling out IV's, being refused care, being called a drug addict, probed about “childhood drinking”, cursing the names of a dozen doctors, refusing consent for feeding tubes. You'd think that the opportunity to look at a room full of medical professionals, some the best in the world, others at the start of their career, and tell them about my suffering, would be an opportunity that I would have abundantly prepared for. But I hadn't. Not even a little bit.

This was one more block in the jenga pile of a life I had created. But this wasn't a stable piece, not a safe move for just anyone to grab at any minute. This piece needed precision, it needed intention, it needed care. I knew it wasn't just my story that I had to tell... I had to speak for Adam and Rose and Luke and Cece and dozens of other young people who have also had to suffer like me. It was the instability that comes with responsibility like this that had prevented me from just grabbing this block earlier.

Three hours and four cups of weak plane coffee later though, I had done it.

I explained my pain-

...a few months into school my biggest fear came true, and I found myself in tears outside of my freshman dorm at 5am ordering an Uber to the hospital because I was in pain so excruciating I could barely talk.... For someone who loves to plan, there's nothing quite as devastating as having no control. I couldn't attend my classes, couldn't plan with my friends, I couldn't even look at my phone some days. I would practice my mandarin and try to read my political theory books in the sweet spots of my day, after the pain medicine mellowed enough that I was able to focus on something, but before it wore off enough that I couldn't stand the pain.

I did everything I could to put not just my identity, but our identities, into my remarks. I talked about how my life was molded by this-

Sometimes I think back to my years of illness and it almost doesn't feel real anymore. But pancreatitis has been a huge part of my life. There are plenty of horror stories I could tell you of scary days and traumatic events, but it wasn't all that, a lot happened in those hospital rooms. I planned my sweet 16, started a relationship with my first boyfriend, celebrated holidays, enjoyed the company of my friends and family, met some remarkable people, and ultimately learned how resilient I am.

I knew I had to tell our stories, I needed to go beyond the pain. Our lives have been molded and guided and flipped upside down in every way. I needed them to know. It's not always easy to get the attention of a doctor. Let alone 200 doctors.

So when the time came, early that next morning, I walked into the hotel, my dad by my side. I had a name tag that made me feel a little important pinned to my pastel floral dress, and when I saw my cue given from across the room... I got to the podium.

I cried writing the speech, I cried reading it to my dad in the car that morning, I cried when my friends responded to my proofreads, I cried sharing it with my fellow sufferers. I was confident I was going to cry.

But I didn't. I never cried.
Instead I spoke calmly. My voice was steady, I addressed my audience with reverence as their prestige called for. But I also got a chance to challenge, to push them. They were there to hear me. Thousands of times I sat in front of people like them, on paper covered tables, on scratchy hospital sheets, looking up to them for hope… almost always to end up disappointed. But now it was my time, our time, to assert how we felt. I did it for us.

The close of my remarks—
But really, if it weren't for my medical teams in Connecticut, Boston, and Minnesota, I wouldn't have any of this. So thank you all for the work you do, may you continue to learn, remain passionate about healing, and always remember the impact your work has on the lives of those you care for.
-gave me an opportunity to express everything I felt. Gratitude for those who saved me, but importantly, a reminder that what they do every day impacts us.

To tell my story is difficult, to tell the collective story of us… nearly impossible. I put off writing my speech because it wasn’t just ONE more thing. It was hundreds more. Hundreds more people, hundreds more stories. It was an incredible privilege but also a remarkable burden to speak for us. My one more thing mentality should be stopped sometimes (oftentimes), but one of the few burdens I take on again and again… that I never live to regret, is taking on one more thing to speak for us.

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The Ongoing Cycle

Anonymous

Sometimes, life feels like an ongoing cycle you can never escape. Whether you’re 11 or 19, you’ll always remember those feelings of powerlessness.

The dark basement of the middle school counseling department kept you way past school time. You couldn’t find any joy for the upcoming Christmas holiday on the serious looking school social worker who eyed you with concern. You felt lost trying to piece together their whisperings of “DCF,” and “Children’s Hospital Psychology Evaluation.” A massive police officer asked, “What’s going on at home, what puts you in danger?” However, the 11-year-old you did not find any comfort looking at the gun strapped in the police’s pocket and listening to the distressed social worker conclude her lengthy investigation by calling you a “liar.” Feeling as tiny and powerless as a 3-year-old, you swallowed the growing feelings of self-disgust and begged, “Can I please go home?”

“I want to go home, please.” The nineteen-year-old you cried again, remembering the same cycle repeating. It all happened so fast. Suddenly, the police were yelling at you for your student ID, and you found yourself escorted to the counseling service in another basement. All you could think of is, “OMG, please don’t make this happen again and again.” The 3, 11, 19 year-old you hid behind the Christmas tree and whined in unison, “You’re not here to help, police always lie and hurt you!” They searched you against the wall, undressed you at the ER, and marked the scars on your body. You’re being held on Section 12, starving without a meal, half-covered in a flimsy hospital gown, with a hospital guard eyeing you cautiously at the door. You were a circus animal - just like the last time they sent the 11-year-old you for a hospital evaluation.

“I’m doing fine. I just want to go home,” you tried to act clear-minded in the best adult voice like a 30, 40-year old. Nineteen didn’t seem mature enough to them as fifty, but age didn’t really matter. Every time they sent you somewhere, you were no more human to them than a stigmatized mentally ill girl or just “some thing” to be observed. The 11-year-old inside you screamed in your mind, “Don’t you know that asking for help can get you trapped?” You knew you needed to respond without hesitation, insisting you’re fine, or they would assume the worst. The 3, 8, 11, year-old you echoed, your parents already taught you what not to say to the social worker at that young age. “Always say it’s a culture misunderstanding, or the outside world will take you away from home and leave you in foster care alone.” The 19-year-old knew how to act at this moment - smile calmly until you’re out of danger and escape the system.

“I want to go home,” the voice resounded inside the 19 year-old you, reminding you of the time it came from the kids in the group home and orphanage you volunteered for. The 15, 16, 17 year-old you couldn’t whisk them away to a perfect place. Still, you always wrapped their tears into your arms, trying to comfort them. “I understand, we’ll see what we can do, alright?”

“When can I go home?” The 13-year-old girl you mentored at the group home tried to hold back her tears, curling up next to you. The 17, 18-year-old you watched her put on the brave smile in front of
the police and child protective service investigators as she claimed everything was fine at home, then immediately broke into tears in your hug. You saw the 3, 8, 11…… year-old you in her brave yet heartbreaking eyes, knowing how it felt to tell a fairy-tale-like home story and hope the Christmas wish for a peaceful home would come true one day.

“Was there anything wrong at home? What was this DCF involvement about?” The ER social worker looked up from the lengthy treatment history form. The 19-year-old you felt your past selves scream, “Why am I being questioned about history with child protective service again, now that I’m a 19 year-old adult?” Cautiously, you repeated a lovely home story, just like that 13-year-old girl you mentored and the 3, 8, 11 year-old version of you always prepared to recite. You bursted into tears once the social worker walked out. Now as a 19-year-old, you still couldn’t promise the kids you mentored a happy solution, nor could you run out of the cycle that’s haunted by the investigation over and over again.

“You’ll be admitted - you’re not going home tonight.” The ER room with its beeping machines, holiday decoration, and pink-clad nurses faded away. Your masked smile washed away with your tears. The 3, 11, 14, 19, and all the versions of yourself crashed into each other in this endless cycle, tearing powerlessly with no place to run.

“How come you all get to go home for Christmas, but I don’t?” You cried curling up behind the exit door you’d not be allowed to open for the next ten days. It’s another Christmas in the hospital, the 11-year-old you reminded your 19 year-old self. No Santa or Christmas tree again. In fact, you haven’t seen any trees or plants over a foot tall at all in this isolated psych unit. No one would come to rescue, no wish would be granted, no outdoor fresh air time - it’s too slippery and snowy, the staff claimed.

“Can I go home for Christmas?” At the group home, the 13-year-old girl unwrapped the tiny Christmas gift you brought her, repeating the question again and again. The 18 year-old you could see hope radiating from the girl’s eyes as you wished her a peaceful Christmas Eve at the end of your volunteering. “Let’s hope the next Christmas will be better,” all you could do was hold her hands as the two of you prayed together.

But now, you’re the 19-year-old whining like a 3-year-old in the nurse’s warm hug as she headed out the locked door by the end of her Christmas shift. The nurse met the 19 year-old you with a sympathetic sigh, reminding you of the time when you met the 13-year-old girl with the best comfort you could provide. No matter how much you empathized, the 17, 18 year-old you knew that you couldn’t take home every wounded child, just like the nurse couldn’t take home the 11 or 19-year-old you. You always see the 3, 11, 14, 19 year old yourself in the tearing eyes and suffering of your clients. Yet, now you’re deciding the fate of the clients in front of you, like those 30, 40, 50 year old professionals who sent you away so many times. It’s as struggling and painful to be that powerless 3-year-old seeing others deciding your fate, as it is to feel like that 30, 40, 50 year old witnessing the clients struggle and the kids cry, “I want to go home. I don’t want to be here.”

“I don’t want to be here. I just want a place to call home.” Your tears soaked the stuffed animal. It’s always there for the 8, 11, 14, 19-year-old version of you that’s locked up in the psych unit, under the supervision of child protective service, or sleeping in the cold airport lobby. The 19-year-old cried silently in your bed as the footsteps and flashlight check-in came by every 15 minutes on this terrifying Christmas night. Ever since you were 4-years-old, you learned to distinguish the footsteps, fight, flight, freeze, or fake asleep as your parents fight. Once again, other people are deciding your fate.

But eventually, they’ll release you back into the cycle. No matter if you are 3, 11, 19, or feel like 30, 55 years old, the tears and tough decisions never end.

“Welcome back!” You’re finally released back to BC - the place you call home. The Christmas decorations at the counseling basement are gone, but the 19
year-old you can’t feel happier hearing your therapist wishing you a happy birthday. You’re turning 20, but still putting together the 19, 18, 11,…3 year-old inside you. You wonder how to walk across campus worrying about being thrown back to the 11-year-old cycle again? “I see a lot of hope inside you,” the therapist says in that sincere tone that always comforts you. Now you realize you’ve always tried to provide the 13-year-old girl and all your clients with that comforting, supporting voice, which your therapist finally offered to the 19-year-old you.

“I will not stop caring.” The statement of the therapist becomes your new mantra, knowing you will always care for your clients with the deepest empathy. The humanity from that therapist helps you integrate and embrace the many versions of yourself from all ages. Life can feel like an ongoing cycle because they are all actively inside you, but you don’t have to feel trapped. When you see your 11, 10, 9, 8, 7, 6, 5, 4, 3, 2, 1, year-old self in the eyes of the clients you serve, you will do everything in your power to pull them out of the cycle. Being a 30, 40, 50, 60, 70 year-old adult with the power to decide the other 11 or 19-year-olds’ fate is not what is most important. The most valuable thing is the promise to always remember how it feels to be 11 and trapped in the cycle with no Christmas wish granted. As you walk by the Gasson basement and think of your therapist’s kind words, you know the 20, 21, 22, 23, 24 and many upcoming years of you will not stop caring for all the souls so they can find the hope that’s always been inside them.

Every age of you came together when you handed that 13-year-old young girl the Christmas card that read, “One day, we’ll create our safe homes and no longer be trapped in any cycle anymore.”

Note:
This piece was written in March of 2019, during my freshman year, prior to the recent pandemic, racial injustice protests, and political polarization that has occurred over the past year. My narration of this story might sound differently now as I continue on my healing journey. Yet, the similar “ongoing cycle” has continued to be reenacted and continues to impact individuals and society collectively even when it’s forgotten at times. My hope is that this piece helps us to think more humanely and ethically about the history of psychology, medicine, and social services disciplines so we can truly care for the suffering others.
Afterward, I looked at the world with a completely new set of eyes. I've always been able to gauge another person's character through a few interactions fairly well, but now I took the time to observe myself. Was I one of the people contributing to the pandemic of ignorance? Had I become what I loathed?

My eyes swept across the halls. I've always strived to uphold a policy of tolerance and inclusivity for myself, but the same novel thought kept perpetuating itself in my mind: *maybe I'm the one who doesn't look at the other person's perspective.* My identity recoiled in shock as I finally began to ask the big question: was I truly the person that I prided myself on being?

I shook my head. Of course, I was; maybe I was just a bit confused. But, in that instant, I became a tad more mature. Sensible. “Grown-up.” As my mind started to stitch itself back together, a pang of clarity hit me. Everyone believes in what they think is right; no one chooses the “wrong” side; no one sees themselves as the villain. My ears twitched as they recognized familiar footsteps reverberating through the hallway—they belonged to a girl whose political views differed from mine. I remembered talking with her months before:

"Don't you see? Healthcare can’t be free! Just because other countries pull it off, doesn't mean that..."

Prior to that day, I wouldn't have responded. Well, not properly anyway. I would have chosen an in-between answer—something that would allow me to weasel out of the conversation without raising a debate.

I sighed. “Yeah, I guess that makes sense.”

Back then, I never even considered the possibility that her argument might have been valid. What if she actually spent time researching her topic, and I completely rejected it based on a snap decision? It all made sense now.

Around halfway through my junior year in high school, I was tasked with writing a ten to fifteen-page research paper on a controversial matter. Some of my classmates looked around with an eager gleam in their eyes. Mine looked at my feet, my sunken eyelids partially covering their view of the grey, striped tiles beneath me. *I hate talking politics.*

It wasn't necessarily politics that I disliked so strongly. It was more the idea of choosing and sticking with a particular side. I prided myself on being a friend to all—a tolerant person who looked at issues logically and always found a middleground. Unfortunately, I would have to abandon my comfortable spot in the middle ground for this essay.

My inner monologue mumbled a groan. I had a deep-seated dislike for the “pandemic of ignorance”—as I called it; my idea was that too many people considered themselves professionals on a subject which they have little to no experience or prior knowledge about. *No one knows everything, so there's no point in debating unless you know all the facts.*

As my classmates lined up to submit their essay proposals, my eyes snapped like magnets to the piece of paper in my hand. They read and reread the rough draft outline that I had assembled over the past week. In bold, the top of the paper read “Topic: Health Care”; underneath: “stance: health care should be
free”.

In a nutshell, my thought process went something like this: *let’s choose the tamest, most boring controversial issue where no one in the class will find any reason to bring up a debate.* And I thought I did.

Although I was never a hardcore believer in any sort of health care system, I thought it was logical for health care to come without a price. *If other countries have free healthcare, why can’t we?* Somewhere in the back of my mind, a little voice told me that other countries have completely different circumstances; I silenced it before I started to doubt myself.

In any case, my essay topic was approved and I started to gather data. The mouse on my screen meandered from article to article with my sleepy eyes not far behind. I let the self-fulfilling prophecy of my viewpoint run its course—without a doubt, all of the articles that I thought were good enough to incorporate into my essay fought for the argument that, in my opinion, was right.

I decided to add one more article to my “pros” collection as my eyes lazily sauntered across my notes page, and; it was late, but I thought the evidence I had gathered thus far was mediocre at best. A few minutes later, I found a document that supported my claim, so my eyes lightly skimmed across its surface. They widened as I began to peruse deeper. As I read the article, a tidal wave of pride and awe washed over me. *This is why universal healthcare is not always the right answer.* I continued to integrate the article into my essay, checking my thesis against the article’s main points. I stopped. My eyes shot back. *Wait, this isn’t my claim.* I had read through an entire article (which I thought included the strongest argument so far), and I didn’t even realize that it was advocating against free healthcare. I reread the article to make sure I understood it correctly. *What now? Out of all of them, I agree with this article the most. Should I change my entire stance on the issue?* My eyes looked up, full of questions but shining with light. *I see now.*

Gone were the days of staying out of debates. I made it my mission to spread my epiphany like wildfire. No one was wrong in taking a specific side, they just generally had different fundamental values. Maybe I was late to the party, but I thought that what I learned was revolutionary.

Afterward, my eyes locked steadfast into another pair while I played devil’s advocate; I knew the girl’s views differed, but now I was ready to address them. We discussed health care reform as we started to months ago, but this time I held my ground.

We continued to discuss the issue until we heard the bell’s three monotonous chimes ushering us to class. A smile broke out on my face as I walked toward my next lesson—at the end of our discussion, the girl and I shared the same glint of joy in our eyes. *If she and I can respect each other and disagree, then what’s stopping the powerful leaders of the world?*

I continued to pride myself on not bringing up uncomfortable controversial issues where they were not needed, but now I could respectfully debate with people who did. My inner lens slowly shifted into a wider-angle shot: I allowed myself to be wrong. I finally saw.
My grandmother held onto everything. Mismatched silverware sets and dishes, dried up tubes of watercolor paint and crusty brushes, dozens of porcelain Yadros packed in water-damaged cardboard boxes. My favorite treasure sat on the kitchen countertop, a liter-sized jar of thick glass packed to its brim with Snapple caps. Each was washed carefully to dissolve any sticky residue and the fun facts remained original no matter how many times we read them. Burning compulsion melted as I pressed into a cap with my thumb, the click-snap indication of a broken seal always satisfying. The jar contained surprise, pleasant in its simplicity, sundry details, and meticulously (seemingly carelessly) composed did you knows. A collection of treasures crammed into a dusty container of rusted clutter.

My grandfather was a yeller. He called the cops on my father when my dad refused to move our family car out of the way to prevent his own dad from furiously driving home with my grandmother in the passenger’s seat. I woke up and heard the rumble of voices through my bedroom door and watched the police car pull up through my window. I saw my grandfather leave, eyes blinded by red visioned fury as his tires wailed and their car careened down the street.

Real Fact: They visit for you.

My mother tells me, her fingers curling against the curved backrest of one of my grandfather’s handcrafted rocking chairs. He gave my mother, his daughter-in-law, not daughter, a new piece of his carpentry in place of an apology for every regret that followed every lost temper. While some homes are cluttered with receipts, mementos, and never-to-be-read magazines, ours is scattered with oak coffee tables, cherry cabinets, and a hope chest given prematurely for my wedding day. His ghost lives in the fibers of presents given with an expectation that he would die before the occasion. Regrets and a bruised history are why we have so many rocking chairs.

I do not remember my grandmother before she faded. I was either too young, or she was too sick, so the memories that stuck were never shared. I am told I inherited her skin and I can clearly remember her voice but not her personality. She lived with my Grandfather even when she couldn’t recognize him anymore, and threw those mismatched dishes and silverware sets at his head. Eventually, it was recommended that she stay in a special care unit for dementia and Alzheimer’s. When she was separated from my grandfather, I saw him cry.

Real Fact: A fish can drown.

My grandfather was a simple man. Every pair of socks were rolled into careful bundles and arranged in rows like a pan of cinnamon buns. The hanging lamp above the kitchen table was a stain-glass dome. Every shard he meticulously soldered together to bring images of dragonflies and spring flowers ablaze with electricity. My grandfather changed after the separation from my grandmother. He visited my grandmother every day, arriving at her room before she was made ready for breakfast. He carried around a blow-up donut cushion with pride, grinned wickedly at my brother’s mortification when he proclaimed
it alleviated hemorrhoid pain. Losing her and still seeing her breathe triggered an outpouring of love. He chose my grandmother's urn and got one to match when he passed away a month after her. He clutched the pot to his chest as if he could feel her through the cold metal. Is it wrong of me to feel grateful for his love, so potent in the final years of his life, when it meant I had to trade knowing her?

Real Fact: While rabbits have near-perfect 360-degree panoramic vision, their most critical blind spot is directly in front of their nose.

I do not remember my grandfather before he bloomed and emerged from the mud, reaching to grasp sunlight through thick fingers. Or at least, I do not remember clearly. Potent images surface to my mind, but it's like swimming through murky waters or trying to see through a smoke fire.

I saw my grandfather die. My parents let me into the hospital room despite the nurse's warning. Children only remember the machinery: the tubes and the heart monitor, and forget embers of searing life. My parents insisted. I would remember everything. I will always be proud of you, I whispered to him and swallowed as he closed his eyes against a wave of tears.

Real Fact: Love hurts.

My grandparents' house was sold before they moved into assisted living. It was a contemporary home, built by my grandfather and packed with secrets and surprises. A curved staircase wrapped around a cylindrical wall littered with alcoves. The floors didn't match up to compensate for high ceilings and stairways that lead to single rooms. A garden surrounded the house, a tangle of ferns and cement statues, cherry trees, toadstools, and a cherub with red eyes boring into the driveway. Junk was difficult to sort. A handmade set of drawers infested with mildew was donated. A simple sketch made by my grandmother was professionally framed. I have no idea where the jar of Snapple caps ended up. Probably in a landfill. The ice tea bottles remained packed in boxes tucked away in

the basement-- their lips nacked and open, collecting dust without their caps. I cannot remember the last time I had a Snapple, but when I hear the click-snap of a cap, I can taste iced tea sipped with breakfast, sugar-free because they were both diabetic, or gulped to wash down sandwiches, hoagies, or burgers. Anyone could cringe at the syrupy tea, always peach infused and peppered with the sharpness of chemical additions-- But when I take I sip, I can't help but find comfort in something so consistently and resolutely, unwaveringly sweet.
Eponymous recognition of a physician is one of the highest honors in the field. There are innumerable diseases, devices, or procedures named after doctors and scientists who discovered or made invaluable contributions to science. From Alzheimers to Purkinje fibers, this ultimate honor allows physicians, their histories, and their contributions to endure the test of time. However, in the same vein, eponyms with unethical grounds allow the horrors of immoral physicians to persist. Hans Reiter was a horrific Nazi physician who was active in forcible sterilization, inhumane experimentation, and other horrible practices. However, early in his career, he discovered a syndrome which was subsequently named after him. Although the syndrome was officially renamed reactive arthritis in the 2000s, through the continued use of the name 'Reiter's syndrome,' Hans Reiter's tainted legacy has been sustained. The story of Hans Reiter and the syndrome that bore his name exemplifies the power of names and the systemic public forgetting of atrocities post-World War II. This case provides an example where renaming is justified as it helps terminate the legacy of Nazi cruelty, and examination of this case suggests reeducation and institutional changes are necessary to reach the goal of increasing morality in the medical field.

In the early 1900s, Hans Reiter was well-liked, diligent, and of high social standing. He was trained at the prestigious Pasteur Institute, St. Mary’s Hospital, and the Institute of Hygiene at the University of Berlin. Reiter shared the ideologies that were commonplace among his colleagues and social class: that the Aryan race was superior, and the perfection and protection of the race was the goal of any German physician (Zaller 2003).

During World War I, a young Reiter thrived in a boom in medical research (Zaller 2003). Wars have always provided doctors with a unique exposure to high quantities of data and practice, and medical innovations are often quick to follow. From the expansion of sterilization in the Civil War to the better understanding of post-traumatic stress disorder during the Vietnam War, wartime healing is strongly associated with medical advancements. It was through this wartime medicine—and Reiter's corresponding exposure to a multitude of diverse patients and ailments—that, in 1916, Reiter observed a connection between arthritis, urethritis, and conjunctivitis (Salako and Kalavala 2013). The syndrome is defined as this triad of these symptoms that occur after a bacterial infection (Wu & Schwartz 2008). The syndrome also often has dermatological manifestations, a key trait that Reiter never acknowledged (Salako and Kalavala 2013). In fact, Reiter was not even the first to observe these symptoms and their connection, and yet the condition was named Reiter's syndrome.

After the war, Reiter resumed his academic work (Zaller 2003). Bruno Gebhard, one of Reiter’s students, recounted Reiter as “the rare combination of a thorough researcher and a brilliant teacher” and noted Reiter attracted students from medicine, economics, law, and more to his very popular seminars (Gebhard 1970). Gebhard’s glowing review of Reiter illustrates his high regard in his field as the Nazi party began to rise in Germany.

Although active in politics and a believer in Nazi ideologies, the largest influence on Reiter's joining the Nazi party was Reiter’s interest in eugenics and the ability to carry out large scale experiments...
through the party (Gebhard 1970). Reiter quickly rose through the ranks and became the president of the Reich Health Office in 1937 (Ackerman 2009). When he entered this position, Reiter proclaimed one of his main goals was “to ensure that inferior genetic material will be excluded from further transmission” (emphasis added) (Zaller 2003). Over the course of his tenure, Reiter was privy to the knowledge and planning of not just involuntary sterilization, but also euthanasia, gruesome experimentation, and murder carried out in concentration camps and hospitals under the supervision of Nazi doctors (Panush et al. 2007). Reiter himself designed an experiment that inoculated the prisoners at Buchenwald concentration camp with an experimental typhus vaccine, which resulted in hundreds of deaths (Salako and Kalavala 2013).

After the war, Reiter was arrested, interrogated, and imprisoned for a time at Nuremberg. However, he was never convicted and was awarded early release—possibly by assisting the Allies with germ warfare knowledge (Panush et al. 2007). Both during the interrogation and for the rest of his life, Reiter continued to deny any part in administering any unethical experiments, even with extensive evidence that only became more overwhelming with time (Zaller 2003). Gebhard said in 1970 that Reiter wrote him a letter in 1962 admitting that “our German activities in the sterilization of persons with hereditary diseases” had occurred, exemplifying his clear Nazi involvement. Furthermore, Reiter integrated himself right back into the Western medical community after his imprisonment, continuing to lecture and publish. He gave the keynote address to the International Congress on Rheumatism in 1961 and at his death in 1969 was given the Great Medal of Honor of the Red Cross as well as a commendatory obituary in the Journal of the American Medical Association (Zaller 2003, Panush et al. 2007).

Reiter is one in a long list of Nazi physicians who committed horrible atrocities during World War II. In fact, the cruelty of these doctors was so horrific that Reiter doesn’t even particularly stand out among this cohort. Reiter may have just been a footnote in the history of medicine in the Third Reich if it hadn’t have been for his characterization of a combination of arthritis, urethritis, conjunctivitis as a clinical officer during World War I that was eponymously named Reiter’s syndrome (Wallace & Weisman 2000).

Reiter’s influence at the time of the naming led to the widespread acceptance of the name. In the United States, the first mention of the syndrome was in an arthritis textbook in 1941 and a journal in 1942, in an article by Dr. Walter Bauer and Dr. Ephriam Engleman, physicians at Massachusetts General Hospital (Altman 2000). In 2000, when asked about the use of the name Reiter’s syndrome, Dr. Engleman stated they used the name because they thought Reiter had originally described the syndrome, and that he did not know of Reiter’s Nazi past, saying if they had known “we probably wouldn’t have called it Reiter’s syndrome” (Altman 2000). Regardless of Engleman and Bauer’s intentions, the name continued to be used throughout the Western medical world for decades.

The first objections to the name came in 1977 when a group of doctors, learning of Reiter’s horrible history, suggested changing the name to reactive arthritis (Yurkiewicz 2019). The objection was brought up again in 2000 by two rheumatologists from the University of California at Los Angeles (Altman 2000). The doctors wrote an article on the topic in the January 2000 issue of The Journal of Clinical Rheumatology titled “Should a War Criminal Be Rewarded with Eponymous Distinction?: The Double Life of Hans Reiter (1881-1969)” (Wallace & Weisman 2000). The article outlined Reiter’s life and Nazi involvement and emphasized his relatively small contribution to the discovery of the syndrome, concluding that “Reiter does not deserve eponymous distinction” (Wallace & Weisman 2000). This publication was followed up by news coverage, articles, and letters to editors urging for the official renaming of the disease.

In 2003, Dr. Richard Panush, Dr. Diana Paraschiv, and Rabbi Elliot Dorff published an extensive article in Seminars in Arthritis and Rheumatism strongly advocating for the name change and removal of Reiter’s syndrome from medical literature (Panush, Paraschiv & Dorff 2003). Their argument was anchored in the Hippocratic Oath, which Reiter clearly broke, thus they argued, Reiter should not be honored through this eponymous
label (Panush, Paraschiv & Dorff 2003). The authors pointed out that the precedent of retroactively removing honors on moral grounds had already been set with Nazi doctors like Pernkopf, Hallervorden, and Spatz (Panush, Paraschiv & Dorff 2003). The paper's final argument stated that Reiter's syndrome should no longer be a part of the medical lexicon and “should be expunged altogether” (Panush, Paraschiv & Dorff 2003).

In 2007, Panush and Rabbi Dorff of the 2003 article, Wallace of the 2000 article, and Engelman (one of the first to publish the name in the United States), all came together and wrote an article published in the *Journal Arthritis and Rheumatology* (Panush et al. 2007). This article was an official retraction of the name Reiter's syndrome and a call for its replacement with reactive arthritis (Panush et al. 2007). The brief article concluded in saying “medicine is a moral enterprise,” and thus, since Reiter was responsible for unethical acts against humanity, he should no longer be recognized via this eponym (Panush et al. 2007). This outcry from the community led to the official retraction of the name in 2009, and its replacement with its current official term, reactive arthritis (Zaller 2013).

Over the course of this campaign, a 2005 study found that use of the eponym in medical journals dropped from 57% to 34% from 1998 to 2003 (Yurkiewicz 2019). Although this drop is encouraging, with pushback against the name starting in 1977—and the official change not coming until 2009—the medical community’s response was a bit slow. Furthermore, papers in the past few years continue to be published using the name Reiter’s syndrome instead of reactive arthritis. In 2016, the article “Bilateral disciform keratitis in Reiter’s syndrome” was published in the *Indian Journal of Ophthalmology*. The author only mentions reactive arthritis once saying “Reiter’s syndrome (RS) also known as reactive arthritis” (Suresh 2016). A simple pubmed search further reveals a number of articles published in 2018 and 2019 with Reiter’s syndrome in the title or mentioned throughout an article.

The story of Hans Reiter and Reiter's syndrome falls in line with the theme of systematic forgetting, which manifested after the atrocities of World War II. There is no question that Reiter knew about and committed horrible acts under the Nazi party. Similarly to Eduard Pernkopf, who continued work on his studies for the rest of his life, or Kurt Waldheim, who became President of Austria after working as a Nazi intelligence agent, Reiter was able to live a long and successful life even after the brutalities he committed earlier in his life (Panush, Paraschiv & Dorff 2003, Zaller 2013). Through this eponym, however, Reiter has been able to live on beyond his lifetime, and Nazi politics continue to be entangled with modern day medicine.

While one would hope the substitution of a single syndrome name would be able to occur in a short timeframe, names hold a lot of power, and there has been considerable pushback against the renaming of Reiter's syndrome. The first argument against the name change is simply the convenience case, where the name change could be confusing for doctors (Yurkiewicz 2012). In another instance, a case has been made about the fact Reiter's was never convicted for his Nazi involvement, contending guilt by association is not grounds for removal of the name (Zaller 2013). Finally, a point has been made that this name change could set a precedent for a total overhaul of medical eponyms and awards, as the Nazis are not the only organization to practice inhumane medical experiments or euthanasia (Zaller 2013). This case also reasons that many physicians have performed executions for cases of Capital Punishment without penalty, and a passionate minority of doctors believe abortions are forms of murder, which doctors regularly carry out (Zaller 2013). Thus, this argument proposes if Reiter’s name should be changed, should the public, or medical professionals, go back through medical history and strip hundreds or thousands of physicians of honors and eponyms?

In response to these arguments, it is important to remember the original naming of the syndrome as Reiter’s was in itself a political act. The naming was only accepted and only became so widespread because of the power Reiter possessed via his Nazi connections (Zaller 2013). Thus, the name Reiter’s syndrome stands for more than just Hans Reiter, but also the power, influence, and horrors of the Nazi party before and throughout World War II. As
for the eponym reexamination argument, why not erase connections to appalling politics, unethical physicians, and breakers of the hippocratic oath, when the community has a chance! An entire overhaul of all eponymous distinctions may be beyond the scope and breadth of any individual or single group of physicians or ethicists, but clear instances of inhumanity, like this one of Reiter’s syndrome, should be addressed and change should be instituted. In fact, this practice should be institutionalized, perhaps by a committee or organization of ethically-minded physicians who could oversee the examination and potential renaming of unethical eponyms.

Now, 10 years after the official retraction of the name Reiter’s syndrome, the unethical implications of the use of the name remain, articles continue to be published, and new generations of physicians continue to learn about Reiter’s syndrome. The solution to discontinuing Reiter’s syndrome’s atrocious and unethical legacy is through education. The answer is not total censorship, as that would erase this entire struggle and the ethical analysis behind the renaming of the disease. Instead, the tale of Hans Reiter and this syndrome should stand as an example for future generations in medical ethics. Reiter’s name should not be used in publications or as a characterization of reactive arthritis, and if medical textbooks include the former name Reiter’s syndrome, the reason for the name change and a brief mention of its ethical implications should be included. The focus of the medical field should always be on healing, but the termination of enduring legacies of awful individuals or ideologies, like Hans Reiter and Nazi atrocities, should always be justified.

References


Revelation Days:
Stories of Suffering, Resiliency, and the Demands of Justice

Justin Schnebelen

Pine Ridge Indian Reservation, a place sometimes referred to as Prisoner of War Camp #334, or the “Rez,” has been home to the Oglala Lakȟóta—a word which means “friend” or “ally”—since they were removed from their native lands during the period of “Manifest Destiny.”

This epoch of rapid western expansion was primed by the appropriation of native lands, seizures which paved the way for the spanning of the Transcontinental Railroad right through the heart of the Lakȟóta homeland. Meanwhile, US Army Officer George Custer discovered gold in the Black Hills in 1874, leading to an inundation of the area with white settlers who began to kill, wholesale, the native buffalo population—a fundamental source of food, clothing, shelter, and spiritual connection for the Lakȟóta. Despite vanquishing Custer in the Battle of Little Big Horn and in numerous other battles, with new U.S. decrees like “sell or starve,” the Fort Laramie Treaty and its protection of native lands grew obsolete. With destinies to fulfill and riches to reap, America quickly confiscated the land. We were tired of sovereignty, we were tired of Ghost Dances, we were tired of sacred hills, we were tired of the Lakȟóta.

Later, the Dawes Act of 1887 fed the Lakȟóta the “American Dream” of individual land ownership, abasing their communal, collectivist identity by cunningly dividing the reservation and handing ten million acres of it to rich, white ranchers—who, to this day, own 95% of cattle present on the reservation, according to a leader from the Thunder Valley Development Community.

Inspired by the Church-endorsed Doctrine of Discovery, boarding schools then separated children from their families under the axiom “kill the Indian, save the man.” In order to rid the Indian of his or her personal value and sense of being human, the student was stripped of her name and conferred a number instead. They were just digits in an indiscriminate mass. Mere animals to be herded, “savages” to be “civilized.” Many were sexually abused by clerics. Moreover, schools prohibited children from speaking their indigenous Lakȟóta language. With no language to pray, the spirituality which gave their entire life significance was lost. Their vision and hope was destroyed. And today, etched among the granite spires of those Black Hills is now the faces of four American presidents who presided over the dismantling of their sacred lands.

Wasichu invasion decimated their way of life, leaving the Lakȟóta to cobble together leftover shards of their identity. The Lakȟóta word wasichu refers to all non-Indian peoples, but another version of the word, however, means “the one who takes the best meat for himself.” It means “greedy.” And after my time on the Rez, I discovered that truly we have taken the best meat for ourselves. That when the myth of American history and its relations with Native Americans was unveiled, I found the visage of genocide vile and distressing. Which may be why high atop the water tower of Oglala, a tattered American flag wails in the plains wind—upside down.

In these pages I will begin to tell the stories, in my whiteness, of being red; of those who have been deprived of their voice, who endure in the want of sustainable economics, who suffocate in the grasp of alcoholism, who persevere through paralyzing trauma. I will begin to tell the story of their spirituality and culture which provides an alternative way of seeing compared to our predominant liberal American model. And more than anything, I will
begin to tell the stories of those who walk amidst the rubble of their own way of life.

Because of its vast area, the remoteness of living situations, and absence of any real public health services, to name a few, validating statistics on the Rez is incredibly problematic. Nonetheless, some estimates gather that life expectancy for Pine Ridge's 40,000 or so tribal members hovers around 46 for men—the lowest life expectancy in all of America, and on par with countries like Iraq and Somalia. Half of the tribe is 18 years old or younger, and many young girls get pregnant by the ages of 14 or 15. Rape is ubiquitous. Children are born into the dereliction of dilapidated trailers and deteriorating homes with battered, exposed, and sunken-in structures. One-third of these have working electricity. Many go without running water, and those that do, they drink and bathe in the same water said to be rerouted through a northern bordertown's sewage line—a line tested over 120 times to be infested with dangerous levels of arsenic, a poisonous chemical.

Oglala Lakota County has the lowest per capita income ($8,768) of any county in the United States. A 2005 U.S. Department of the Interior data publication recorded an unemployment mark of 89%, and has since ceased from publishing employment data on the Rez. At small businesses, organizations, or churches like Our Lady of the Sioux in Oglala, hours are scarce and many can only afford to allot 12 hours for every two weeks. Tribal members I spoke with working for the Bureau of Indian Affairs lamented the devastating five weeks they went without pay during the latest government shutdown. The Lakȟóta understand one of the only way routes to a modest living means working for the government—most often the military.

During my time I worked with a kindhearted man from the Oglala Housing Development just down the road, removing snow fences, repairing shattered windows, and escaping our duties to take drives through town. He graduated from Pine Ridge High School at the age of 15, and, hoping to evade the snares of booze and trouble, appointed his drunken brother to sign his enlistment papers for the Navy soon after. When he noticed his training began to incorporate more close-quarter street fighting, it wasn't long after that he found himself on a boat in the Persian Gulf. 17 people from Oglala, which is essentially the size of a suburban neighborhood, were deployed there. Only 9 are still alive—the rest have killed themselves. After returning home from Kuwait for a stint, he was deployed as a FEMA relief worker in New York City on the morning of September 11, 2001. He remembers his ex-wife thinking that his sudden departure was a cruel joke, all the way up to the moment her husband slipped through her fingers and she watched him board the plane east towards the crumbling towers. Staring out over the cratered hood of a hail-damaged Chevy, he recounted images of mangled people, fingers and toes strewn along the ground and the bare skin of a dismembered torso tattooed by the melted metal of his NYPD badge.

Years later he was blasted several feet into the air by a roadside IED in Afghanistan. Though he's since relearned how to walk, every day he struggles with PTSD and with the triggers that remind him of the trauma, of death. His memories are one chip in a wide mosaic depicting how trauma, and, in turn, strained family life, are the deeper scars of militarism and depleted economics. How when America has gone to war, so has the Lakȟóta.

The other option, of course, is abandoning family and the reservation to work in bordertowns, principally Rapid City, SD, which lies an hour and a half north of Oglala. Rapid City, like many towns bordering reservations across the country, is considered among Lakȟóta to be deeply discriminatory. In addition to alarming disparities in access and quality of education, housing, and nutrition, numerous civil rights complaints have underlined discriminatory treatment by law enforcement and administrators of justice (U.S. Commission on Civil Rights). As one Lakȟóta elder
told me, in a place where families of upwards of 15 people live together in one cramped trailer, “the power of family is too strong” for their people to live disconnected from their homeland; in fact, most who do leave eventually return home. Nonetheless, deprived of access to work, a very basic human right, Lakȟóta people are deprived of a why, a vocation, a way to transform their lives, a reason to live. Many turn to the bottle to fill this void. Though the reservation is “dry,” bootleggers and bordertown alcohol vendors boom. Drunkenness is overwhelming at all hours of the day. With no work, many are indentured to the bottle and other drugs like methamphetamine (often despite being pregnant), leaving children neglected or in the care of their grandparents and sober relatives. Apathy, which can at times be a necessary coping method, is pervasive and numbing. Approximately 85% of families experience alcoholism on the reservation, and 1 in 4 children are born with Fetal Alcohol Syndrome. Tribal members spoke of the immense pressure to drink, even as children, to fit in socially, while others pointed to it also as an escape from a despairing reality, inundated with alcohol and drugs. Some children simply begin to drink by imbibing the remainder of their passed-out parents’ bottles.

The implications are devastating. Estimates say about 8 in 10 people experience substance abuse or violence in the home. The deterioration of family life rages on, outmatching the measly sum of 5 mental health professionals to care for them, particularly teenagers. With a school dropout rate of 70% and teacher turnover 8 times higher than the national average, the education that could be an escape, that could liberate, is powerless.

One parishioner of Our Lady of the Sioux fell fateful into the abyss of alcoholism too. Effectively vacating the life of his son, his boy only knew an inebriated world and a father drawn away by the bottle. And one night, while he drank with other friends, his son strung himself to the ceiling fan of his room—just outside where his father was drinking. He wasn’t found until two days later.

Another morning earlier in the trip, amidst a driving rainstorm, I travelled with a Lakȟóta elder to pray at the site of the 1890 Massacre at Wounded Knee. Through sludge we trod to the elegy of rain, thunder, and mud smearing under our shoes. It was here at Wounded Knee that his ancestors were slaughtered by Major Samuel Whiteside, commander of the U.S. 7th Cavalry, who surrounded the Lakȟóta in the snaking gullies as his men, their fingers coiled around new military test weapons, called Hotchkiss guns, perched high in the hills above. His crew opened fire, the rapid-fire, revolving cannons cutting down over 300 unarmed Lakȟóta—a large majority of them grandparents, woman and children. They were research subjects in the science of erasing life, and doing it as quickly as humanly—or inhumanly—possible. American soldiers eviscerated the Lakȟóta women sprawled and stacked on the snow, mutilating their breasts and carrying them off as war trophies. Left overnight, a blizzard froze the mangled dead in grotesque poses. 20 Congressional Medals of Honor were doled out for the 7th Cavalry’s “valor,” the most of any single “battle” in American history—more than WWI, WWII, Korea, Vietnam, Iraq, and Afghanistan. The
late Lakȟóta Holy Man, Nicholas Black Elk, who witnessed the massacre, is translated in Black Elk Speaks, mourning, “I can still see the butchered women and children lying heaped and scattered all along the crooked gulch, as plain as when I saw them with eyes still young. And I can see that something else died there in the bloody mud and was buried in the blizzard. A people's dream died there. And it was a beautiful dream.”

Atop the hill, though his mouth was open, he couldn’t speak, and I sensed his throat—like sinews of a rope—tighten. He peered into the darkness of the sky, and his tears, falling, merged with rain.

“You only know what America tells you.”

The centuries-long pressure of poverty, oppression, and genocide, examined crudely here, has, in its long, grueling work, eroded their voice and degraded their freedom. They are molded by economic and cultural domination which has insisted, both subliminally and explicitly, that they were and are “savages.” Their collective agency has been suppressed, and, hopeless, many feel like spectators to a destiny which never involved them. And in a capitalist society, who can blame the 89% plundered unemployed for capitulating to the erroneous cultural suggestion that joblessness means uselessness, and uselessness, meaninglessness? Let the sinless one among us be the first to cast the stone.

Living in the squalor of a reservation, being labelled as the “school shooter,” being watched with suspicion in a store, your wife’s perfume reminding you of napalm, car exhaust of Chinese concentration camps, living on the battlefield where your ancestors lie buried, or seeing the faces of your oppressors scored, like idol gods, along the stone of your sacred hills in the distance—this crucible produces an effect that is truly immeasurable and utterly inexplicable. And when transmitted generationally, these wounds on each Lakȟóta heart manifest in haunting trauma, in excruciating pain—more agonizing than any statistic ever can capture. Generational trauma seems to be this erosive work, this depletion of spirit, on a collective heart. It is the handiwork of a provisional existence where the future is uncertain and it is impossible to gauge when, if ever, this form of dehumanizing existence will end. An existence which impelled one Lakȟóta elder to ask sincerely, laboring to get into the car to celebrate Sunday Mass: “Are these those Revelation days?”

Few Are Guilty, All Are Responsible

No history book accurately captures the trauma and devastation of American colonialism. Living with them and listening to their stories is the one true pedagogy. A pedagogy of how the past can bear decisively, even against one’s will, on the now. And as a white, American male, this education leads me to insist that the reality of life on Pine Ridge must evoke a reckoning. That when we, as a nation, stand before God, we will have to answer to our history.

So, for the sake of human rights, the demands of justice, and our own penance, America must transition from its oppression into an epoch of restoration. If we cannot redress our wrongs and remove them from the very tree we crucified them to, we as a nation can never truly call ourselves free. We can never truly speak of justice. We can no longer be the nation we claim ourselves to be. How long must our brothers and sisters live imprisoned and dehumanized, reserved from the vitality of a dignified life? The question is really life and death. Meanwhile, America’s liberal model is revealing its limits on Pine Ridge. As the spokesperson for the tribal president said to me, “Give your capitalism, your western civilization, another look. It doesn’t work here.” But if we let the Lakȟóta speak to us, every American may find how the Lakȟóta’s own spirituality and social ethic can enrich new ways of seeing relationships between individuals, among society, and with God. It is by listening that the dream will rise again.

The Lakȟóta phrase mitákuye oyás’ini is the bedrock of Lakȟóta Spirituality and means “we are all related.” The understanding comes from the Lakȟóta belief in the respect and sacredness of all things, and that the divinity is infused within every particle of creation. Each creation, then, is spiritually equivalent to human persons in dignity and shares a common heritage of divinity. They see themselves
as inherently dependent upon the land, water, plants, animals, and all other things for their existence, and those, in turn, depend on them—their lives are in accord with the earth. Because for the Lakȟóta, full humanization is discovered outside oneself in the significance one feels as an indispensable piece of the great web of cosmic existence. Consequently, eagles are sacred creatures for Aboriginal peoples because they, who reach greater heights than any other bird, can see the relatedness of the world. Their cornerstone of wóunkila, kindness, compassion, and mercy, is why picking up hitchhikers is expected, and why families distribute money among themselves to survive. In what they would call a spirit of wačháŋtognak, or generosity, their love is exemplary. When one Lakȟóta elder’s daughter called and revealed that her husband left her, stole her purse, and now has nothing left, she called me to take one of her only—and most culturally sacred—possessions, a star quilt, and sell each one she owns without a second thought. These truths fly in the face of American individualism which, rejecting the orders that conferred significance and transcendence in a charged world, has turned disenchanted. While Lakȟóta prophecies tell of the unification of all the peoples under one sacred “hoop,” meanwhile, America has grown mute, unable to speak about cultural values, moral horizons, and collective vision. Bodies are cheapened and commodified for the media and marketplace, and the environment is raw material—instruments for our projects. We care less. We live for ourselves. Depersonalized and disconnected, with income inequality widening to its greatest lengths ever, border walls being erected, and nuclear weapons tested and armed, we are less concerned with the well-being of others. And while the Lakȟóta believe in a socio-centric self embedded in a world erupting with ineffable Spirit, in our model powerlessness cripples, nihilism demoralizes, and resignation to the status-quo—the sense that things cannot change—shackles. Ultimately, no way of seeing, even the Lakȟóta’s, is perfect; but what could we learn? What we might find is that in the truths of the oppressed lies our own salvation.

To the Lakȟóta, no action, however disharmonious to the totality of the community, can ever be deemed irreconcilable. They insist humans are fundamentally good, and so, unlike the American criminal justice system, no person is disposable, and peace never unachievable. Seeing justice like the Lakȟóta requires seeing justice—and the universe—relationally. It requires seeing that equality, harmony, brotherhood, and kinship among all peoples is the natural order. This restorative alternative can challenge our reigning model of retribution by actually engaging power dynamics and the core of abuse and trauma, seeking to heal relationships now infiltrated with diseases of mistrust and fear, rather than punishing and burying them. While retributive justice should condemn us to death for our centuries of racism and hatred, restorative justice holds out hope for reconciliation. Though the centuries-old scars of oppression may take many more centuries to heal, ultimately, these ethics of relationality, interconnectedness, and healing can not only frame the Lakȟóta’s liberation, but also makes America’s own healing possible. Lakȟóta justice leaves the light on so that, amidst the darkness, oppressor and oppressed might rise and return to encircle the warm hearth of brotherhood.

In all, life on Pine Ridge exhibits this truth—that in addition to the inhumane conditions, our system of oppression, merely probed here, is revealing our nation’s failure to satisfy one’s most intrinsic right: the right to be fully human.

And so the American is an inheritor of this brokenness, and though you may not have pulled the trigger of a single Hotchkiss gun, you are still responsible to own the shadow which now hangs over Pine Ridge. This history and present reality is our problem, this is our responsibility, and the only thing worse than our history of oppression is our ongoing indifference. Thus the first step to restoration is caring enough to experience a true awakening to the truth that our ancestors crucified this people, our brothers and sisters, and that because our humanity is bound in kinship to them, our own hearts need healing. We must awaken to our identity as the “them” in Christ’s last words: “Father, forgive them, for they know not what they do.”

We know not what we do. We know not the truth of the remaining prisoner of war camps in America. We have not beheld the bare bones of when the best
meat has been taken for ourselves. For determined to kill all that is Indian, we are determined to kill ourselves (Brown). And only through forgiveness can all be born again.

One afternoon as I drove under the outstretched sky, I approached again the site of the Massacre at Wounded Knee. Tumbling over the land rumored to contain a mass burial site of countless women and children, my tires headed down towards the gulch where bullets from the test-guns were hurled. Where a dream had died. I imagined the chaos, the squealing of horses, rising, bucking, falling. There was no one at the gravesites, no one peddling art trinkets in the parking lot. All was quiet.

But as I continued further on the road, I noticed a man straddling my lane line who appeared to be walking towards me. His thumb was not outstretched, and he did not appear like he needed a ride. As I got closer, time slowed and I began to make out a man strutting in black, a red bandana sealed tight over his mouth, a flat bill cap cocked sideways, black sunglasses draped over his eyes. He stopped. I froze.

And suddenly he raised his arms like he was coddling a rifle, peering down a barrel which aligned straight through my brain. I stopped breathing for a moment, for several moments, for a minute. I don’t remember. I rounded the bend, looking in the mirror as he held that pose until I disappeared into distance.

I still reel from this moment.

What if the imaginary gun was real? Maybe these words wouldn’t be here. By retributive standards, wouldn’t I, the wasichu, the one who for centuries has consistently taken the best meat for himself, have deserved it?

Something tells me he was just observant, attentive, astute, learning from the way his oppressor secured her own “destiny.” Maybe it was just a little imitation.

A little performance of what it might be like to be Lakȟóta: a gun aimed towards your innocent body as America asks, “So you want to be Lakȟóta now?”

References


Bloody Hands

Rayland Van Blake II

A small light illuminates
the face of a bright boy consumed
by a billowing sea of black.
His metronomic pace
down that murky street, steady like the
hand gripping the phone in his sight.

Shadows wait for the moment, their chance to prey
upon the light resting within his hands.
Makes no difference if
Mom prayed for his deliverance,
maybe it was ignorance that
brought him there to begin with.

A starless sky opened up and wept
for the soul of a boy begging for lies,
staring at that light looking for life—
A reason to live.
He quickens his stride
and continues his advance.

Snapped out of his trance
by light’s inherent transience
he looks into the swelling abyss.
Shadows erupt in envy, lunging
at that seductive light shining bright
on the deadly.

He takes a right at the deli
on the corner of his block
and froze.
Face to face with the
barrel of a glock he knows
like the back of his hand.
Because behind the grip in his palm
stood a man, smirk strewn
across his lips that could chill to the bone.
The eyes staring back, filled with hate, were his own.
If he could send just one more text
before he’s finally alone
he’d tell the world that he couldn’t wait
until dawn. Make it clear before he’s gone
that it couldn’t be stopped.
He was already lost even when the lights were on.
For Roelf

I
Leisure time

Even if I own Starbucks
at all airports and shopping malls
rivers stream with chocolate milk
volcanoes erupt with tons of prime steaks
ravines fill up with millionaire's pasta,
you won't be joining me ever again
and your favorites will taste like nothing.

Even if I sleep every night
with just another man or ten at once
anoint the masses with gallons ylang-ylang oil
from planetwide sex shops
but you're not breathing beside me
and I can't touch you,
it leaves me nauseously cold
just a piece of aching flesh
without any love.

II

Paraphernalia

But now
I'm done with the objects of
a cancer patient
no longer staring at bottled morphine,
pain plasters and ostomy bags
no longer searching for adult nappies on sale.

Eventually I saw
how faith, hope and love really are
and thoroughly know
the greatest of all:

metastatic loss.
always thought C was

a six-pack cartoon giant
slashing down
The Wall of Shame
his superhuman biceps
a respite from The Bold and the Beautiful
and marketing bling
He-Man and the Masters of the Universe
CAN
defeat everything

or a cuddly creature of the Association
hopping around at a thousand school assemblies
with strange little things on his head
The Wise Beetle says: “Children, please mind the sun!” –
magic lotion in his boxing glove
a rainbow of charity stickers on granny’s door

or a zodiac sign in Cosmo
or People Magazine, popular futurology
below a clumsy little crab:
One day your perspective will change forever,
keep the faith, adult knowledge will follow soon…

CANCER is

pleading bones in isolation
stinking scarecrow friend of mine
beeping decay
On one side,  
A void.  
Thoughts so dark,  
Like the pitch black night.  
Not a single star  
In sight.  
Not even the moon  
To guide your way.  

Cynical.  
Judgmental.  
Morbid.  
Pessimist.  

To be arrogant,  
Looking down on others  
For not seeing  
The World  
For the Evil  
That it is.  

How can people  
Be so naïve?  
To think  
The best  
Of humanity?  
To assume  
We are inherently good?  

Fools.  

There is  
No True Good.  
Only lies  
And manipulation.  
Craving of attention,  
Not altruism.  
Only hurt
And Yet.

On the other side,
   Light;
   So much of it.
Nearly blinding,
   It is so bright.
Colors,
   And vibrancy,
like the World
   Blossoming;
A perpetual Spring.

   Playful.
   Accepting.
   Content.
   Optimist.

   To be loving
   And open
To a World
   So full of
   Possibility.

   To roam freely
As when we were children.
   To love and care,
Embrace and rejoice,
   Joke and play,

   Without Fear.

   To let in all
That there is
   To be offered
By humanity;
   And to allow ourselves
To feel it all.

   To deny
All parts of ourselves,
   All parts of the world,
Is to never
   Truly
   Be
   Happy.

   If I am
To survive
   In such
Unpredictability,
   I must
Find Love
In all its facets.
I must
Protect
The Light.
Resilient.
Brave.
Compassionate.
Liberated.

Two sides.
I look one way,

See Darkness Visible.

I look the other way,

See Sunshine Eternal.

And yet,
I cannot choose.

Am I Evil?
Dark?

Or Good?
Or Light?

Who Am I?

This side
Seems so toxic.
Should the choice
Not be obvious?

This side,
So beautiful.

A confusing,

I think not.

I do believe

In such

crazy World,

In fact,

I like it

Here.

Dead.
Center.
The Waiting Room

Stephanie Robinson

Six Desks
   Six single chairs

Three Tables
   Six 12 Lamps
   two bulbs a lamp; 12 x 2 = 24 bulbs

1 TV, and eight hours of time

Wood paneling everywhere. pecan stain
I hate the color.
The more I stare at it the more it stares back at me, (into me, my broken body)
Once posh, upscale and varnished interior, meant to reassure “of course we know what we're doing, just look at our modern design”
Now a taunt.

It’s the same color as my high school auditorium paneling.
A place of assemblies, of meetings, of waiting,

How could an inanimate wall taunt me? My brain rots and tortures itself
Or maybe I’m impatient (im a patient now). Can’t occupy myself. Anxious. Scared.

Third floor.
   13 boxes of tissues   13 bottles of hand cleaner
   ten ceiling lights

waiting
I have recently become fascinated by the concept of entropy, as it parallels the constant change and chaos we encounter in life. In my work, I explore a period of change in my life through an inner psychological evaluation during these chaotic times. Events such as the pandemic and coming out have stirred up novel and unique feelings, my self-portraits investigating the complexities of who I am through expression, contradiction, and a distorted reality that lives in my head. Complementary colors, abstracted forms, and dynamic brushstrokes serve as expressions of conflict that I have experienced. Flowers represent the happiness I have found in embracing change: glimpses of beauty and hope amidst otherwise disorderly landscapes. My work demonstrates a creative process that has become more expressive and reflective, rather than planned and structured, focusing on the use of complementary colors and contradictory styles. This past year, my method of external exploration and observation has become internalized, looking within myself to find inspiration.
Q: How did you begin creating abstract art?

A: “Growing up, I really enjoyed art as a hobby and used to draw photographs that I took. Old school artists kind of frowned upon painting from other people’s images because photographers set up their own composition and tell a story, so I took and painted my own. I struggled with abstract art at first because I didn’t know how people came up with the ideas in their mind. I felt as though I didn’t have enough life experience to convey the abstract concept of life and always went into my pieces with an end goal in mind. I struggled with a mental block but when I took a class at BC called “Pandora’s Box”, I was introduced to a completely new perspective. The class focused on different archetypes found in folktales, mythologies, and all kinds of stories- showing me that you can get inspiration from anything. I used to be too focused on putting meaning into my work rather than deriving meaning from it. I learned that it’s totally fine to get to a blank canvas and do whatever you feel compelled to do then take a step back and make connections afterwards.

Q: What inspired you to switch up your artistic style?

A: “I had been thinking a lot about a state of ‘in-between.’ Daniel Caesar (who is one of my favorite artists) came out with a song called ‘Superposition’ about entropy and the complexities of life. Superposition is used as a metaphysical term to describe a point in time where someone is both alive and dead… like an in-between state. When I heard this song and read more about its meaning, I really wanted to explore what that meant visually for me. I know there’s life and death, serenity and entropy… but what is in the middle of those? There’s a quote from a Greek philosopher, Heraclitus, that says “the only constant in life is change.” With the emergence of the pandemic last year and my recent coming out on my mind, I really had to accept that there was so much change in my life… the in between of my superposition. My art kind of shows me going with the flow of change and embracing it.”

Q: Can you tell me more about your piece “The End?”

A: “‘The End?’ Is kind of like the end of a story… except it’s not really the end. In this piece, there are two people at the top of some canopy or mysterious forest that you would see in a folktale, looking into the horizon. The concept of time is inconspicuous and their surroundings are a bit ominous. Are the people aware of this and ignoring it? Despite the uncertainty around them, they seem relaxed with one of them pointing to the future in front of them. Instead of cowering in terror from what seems to be the end, they have confidence in the face of fear and change. It isn’t the end, but rather the start of a new beginning.
This past year, I have appreciated being able to work with different mediums that push me to explore my art and express myself in various ways. I mainly work with acrylic paints as my primary medium in which I enjoy the freedom and opportunity that a fresh white canvas provides. The harsh strokes, earth tones, complementary colors, and lack of a specific structure allows me to paint however and whatever I want. Painting has been a therapeutic outlet for me to unleash my creativity, especially how I am feeling in the moment, and also how I may have felt at a specific moment in time in the past when I try to recreate that feeling or place. I relish in the agency I have to put my brush to canvas and see what happens when I let myself go, which is why abstract art is my go-to genre. My self portrait was an exploration between flat and harsh surfaces. I struggle with painting realism and this project was a welcome challenge for me. On the contrary, tattooing people requires a different kind of focus; one that is detailed and meticulous. The stakes are higher, since I am altering someone's body permanently, and these people come to me for something very specific. I change my approach to my art when it comes to tattooing because it doesn't just involve me and my brushes, for example. It involves other people and it becomes a collaborative process with the person I am tattooing to ensure that this is what they want. I practice tattooing with informed consent, meaning that I ask questions throughout the session to check in and ensure that there is clear communication throughout before putting anything on or touch one's body.
Q: How did you start tattooing?
A: I got a stick and poke in July during quarantine. 2020 was the year of ‘yes’ for me- the year before, I left school, went home, and went on a mental health journey. I realized that our time is limited so I’ve been trying to be more open in saying ‘Yes’ to everything. Covid limited a lot of things we could do so I really wanted to take advantage of the things I did have control over - like getting a stick and poke!!” When I came back to school in August, I started practicing on grapefruit from lower, ha. I actually got some business inspiration from TikTok- I found a girl on there who was willing to give me some advice which was very helpful and then I started the process: buying materials, doing research, setting up appointments. I tried to do it a couple times a week for practice.

Q: Who were your main ‘customers’ when you first started?
A: The people most willing to get stick and pokes were mostly queer POC’s, actually. I found them to be more open and receptive to the idea than other people generally were. Something that’s really interesting actually is that ink heals differently on different people and tattooing needs to be more intersectional than people realize. I had been practicing on various different shades without noticing and was happy that people trusted me to tattoo them. Now, I have been able to meet and tattoo a bunch of new people. It’s definitely an intimate experience and different than the usual “hang out.” I’m with people for longer periods of time because I like to make sure they’re comfortable and like what’s going on in their body for everyone to have a good experience. I’ve also been able to make connections with people outside of the BC community.

Q: Tattoos aren’t your only form of expression; can you tell me more about your painting “Anguish”?
A: It was inspired by another hate crime turned into people’s own benefit. I didn’t know how to react to the news of the crimes committed against the Asian American women in Atlanta other than really wanting to paint something for myself; I wanted to respond to this for me. I didn’t know how to talk about it because it had just happened. The process for this painting was really important to me: I had a sketch and wanted to finish it in one go. I went into the studio at 8 and finished around 10. I’m usually a perfectionist when it comes to art but this time I just developed it as I went. As a queer Asian woman, this very much so represents how I was feeling at the time. I was affected by the heartbreaking news and needed an outlet for myself to process. At first, I wasn't going to share this with anyone but I then thought this would be a good opportunity to create a platform for conversation. I called it ‘Anguish’ because of how powerful of an emotion and word it is. I came up with it as I was painting: a word to reflect the deep sorrow and hope I was feeling at the time. The eight arms represent the eight women (Xiaojie Tan, Daoyou Feng, Delaina Ashley Yuan Gonzalez, Paul Andre Michels, Soon Chung Park, Hyun Grant, Suncha Kim, and Yong Ae Yue) with a yellow background representing hope. I usually paint activist paintings and this isn’t my usual abstract style, but this was very personal to me. I am Asian American. I am a woman. I am a queer Asian American woman. I just kept on adding on the layers of my identity.
“Anguish”