THE MEDICAL HUMANITIES JOURNAL OF BOSTON COLLEGE

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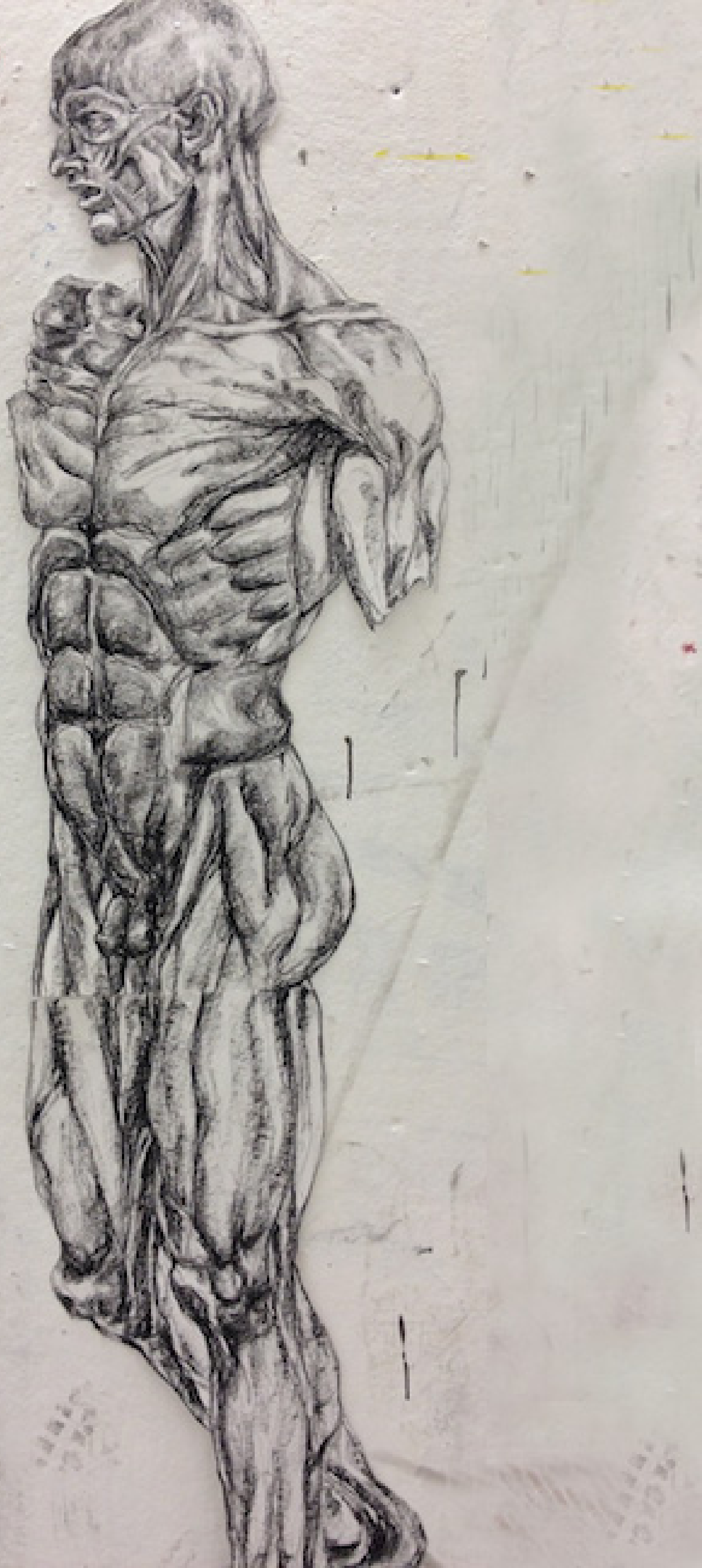

MISSION STATEMENT

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.

THANKS

We would like to thank Boston College and the Institute for the Liberal Arts for the financial support that made this issue possible. We would also like to thank Amy Boesky, the director of the Medical Humanities minor, and Rachel Ernst, the graduate assistant for the Medical Humanities minor, for their support and work on this his inaugural issue.

QUESTIONS & CONTRIBUTIONS

If you have questions, please contact the journal at **bc.mhj.1@gmail.com**. Visit our website at **www.mhjbc.org** for more information about submissions and an online version of the journal.

COVER

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LOGO

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***The Medical Humanities Journal of Boston College*, Volume 1, Issue 1, Spring 2015**

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MEDICAL HUMANITIES JOURNAL STAFF

EDITORS' NOTE

"We tell ourselves stories in order to live."
–Joan Didion, "The White Album"

"Maybe instead of strings it's stories things are made of …"
–Paul Murray, *Skippy Dies*

Medical science contends that what gives life matter are genes and atoms and strings.

Medical humanities contends that what makes life matter are stories.

Scholars and students of medical humanities have committed themselves to studying the stories of health and illness we all carry. In this area of study, we interrogate the issues of illness, health, caregiving, representation, bioethics, and disability from multiple vantages. At the intersection of the humanities, the social sciences, and the natural sciences, we consider the cultural and humanistic implications of these matters. This is an intellectual and creative space in which statistics and science and stories intertwine. Bearing witness to the individuals and communities in whom these issues and stories emerge is crucial to medical humanities.

The story of this journal has its roots in the medical humanities minor here at Boston College. Under the direction of Professor Amy Boesky, the minor has developed into an inspiring and active community of students and professors. When students and faculty from across Boston College come together—whether in the classroom or in the minor's events and extracurricular organizations—the enormous potential of interdisciplinarity emerges full force. We approach the issues of medical humanities from different perspectives and disciplines, so weaving together these threads ensures that we consider seriously what is at stake in medical humanities.

In this inaugural issue of *The Medical Humanities Journal of Boston College*, we have gathered work of the highest merit across many disciplines and genres. The contributors are among Boston College's finest students, and their works underscore the significant and far-reaching reverberations in the medical humanities. From biology to English to Sociology to fine arts, these pieces take the form of short story, research essay, poetry, artwork, memoir, and literary criticism.

In the guest folio of this issue, we feature the work of four alumni of Boston College—Caitlin Keefe Moran, Samantha Rodriguez, Ilyssa Tamler, and Sahil Angelo. To them we express sincere gratitude for extending the conversation of the medical humanities community beyond the Heights. All the work collected here bears witness to the countless stories of health and illness that medical humanities attends.

With admiration and humility, we express our most sincere gratitude to Professor Boesky and Rachel Ernst and to the entire staff at the Institute for the Liberal Arts for all their work and support. Additionally, we thank Dr. Annie Brewster for writing the foreward to the journal. As doctor, story-sharer, and listener, she inspires our work here and demonstrates how crucial medical humanities is to everyday life. To the executive and editorial boards of *The Medical Humanities Journal of Boston College*, your rigorous work and dedication to this project continue to inspire us—without you all this journal would not be possible.

We invite readers to take pause with this journal, and to read its contents carefully and thoughtfully. We hope this journal bears witness to and honors the stories of health, illness, and ethics that invigorate medical humanities as a discipline. These contributors remind us that stories—more than genes or atoms or politics—connect us. These works remind us that to be human is to listen to and to share stories.

All our gratitude,

Christopher Kabacinski and Emilee Herringshaw
EDITOR-IN-CHIEF AND MANAGING EDITOR

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FOREWORD

Stories are what make us human. Stories connect us. Stories heal. As a medical doctor, a patient with Multiple Sclerosis and the Founder and Executive Director of Health Story Collaborative, a nonprofit dedicated to honoring and sharing stories of illness and healing, I am a firm believer in the transformative and healing power of stories.

On the individual level, stories empower us. Health challenges–our own or a loved one's–are turning point moments in the continually evolving narrative of our lives. As research has shown, the process of constructing and sharing such stories promotes positive mental and physical health. In telling stories, we are able to make meaning of our experiences and ideally to integrate these aspects of our lives in productive ways. Collectively, stories make us feel less alone, and therefore stronger.

In the context of today's efficiency focused and increasingly technology based medical system, patients and their loved ones often feel rushed, ignored, and alienated. To counter this dehumanization in healthcare, we must work to keep personal stories alive, now more than ever before. In our lifetimes, we will all face health challenges, either directly or indirectly. The stories that we tell about these challenges transcend illness as a celebration of hope, resiliency, dignity, and ultimately of the human condition.

I applaud the Founders and Editors of The Medical Humanities Journal of Boston College, and am thrilled to see such a publication at the undergraduate level. This is a high quality, multidisciplinary, rich collection of stories, shared in various mediums, including personal essays, research articles, poetry and the visual arts. In setting out to "examine critically and to represent creatively the ideas of health, illness, caregiving and medicine", this journal will stimulate an appropriately complex and enlightening discourse among contributors and readers alike. This is an antidote to the disconnectedness of today's healthcare system, and a gift to all of us, individually and collectively.

Annie Brewster, MD

Executive Director and Founder, Health Story Collaborative

SMTWTFS

MEAGHAN LEAHY

I don't remember how old I was when I learned what Risperdal was, but I remember how I felt when I saw her take it for the first time. Used to treat schizophrenia. Atypical antipsychotic. Dopamine antagonist. The good news? It calmed the irritability, or the doctor said it would anyway. The bad news? Side effects include weight gain, metabolic problems, and death. Also, despair, guilt, and hatred for a God who wasn't even listening, but who's counting anyway?

***

I watched as the fifteenth tour group passed through the Quad early this morning, and thought about how happy I was that my college application process was three years behind me. Sure, I haven't entirely figured out my future, but I have the luxury of doing so on the most beautiful campus with the most wonderful people. Could it get better than this?

The sixteenth group walked right next to my bench, and a family of four took up the rear. Well-dressed parents, listening intently to the guide in front of them, followed by two whispering, giggling, teenage girls with a clear resemblance to each other. Sisters.

I guess it could get better than this after all.

***

My parents planned that we would be seventeen months apart. They planned that we would be close in age, and therefore experience the same things at the same time. I told that to my friend Jenny once, and all she could say was, "Ew! They planned that?" I wasn't sure why the idea of chronological family planning was so appalling to her. Did she think that the stork showed up on her doorstep shortly after she was born with three more baby girls perfectly aged, ready to live and learn and love and lose together? Did she think that every family was just like hers, had kids with cute rhyming names (Katie, Allie, Jenny, and Annie) who all went to the same school and had the same teachers year after year? (Sometimes Jenny would complain about Mrs. A. calling her by one of her older sisters' names instead. I didn't feel bad.) Did she think that every family had children who grew together instead of apart? That, for everyone, one kid turned into two turned into four, and they lived happily ever after?

Regardless of her thoughts, it felt that way to me. It felt like everywhere I looked there was another perfect family with 2.5 neurotypical kids walking down the damn street with their perfect dog, turning into their perfect driveway, and going inside their perfect house. The more kids they had, the more I compared myself to them, and the more I thought about my own family.

***

In our home, it's just me and my sister, my sister and me. After my parents found out, they were too afraid to risk having any more children, and I don't blame them. At the time, it could have been anything—literally anything—that caused her condition. Was it her diet? Did my pregnant mother have too many mercury-laden foods? Was she a cold and heartless "refrigerator mom?" Was there mold behind the headboard or did my dad give her a defective chromosome, now lodged somewhere in her genetic blueprints? Many theories have been discredited, like the MMR vaccine link and the gastrointestinal idea, but in the '90s, no one knew that. No one really knew anything except that parents with one kid affected were more likely to have another. Today, it's a 2 to 18% chance.

So, I was born on January 24th, 1993, and she was born on June 22nd, 1994, and we grew up together, albeit a little differently from the family down the block with four (to me, it may as well have been thirteen—when you've only got one sibling, it seems as though any family with more than two kids is huge) similar, beautiful, rapidly developing daughters. One Big Happy Family. Whatever, Jenny. Whatever.

***

Paxil is an antidepressant drug of the SSRI variety. Used to treat major depression, obsessive-compulsive disorder, panic disorder, social anxiety, post traumatic stress disorder, generalized anxiety disorder. Side effects also include weight gain, increased risk of birth defects, higher rates of nausea and sleepiness, and also maybe probably definitely death. Who knows? I sure don't.

***

I have happy memories of our old house at 9 Salisbury, I really do. Stewart Manor was a great place to grow up, and our avenue was the best of the best. The Limontas (three kids: two boys, one girl), the LaBarbaras (four kids: all girls), and the Coxes (two kids: one boy, one girl) all lived on my block, and if they were busy I could bike the three intersections to the Butchers (three kids: two boys, one girl) or the five to the Kennys (three kids: all girls). Only thirty minutes away from midtown Manhattan, our tiny duplex nestled in the perfect suburban community made me feel like maybe something was perfect for us too.

I remember filling up the big plastic pool and splashing around with the plastic ducks that we took from our Lucky Ducks game. My sister and I pretended to be characters on Sesame Street. I sang Ernie's Rubber Ducky song, and she laughed along. I never really knew if she was laughing at me or at the sky, but she was happy, so it was okay.

I remember every time Mommy came to tuck us into bed, I would wait until I heard her feet glide back down the stairs and once she was gone, I would set up all our stuffed animals on the floor across from my bed and tell my sister to wake up. I performed the Star Spangled Banner and the theme song from Barney and took a deep bow as she clapped for me, in awe of my amazing singing voice.

I remember pushing each other on the swing set that

Daddy put together and having secret spy missions under the picnic table. She was always the silent spy, and I was the handler. Chatty and full of information to convey.

I have a few unhappy memories, but I try not to dwell on them. I remember when her therapist's voice came running up the stairs almost as fast as Daddy went running down when he heard, "Joe! JOE! Come down here!!!" Mommy was right behind him and then all of a sudden she was back in the kitchen, grabbing at the phone. As she called 911, I learned that watching someone you love lose control over their body was similar to being strapped into a thrill ride at Rye Playland. The High Flyer swings you back and forth in a giant pendulum, and brings you higher and higher until you start flying around in full circles. The Grand Mal Seizure Machine swings you back and forth from confusion and fear, spiraling you lower and lower into utter panic until the ambulance arrives.

I remember when Daddy went into work on Tuesday and didn't come back until Sunday. Something had happened in Manhattan, my mom said, and he was staying at the firehouse. I had this habit of falling asleep on the extra mattress next to my Daddy's side of the bed, because I liked to hold his hand and play The Initial Game as I drifted into dreamland. To combat the loneliness of his absence, I slept in my sister's bed every night until he came home. I don't know if she knew what I did—she couldn't tell me if she understood what the news was saying—but I know she hugged me back as we laid in bed, crying.

I remember when I yelled at my mom four years later, asking why no one cared about what I wanted, and why I had to leave my school and friends. Why did we have to move to another town just because there was a better program and better bussing for my sister? I also remember yelling at my sister for a different reason, when I was much, much younger. She had taken my favorite Barbie, and wouldn't give it back. I pulled and pulled, and even smacked her, but her yelling was louder and her thrashing was bigger, so Daddy said it was hers now.

I was full of resentment as a kid, but I also loved her. I was mad that I didn't have a real sister, like everyone else did. I was mad that I never got to do what I wanted, or so I thought, because she would be upset. I was mad that she didn't build blanket forts with me or look me in the eye. She usually shied away from my hugs and wouldn't stop stealing my favorite VHS tapes in order to stack them all, one on top of the other. But at the same time, she was the only sister I had. Sometimes watching Ghostwriter together wasn't that bad. It was even kinda fun, having the same favorite TV show and laughing at the same jokes. It was like we had something in common, something other than our genetics and last name. We had a thing, a bond. Jenny and Annie liked watching Bill Nye the Science Guy, and we liked watching the Ghostwriter gang solve the latest mystery. Maybe one day they could solve my sister for me.

***

Topamax is an anticonvulsant (antiepilepsy) drug. In late 2012, the Food and Drug Administration approved the drug in combination with phentermine for weight loss, probably because it had previously been used off-label for this purpose. People were voluntarily subjecting themselves to the "very common, >10% chance" side effects of dizziness, paraesthesia, somnolence, nausea, diarrhea, fatigue, nasopharyngitis, and depression, to drop their unwanted pounds. I hated those people.

***

By the time I reached middle school, I grew out of my resentment, but it wasn't all peachy-keen over in the Leahy house. After we moved 1.1 miles to our new house in Garden City, I got my own room. It was cool, I guess—I had privacy and the newfound ability to structure my night around my own needs, not around my sister's bedtime. But in another way, it completely cut out the little time I spent with her after I started growing up. I no longer held sold-out shows of the Backstreet Boys' latest album or sang the National Anthem to a crowd of plush and one human. I hung out with my "real" friends and I stopped paying attention to her, unless my mom started crying. Sometimes, or all the time, she would get upset about my aloofness. My relationship with my sister obviously left something to be desired, but I didn't feel like giving it (nor could I really put my finger on exactly what that "something" was—bonding time? understanding? love? patience?) and she physically couldn't, so that's where it stayed. Stagnant and devastating to my mother, who had planned to have two best friends, born just seventeen months apart.

But it's not like I didn't care about her. We finally went to the same school, and I stepped into my long-awaited role of Cool Older Sister Who Already Knows Her Way Around the Hallways. I told all my new friends that I had a sibling in the self-contained classroom right off the main hallway, and they should say hi to her or help her open her locker if she was struggling.

One day, from the music wing, I heard her voice. Screaming. The class stopped singing and turned to look at the door, and then the Abercrombie-clad, evil little thirteen-year-olds started to echo her self-inflicted agony in whispered shrieks and feinting movements. I took one look at the demons, their stupid faces red from laughing so hard, and I bolted out of my seat. I had one foot already out the door before I remembered to turn back and explain to my teacher that she was mine (not theirs, not theirs to ridicule). She was my sister and they were making fun of her and I needed to leave right now.

By the time I got to her classroom, she was already in the Nurses Office, waiting for my dad to come and get her. I waited too.

A few more episodes like that, and we stopped going to school together.

***

Things have to get worse before they can get better (at least according to every grandma ever on the topic of the flu), and, man, they sure got worse. Before I moved on to our local high school, my sister enrolled in a special school for kids just like her. She screamed until her throat was so raw she couldn't say a word. She rubbed at the skin just under her eyes and on the bridge of her nose until it bled in a steady stream down her face, unable to clot and scab and heal because she would just go at it, again and again. She lost about thirty or so pounds because her latest thing was essentially doing crunches while sitting upright on the couch. We tried a new medication and the symptoms abated, only to be replaced by new ones (at least they were more manageable—repeated shaking of the head, eye movements, repetitive counting and conversation).

The better things were the increased eye contact (they're the windows to your soul, I've heard, but I had never seen how blue hers were until my 16th birthday) and the improved speech ability. We worked from scripted responses—if you asked her how her day was, the answer will always be, "It was good," regardless of how it actually was—but we were able to have an almost-normal conversation. I would wait for her bus to arrive outside and open the door, she would come upstairs, and I would ask what she did that day. The whole family would gather around the coffee table and listen. It was right out of a sitcom, except the same episode aired every day.

Best of all, I grew up. I got over the resentment, the needing-to-fit-in-at-school. I'm not saying our relationship was perfect—or is for that matter—but I realized that she had thoughts and feelings too. One December afternoon, she got off the bus crying. I asked what was wrong, she said, "It was good," and kept silently crying until Mom came home with pizza for dinner. I still don't know how her day went, or what made her so sad—and I never will.

Our experiences thus far were uniquely intertwined yet distanced: so many things happened only because we both lived in the same place, but we weren't living and learning and loving and losing the same way that freakin' Jenny and her siblings were. My own feelings weren't insignificant; I was allowed to feel neglected, angry, and guilty. I was allowed to feel pissed at God for not giving her diagnosis to me, and I was allowed to simultaneously feel just a tiny bit relieved that it wasn't me, really. But everything I was feeling, I'm sure she was feeling to the nth degree. That's what all those tantrums were: anger, rage, sadness, frustration, excitement, happiness, love—all simmering under the surface until they boiled over.

I went to the Spring Fling and worked on the student-run literary magazine. I excelled in my honors classes and took more AP exams than I'd like to count. (More importantly, I leaned against my locker as the boy from first period World History flirted with me.) The rest of my high school career was par for the course, maybe not as glamorous as the movies but as well-above-average (just like my grades) as it could be.

But I'll always wish she was standing next to me in the pre-Prom pictures. I'll always wish she started lifeguarding with me when she was old enough. Once, before I had my real license, my parents were with some friends for a much-needed night out, so I told her to get in the passenger side of our 2000 silver Toyota Camry and strap in. We drove around the block, like twenty times, with the windows down. We blasted Katy Perry's "Firework," and for a second I felt like this is how it would have been if, you know, we had been like every other family in this too-small town. I made her promise not to tell, even though I knew she couldn't. I guess I did it because it felt like something normal kids would do.

***

Clonazepam is a benzodiazepine drug having anxiolytic, anticonvulsant, muscle relaxant, sedative, and hypnotic properties. Muscle relaxant? Sounds like a good idea. But the commonly associated drowsiness, motor impairment, personality changes and behavioral disturbances don't seem as great. And doesn't the induction of seizures or increased frequency of seizures directly contradict what we're trying to do here?

***

Freshman year, I went over to the Law School to get some paperwork notarized. On April 24th, 2012, I became the Standby Guardian for my sister. I became the First Successor to the modest trust my parents have set up for her future, slowly saving their civil servant wages for the day they can no longer provide for her. No waiting until I'm twenty-five and having a relative handle it in the meantime—I'm one tragic accident away from losing my parents and subsequently becoming responsible for another human life.

On a lighter note, I actually have my license now, so no more definitely-illegal activities for us. But there was this one time this past summer when my sister and I went to the mall and picked out earrings, then got a slice or two or definitely five at our favorite pizza joint, and walked around town with Starbucks cups and big sunglasses on. When we got back home, we scooped ice cream and had a dance party around the kitchen in our pajamas before watching Good Luck Charlie on Disney Channel and then going to bed. Her new therapist is working with her on e-mailing. The other day she wrote to me, listing the things she did that day (went to the gym with Daddy, going to a special dance). I almost responded that I was going out to get ice cream with my roommates and my boyfriend, but then I remembered that she won't ever have those relationships, so I said I was studying for a test instead. When I came home for spring break, then-boyfriend in tow, she came up to me—unprompted—and said "I'm glad that Meaghan's back! Meaghan's home!" I introduced her to him, trying not to cry.

***

I wrote my Common App essay on what I learned from her. On what I learned from watching over the years as she took more medication than should ever be allowed for a vibrant, kind, and naturally athletic young woman. Catapres, Risperdal, Haldol for the tics. Paxil, Seroquel, Celexa, Zoloft, Neurotonin for the autism symptoms. Klonopin, Topamax, Zyprexa all under her latest doctor. These were the bottles I became familiar with over the years. I watched as each new medication was introduced, then taken away, only to be replaced by another. She was never on all eleven drugs at once, but always one or two at any given time in her life. She recently tried Clonodine and Clonazepam for the tics (they've gotten way, way worse; that moment where she stopped shaking long enough to meet my boyfriend is a rare occurrence these days) before my dad decided he didn't want his little girl to be stuck on the couch in an over-medicated haze. He would rather watch as she shakes her head back and forth and listen as she repeatedly asks to wipe her hands, than see her without the energy to laugh and play. Without the energy to live.

Something I've always found to be intriguing is that even with all of these medications, we never needed one of those weekly pill organizers in the house. No plastic container with SMTWTFS emblazoned on the front, implying that the neurologically disordered are too stupid to know how many to take and when. Nope, Kelly is a smart chick. She knows to take one Zyprexa and one Cylexa every night before bed and if I forget to get it for her, she will come and interrupt my binge-Netflix-watching-session to tell me the exact dosage. I guess Jack Bauer can wait. This is the everyday in our house, the Sunday-Monday-Tuesday-Wednesday-

Thursday-Friday-Saturday.

I got into Boston College, I believe, not because of my grades and extracurriculars (although they may or may not have had something to do with it), but because of Kelly Ann Leahy. The admissions officers read my essay and they couldn't not fall in love with the young woman I told them about. The strong autistic girl who battles everything that holds her back—her sister, the world, her own disorder—every day, and consistently comes out on top. I bet they wanted to accept her instead of me, but settled for the lesser option.

***

The perfect family in that sixteenth tour group stood outside of Devlin Hall, laughing and chatting as the sun kissed their blonde strands perfectly. Perfect. After all these years, I still can't escape that word, still can't escape the idea that another family was more perfect than mine. My Common App essay explains how Kelly changed me, how my resentment for her diagnosis grew into love for her personality. But reading over it again, I feel like a fraud. There's a small voice in my head that never stopped resenting the picturesque family on the lawn, or down the block, or on the sitcom—never stopped comparing us to them. Back in high school, I accepted my sister for who she was, sure, but I never accepted my family for who we were. I picked the best things about this experience and I polished them off, showing only the good things to admissions counselors. They didn't see what I did to make my sister's life harder—I ignored her, I neglected her, I yelled at her—and they didn't see what I did to try to make up for that either. They didn't see the swimming lessons or the ice cream cones, they didn't see the joyride or the webcam selfies framed in her room. They didn't see my confusion.

I told them that I had already come to terms with the fact that the cultural idea of normal was never going to be mine. But that was a lie. I'm still struggling with it every day.

***

It's 2015 now, and Kelly's twenty-first birthday is in a few months. All this time, no one outside of me, my family, and the recipients of my Common App has ever read what seventeen-year-old me wrote in 2010 about my younger sister, my role model. But I think everyone should, so here it is. When you're done, call your siblings and tell them you love them, and, most importantly, that you're thankful to be able to tell them at all.

***

I am certainly not the only person in the world with a sibling. A friend from school is one of fourteen kids and another is one of eight. In fact, most of my friends come from larger families than my own, but I like to think that living with my sister is a little different than having thirteen siblings.

My sister Kelly Ann is a sixteen-year-old girl with autism and Tourette syndrome, and she has been this way for most of her young life. Diagnosed with autism at age two and Tourette syndrome around age eleven, my sister has had to deal with more obstacles than most kids her age, as well as most adults I know. To be honest, one of the challenges she has had to deal with is me. My parents love to tell the story about the day they brought Kelly home from the hospital and I stormed out of the living room upon seeing a new baby. As a child, all I saw was that if Kelly threw a tantrum she would get her way, and I'd be forced to watch Barney instead of Justice League. Sometimes I would even yell at her for repeating gibberish over and over. Don't misunderstand me, I love her, but I think, I always resented her for being the younger, prettier sister who ultimately got everything she wanted.

It wasn't until I grew up and came to terms with Kelly's challenges that I realized she didn't have it as easy as I thought she did. First, autism hinders social interaction and communication. The tantrums she threw were not to get her way like I once thought; they were actually to express the feelings she couldn't tell us verbally. And all the times I ran out of the house to hang out with my friends? Kelly was never able to have that escape. I had taken the autism for granted because it had been there my whole life, but it wasn't until Tourette syndrome manifested in the summer of 2005 that I sat up and took notice. It was at this point that my little sister taught me more than I ever could have learned from a chalkboard.

Endurance. *Every day, Kelly has hundreds to thousands of tics due to the Tourette's. Many of them are self-injurious, such as when she rubs her face so much that the skin breaks, and when she screams repeatedly until her throat goes raw. Regardless of how physically taxing her tics are, Kelly always seems to continue through her day as if nothing is wrong. Before this realization, I would call it quits if I were a little tired while running or too cold while swimming. Now, even when I am very tired or cold, I've realized that I can't just stop when things get tough. My sister has taught me to finish what I start.*

Patience. *Since being diagnosed with autism, Kelly has had a string of different therapists come to our house in order to teach her things the rest of us do naturally. Using the bathroom independently, writing legibly, and reading out loud are things that took her years to learn, and these skills didn't come easily. When the Tourette syndrome developed, a giant wrench was thrown into our lives and Kelly had to relearn many of the skills she had previously acquired. Through this process, Kelly has taught me that patience truly is a virtue. If she gave up every time she became frustrated, she never would have made it past where she was at age three. My sister has taught me to be patient with her, myself, and others.*

Innocence. *Kelly still quotes her old Barney tapes and watches Caillou on TV. Although this could be considered immature to an outsider, I actually find it refreshing. After coming home from a day at high school where everyone seems to be growing up too fast, spending time with my sister in a manner reminiscent to our younger years is time I value. While our topics of conversation are not typical of two teenage sisters, they are easy and they are honest. Her influence has kept a part of me young at heart, even though the rest of me has to grow up. With Kelly's help, I like to think I'm maintaining my innocence while still being informed, and enjoying the present moments of my life.*

Independence. *My sister will never be fully independent, and as I get older this fact starts to sink in more. I'm never going to have Kelly drive to pick me up from the airport, be the maid of honor at her wedding, or be the godmother to her children. She will live with my parents until they're gone, and then I'd like to think she'll live with me. Because of this, I am faced with the challenge of thinking forward – considering both her needs as well as my own. I am forced to think about a time in the future when the outcome of both of our lives will be my responsibility. Because of this, my sister has taught me a greater, more important form of independence. The sixteen years of her life have been filled with ridicule, whether it is laughing children or adults who can't seem to stop staring. Instead of crumbling at the will of these ignorant people, Kelly continues to work to overcome her challenges. Thanks to her example, I've stopped being so self-conscious and I'm happy with who I am. This allows me to focus on how I can continue to work on my own goals without being sidetracked by superficiality.*

Kelly has influenced my life in ways that can't be paralleled. My childhood has been different because of her influence, and I expect the same of my adulthood. Kelly's impact on my endurance, patience, innocence, and independence (among other qualities) has helped me grow into the person I am today. I know her continued influence will help me develop into the person I want to be: a responsible student, a good friend, and a devoted sister.

CEILING, FOUR WALLS AND A FLOOR

Peripheral Neuropathy—allodynia without the Greeks.
I met Jackson in the waiting room on the day before
the day they told me I had it. Casey had cut
his forehead running down the hill in front of their house.
He was going too fast, Jackson had said, and sometimes

you can't stop things like that. Seven stitches they gave him
and a popsicle stick with a sticker like a small picket sign
to bring home, adhesive souvenir. When they left,
the pale walls sucked me in and suctioned me
to the seat where I was sitting.

What does it feel like, the doctor asked. The tingling
in your hands, the numbness that came and then stayed
without warning. What is that like—its like my knuckles
and palms are tied up in a stocking, I said. Rubbing thumbs
and index fingers together, I could feel the soft nylon

shielding textures from my fingertips. My cuts and callouses
wrapped up, small lady's foot. They pricked me and pulled me
and blood filled their tubes until I was certain I wouldn't
have any left. One wince more, he said.
That afternoon they sent me home with the promise that

an appointment would be waiting for me tomorrow
and a bill, like a sticker, my souvenir. It was Peripheral
Neuropathy, they told me—allodynia without
the Greeks. Casey's forehead healed in two weeks.
But, at that point, I had trouble bending my fingers to feel

the fissures his fall had left behind. These days,
I can think my hands to move, to grasp things
that shouldn't be hard to hold. The oxycodone helps
with the numbness, except for the nights when it nets me
in my sleep, wrapping my body in dream-hemp and catalepsy.

JUST THE TREATMENT WE NEED

A CLINICAL EXAMINATION OF THE GLOBAL PHARMACEUTICAL SYSTEM

LUCAS ALLEN

Our world is ravaged by a terrible health problem, with blatant symptoms manifested by the suffering of millions. In a modern installment of the chronic problem of inequality, inadequate access to essential medicines causes millions of unnecessary deaths each year. Inequality is nothing new—almost two millennia ago, the Greek historian Plutarch said, "an imbalance between rich and poor is the oldest and most fatal ailment of all republics".[1] Yet somehow as science prevailed over some of nature's deadliest diseases, and as the world became more interconnected through technology, economic interdependence, and the rapid exchange of ideas, this "fatal ailment" metastasized. Advancements in modern medicine have greatly improved the lives of the wealthy, while much of the world remains trapped in a self-perpetuating cycle of poor health and lack of economic opportunity. With a pharmaceutical industry worth over US$300 billion a year, the pressure to profit hinders the just distribution of the social goods it produces.[2] The reason this malady persists is not because it is incurable, but because we have failed to prescribe a proper treatment. It is time to put the pharmaceutical industry in the clinic to find out what ails it and how it can be restored to good health in order allow for human flourishing and social justice.

I: Medical History

Beginning with the so called "Great Divergence" of the Western world in the 19th century and continuing into the global age, inequality has expanded from a local ailment of republics to a global health catastrophe. Miraculous advances in Western medicine have brought an unprecedented capability to prevent and treat diseases, but the progress in efficacy is tarnished by a simultaneous decline in equity. Throughout recent history, the advanced economic standing of developed countries has allowed them to improve the health of their populations and the efficacy of their medicine, and economic inequality has reinforced health inequality as developing countries remain unable to fund these improvements.

It was in this context of rapid improvements for some and stagnation for others that an international system of intellectual property rights was born.As pharmaceutical companies developed new and effective drugs, they lost profits as competing companies produced generic copies of the drug and sold them at lower prices. In response, governments in the developed world instituted strong patent protections in the pharmaceutical sector throughout the late twentieth century. The purpose was to incentivize innovation of new drugs by giving pharmaceutical firms a monopoly over their products for a set time period (usually twenty years), allowing them to recoup the high costs of biomedical research.[3]

At the same time, however, many developing countries weakened or eliminated patent protections in order to lower the cost of medicines and increase access to those who needed the drugs.[4] This threatened the profits of transnational pharmaceutical companies in developed countries, who then used political pressure and lobbying to convince their national policymakers to impose globally uniform patent laws.[5] In 1994, a pharmaceutical industry alliance drafted the Trade-Related Aspects of Intellectual Property Rights (TRIPS) agreement, and the alliance's powerful host countries made it a requirement for this agreement to be translated into the national law of any country seeking membership in the World Trade Organization.[6] This was a pivotal year in the history of the global pharmaceutical system as intellectual property rights for new pharmaceutical products became more regularized across the globe.

II: Symptoms

There is fervent debate on the relative merits of TRIPS compared to the pre-TRIPS era, but if the symptoms of the current state of global health can be any indication, the present system is undoubtedly ailing. There are 4.8 billion people living in developing countries, 2.7 billion of whom live on less than $2 a day.[7] The majority of these people lack access to life-saving medicines,[8] resulting in ten million deaths every year that are preventable by Western medical capabilities.[9] Peter Singer and Doris Schroeder (2010) distinguish between two failures of the global pharmaceutical system: the accessibility problem and the availability problem. These problems emerge when drugs are too expensive for those who need them or when no drug has been researched and developed for a particular disease, respectively.[10] By imaging an ideal pharmaceutical system that is equitable and allows for the fulfillment of the human right to health, it becomes clear how these two problems push lived reality further away from this ideal.

While an ideal pharmaceutical system would provide access to life-saving medicines to those who need them despite their nationality or income, much of Western medicine is distributed based on who can pay, leaving the poor without treatment. This is the accessibility problem: drugs exist and are available, but they can only be used by the wealthy minority that can afford them. Despite the Millennium Development Goal 6 target of universal access to antiretroviral treatment by 2010, 1.7 million deaths from AIDS-related illnesses in 2011 prove that the target was not attained.[11] There are effective treatments to prevent people living with HIV from dying due to AIDS-related illnesses, but they are too expensive for many individuals and health systems in developing countries. In 2001, only 30,000 of the 28.5 million Africans living with HIV/AIDS had access to life-prolonging drugs.[12] The "pills if you can pay" system is especially problematic for communicable diseases such as AIDS and tuberculosis precisely because leaving them untreated (or worse, partially treated) increases the likelihood of the infections spreading or becoming drug-resistant.

This lack of accessibility is also disastrous for noncommunicable diseases, which—contrary to the oft-misleading logic of "epidemiological transition"—are the cause for much more mortality in the developing world than in the developed world.[13] Rheumatic heart disease is an example of a noncommunicable disease that has been eliminated from developed countries through advanced prevention and treatment, but still looms large in low-income countries.[14] The accessibility problem begins with economic inequalities, but over time it translates into massive health inequalities as the inability to afford medicines increases the burden of disease.

The ideal pharmaceutical system would also provide adequate availability of treatments for the deadliest diseases, and research drugs that promise the largest health gains (e.g. lives saved). The gains targeted in our current system are not increased health, but rather increased profits. Because of this, the drug industry has focused on diseases that afflict people in rich countries; at the same time. the industry has remained cautious about researching drugs for diseases affecting developing countries due to the low potential for profits.[15] This exacerbates the availability problem, in which the drugs needed to treat a disease simply have not been created. For example, there are an estimated 1 billion people living with neglected tropical diseases. The three tropical diseases with the highest mortality rates (Chagas disease, human African trypanosomiasis, and visceral lieshmaniasis) have no effective treatment due to international neglect and low funding.[16] Diseases that add up to 90 percent of the global burden of disease only receive 10 percent of pharmaceutical research and development, a disparity known as the "90-10 gap".[16] Over the last two decades, a fivefold increase to about US$250 billion in pharmaceutical funding has wrought amazing results, but these advances have served the wealthy and left the poor without treatment; only 1-2% of this increased funding addresses infectious diseases in low-income countries.[17]

While Singer and Schroeder's (2010) accessibility and availability problems are telling symptoms of an ailing pharmaceutical system, the issues do not stop there.[18] Systematic inefficiencies also prevent the system from reaching its ideals; little of the money spent goes toward improving the health of human populations. As developing countries fight patents to provide drugs at cheaper prices, a significant portion of industry money is spent in lawsuits protecting patents. When South Africa adopted a National Drugs Policy to provide effective drugs at low cost in 1996, 39 pharmaceutical companies filed a suit to protect their patent pricing.[19] Large pharmaceutical firms spend about one sixth of their sales revenue on research and development, while spending twice that on marketing their products.[20] This spending disparity indicates the importance of informing consumers through public channels. With their exorbitant funds, these pharmaceutical firms are able to broadcast their messages to the public, no matter how biased the information may be.[20] These excess expenditures surpass the already high cost of research and innovation, requiring companies to set their patent-protected prices above what many health systems are able to pay. These higher drug prices contribute to cost escalation, which is a major problem afflicting health systems—both rich and poor—around the world.[21]

In lieu of scientific impact assessment, the profitability of a drug can be determined by how well it is marketed rather than its effectiveness. Even when impact assessment is used, data uncertainty provides space for manipulation to find configurations that favor commercial interests.[22] Interviews with company employees reveal that they are pressured by drug companies to produce favorable analyses by reconfiguring models.[23] When government funding of research declines, academic-industry partnerships become more common, resulting in more conflicts of interest.[24] Through advertising and manipulation of impact assessment, pharmaceutical companies can make a new product profitable even if it is truly no better than what was previously used. At the same time, companies are incentivized to develop maintenance drugs that reduce symptoms because they are more profitable than more cost-efficient, high-impact treatments such as vaccines and curative drugs.[24] Thus, the inefficiencies of the pharmaceutical system can be linked to increased spending that is unrelated to research and to the development of drugs with inconclusive positive impacts.

III: Case Study: Brazil

It is important not only to see these symptoms in the global context, but also to understand the concrete effects they have on developing countries. Without the financial means to afford drugs or fund innovation, low-income countries suffer most acutely from these problems of access, availability, and efficiency. Yet even middle-income countries in the midst of substantial economic growth, such as Brazil, find their efforts to improve their quality of life hindered by the high cost of medicine. Despite being recognized as one of the BRIC countries enjoying rapid economic growth and newfound global influence, Brazil is still a nation with great disparities of wealth and a long history of oppression by race and gender that continues to have an impact on population health.[25] In the late 1980s, a massive wave of social mobilization led to the removal of a military dictatorship and the creation of the Constituição da República Federativa do Brasil.[26] The new constitution declared a right to health for all, establishing the universal Unified Health System (SUS).[27]

The SUS immediately faced funding shortages due to structural adjustment policies promulgated by the International Monetary Fund in the early 1990s.[28] One decade after its creation, AIDS activists used human rights language to argue that the SUS was not maintaining its constitutional promise to fulfill the right to health, as expensive antiretroviral treatments were inaccessible for many.[29] Since prices were then protected by TRIPS, the health system was confronted with the accessibility problem. To address this, the Brazilian Ministry of Health breached the rules of TRIPS by developing generics and bargaining down prices, drawing condemnation from the U.S. government and pharmaceutical companies.[30] While it received criticism, the National AIDS Program (NAP) saved $1.1 billion[31] and was named by UNAIDS as the best AIDS program in the developing world.[32]

In a pharmaceutical system as troubled as ours, however, even success stories can be problematic. Rather than withdrawing from Brazil, pharmaceutical companies took the NAP as a chance to become more involved in the future of Brazilian health care. As older antiretroviral treatments lost their efficacy, the SUS needed newer and more expensive treatments that were covered by patents.[33] Furthermore, the understanding of the constitutional right to health expanded to include access to more and more drugs, and the public hospitals in less affluent states could not provide them.[34] The pharmaceutical companies were complicit in this process, and were even caught rallying Brazilian citizens to demand their products as part of their right to health.[35] Now, since patients have a constitutional right to health and their cash-strapped health system is failing to provide the medications they need, they are suing more frequently the Brazilian government in order to obtain medications.[36] The judiciary continues to make the growing number of drug-related decisions on a case-by-case basis, but access is granted in nearly every case.[37]

Since the Brazilian constitution promises an ideal health system that provides the right to health at no cost, it is a perfect case to illustrate just how far this ideal is from the current reality. The high price of patented medicines drains the limited funds available and detracts from the capabilities of the SUS to reach rural areas and urban slums.[38] This accessibility problem leaves the poor without drugs and without primary care, forcing them to file suit as a last resort. Proponents of TRIPS argue that it alleviates problems of availability by incentivizing innovation in developing countries. But rather than increasing Brazil's domestic innovative capabilities, TRIPS led to a greater reliance on importing innovations from foreign pharmaceutical companies.[39] The inefficiency problem has also been catastrophic in Brazil. A large portion of the money allocated for the SUS is now used to provide specialty medications to patients who have demanded them in court. Due to public demand, new drugs that are questionably effective but undoubtedly expensive have to be purchased en masse by the SUS.[40] The alarming inefficiency of the SUS was summed up by health secretary Dr. Osmar Terra, who said, "We try to guarantee the availability of medicines. But it is extremely perverse that we have to guarantee the most expensive medicines, which have no effect whatsoever. The laboratories use patients to increase profits".[41]

While this case study focuses on Brazil, every country in the world is adversely affected by the failings of the global pharmaceutical system. Venezuela faces a crisis similar to Brazil, in which drugs that are supposed to be cost-free in a universalized health system are too expensive for the government to provide.[42] Even the United States faces access issues that prevent drugs from reaching those who need them. The first hepatitis C treatment was developed in 2014, but the patent-protected price is an "astronomical" $84,000, which few people with the disease could afford.[43] While these Western-hemisphere populations are suffering from the lack of medicines, Africa and Southeast Asia have been hit much harder by the failings of the global system.[44] Diagnosing these problems of accessibility, availability, and inefficiency demonstrates how the state of the global pharmaceutical system is morally unacceptable.

IV: Diagnosis

These symptoms are substantiated by a heap of global health research. Given the same evidence, however, arguments have been made for varying diagnoses of the problem. United States policy and the pharmaceutical industry create a barrier to reform by arguing for the false diagnosis that poverty is the only significant cause for limited treatment. By overstating the effect of poverty on access to medicines, the blame for the 10 million deaths and countless additional costs of human suffering is shifted from any human-controlled factors to "simply the way the world is".[45] This restricts any potential action for improvement by covering up the insidious structural violence that contributes to the problem.

Instead of being considered as a potential factor in reducing access to essential medicines, patents are often thought of as part of the solution. It can cost hundreds of millions of dollars to research and develop a new drug, and patents are the only way to recoup the price of innovation.[46] Without innovation, there will be fewer life-saving drugs in the future, and the result will be just as bad as the lack of access now.[47] As a result of stronger patents, the TRIPS era has improved the availability problem by giving pharmaceutical firms a financial reason to develop drugs that help the poor.[48] However, the situation of Brazil and many other developing countries proves that TRIPS does not live up to its promises on the availability problem. Also, there is no doubting that patents are an important contributor to the accessibility problem, because they raise the prices of drugs beyond what is affordable for developing countries. Singer and Schroeder (2010) argue that rather than judging TRIPS against the worst-case scenario or the pre-TRIPS era, we should compare it to the ideal to reveal how the system could be improved.[47] It is not enough to settle for TRIPS just because it improves the situation a little, while ten million humans die preventable deaths every year.

This continuing tragedy cannot be attributed to individual moral failings, but rather to a misalignment of the system. Despite their mission statements, the primary aims of drug companies do not align with public health and the public good.[49] As economist Milton Friedman wrote, "the social responsibility of business is to increase its profits." The solution to this problem cannot be reached by vilifying the pharmaceutical companies, who create the life-saving drugs. If a virtuous pharmaceutical company developed a cure for human African trypanosomiasis in the current system, it would be unable to recoup the costs of the research and would subsequently go bankrupt. The methods required for companies to fulfill their responsibility to shareholders and stay afloat do not align with human health needs.

The reason the pharmaceutical industry faces so much criticism is that the unjust distribution of pharmaceuticals is perpetuated by human-controlled factors, such as TRIPS. The agreement has "had an adverse impact on prices and availability of medicines, making it difficult for countries to comply with their obligations to respect, protect, and fulfil the right to health".[50] It has also widened the health gap between the developed and the developing countries.[51] Finally, it unjustly entrenches low income countries in a position of need because they do not have the economic capabilities to develop their own production and innovation.[52] As I see the diagnosis, the global pharmaceutical system has significant problems stemming from the incentive structures that are maintained by TRIPS. The power of strong patent protection over the most vulnerable populations is structural violence, favoring profits over human lives and human dignity.[53] Without this understanding of the group processes and incentive structures at the root of the illness, it is impossible to prescribe a proper treatment that alleviates the suffering caused by an unjust pharmaceutical system.

V: Treatment

By realigning the incentive structures of pharmaceutical development and distribution, it is possible to create a global pharmaceutical system that allows for human flourishing. There are ways to incentivize innovating for the future without causing so much suffering in the present. A number of philanthropic measures have been used to increase access to medicines in impoverished locations, but these interventions do not change the nature of the unjust system. Sometimes, philanthropy is even used to defend the TRIPS system and perpetuate the larger-scale injustice.[54] A more sustainable intervention is tiered pricing for pharmaceuticals in low income countries based on the ability to pay. It is economically irrational to keep patent-protected prices high in low-income settings, because few people can afford to buy the product and profits are miniscule.[55] By lowering prices in developing countries, the accessibility problem would be reduced without sacrificing much profit. However, any loss of profit in the pharmaceutical industry will face steep resistance, especially with the political influence of lobbies.

A relatively new proposal that has the potential to realign the profit motive toward a more just system is the Health Impact Fund (HIF). Briefly, pharmaceutical companies that sign up for the HIF would agree to sell their products at much lower prices, forgoing all profits from sales. In return, the company would receive profits from the Fund proportional to the health impact of their product.[56] This would almost eliminate the accessibility problem, as prices of medicines would fall to the miniscule marginal cost of production. It would also significantly improve problems of availability because there is much more potential for health impact when drugs are developed for neglected diseases that affect the developing world. Finally, the system would be much more cost-effective because drugs would only be profitable if they have an impact, and firms would no longer need to spend so much money on lobbying, court cases, or salvaging their public image. Pharmaceutical companies would willingly register for the HIF because it would give them the chance to make more profit.[57] This new system would solve the problems faced by Brazil and so many other health systems around the world, giving governments a chance to provide the human right to health to all their citizens.

VI: Conclusion

A reformed incentive structure in the global pharmaceutical system is just the treatment we need to ensure that all humans receive the treatments they need. However, curing this ailment will be possible only if the failures of the current system are properly diagnosed. Here I have pointed to the structural deprivation of essential medicines in developing countries which results from the patents and incentives of the TRIPS regime. If the United States has been instrumental in forming the global pharmaceutical system system that puts patients and profits at odds, we must consider accepted and embraced the responsibility of healing the ailing pharmaceutical system. For this reason, we must dare to envision a system that respects human life and promotes a world in which every person has access to the medicines they need to survive and flourish.

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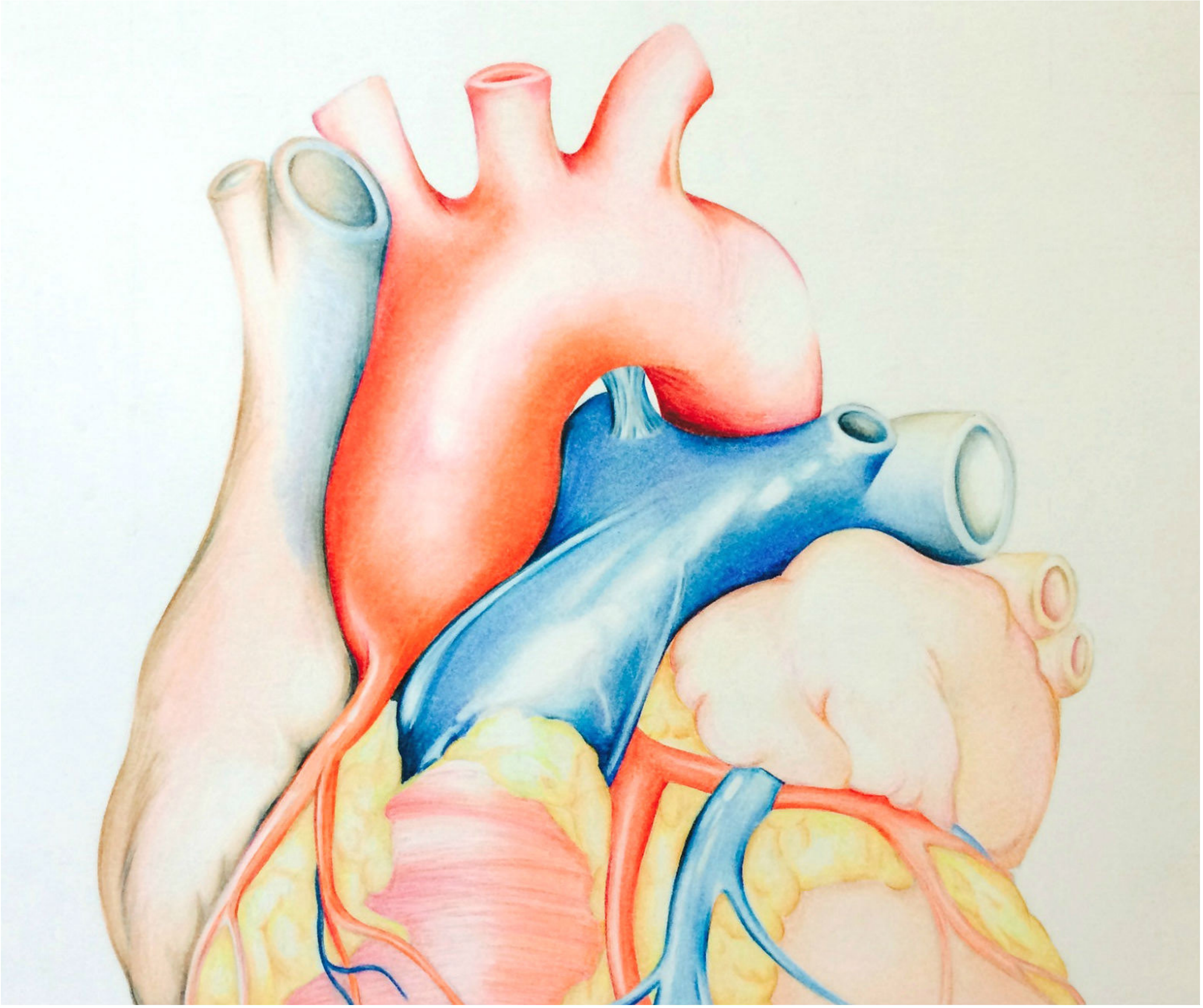

HEART

KATHERINE CARSKY

THE ONES

MICHELLE TOMASSI

I didn't ask her to accompany me here to Dr. Sheraton's office, but she insisted on being "the one." I would have asked Dennis, Ma—hell, even my sonofabitch stepfather, Larry—but Emma volunteered to hold my hand and wipe my tears and tell me everything will be *okay* when in reality it's all a lie. I'm standing in this godforsaken waiting room because they would only tell me the test results in person, which can only mean one thing: I'm a goddamn goner.

I'm not gonna lie—I should have seen this coming. It started with the headaches; mild at first, like when you haven't eaten for a while and your brain starts to hate you for being such a lazy asshole and not getting off the couch to feed yourself. That only *really* happens when Ma's too busy to go shopping, because she has to leave Jersey and go to New York for business meetings. Or when Dennis and his friends clean out the food supply after one of their Call of Duty marathons, like *they* were the ones coming off the battlefield. The one time I tried to be a good son and restock the fridge, good ol' Larry yelled at me for only buying Totino's Pizza Rolls and Oreos.

Anyway, the headaches eventually got worse. Sometimes, I would be sitting on my bed, watching *Friday Night Lights* with Emma, when all of a sudden I'd feel the blow. I remember the first time it happened—it was like my head was caught in between the closing doors of an elevator. One minute, Coach Taylor was having one of those heart-to-hearts with the football team, and the next I was curled up, knocking over the bag of chips that was sitting in my lap. Emma *begged* me to see a doctor after the first time, but there was no way in hell I was gonna do that. No—I just kept having those god-awful headaches, blaming it on "the stress of college applications" or some other shit that the school guidance counselor would probably say.

Well, Emma finally got her wish. I was in the grocery store with Larry, walking behind him as he pushed the cart along, saying something about how "real men buy groceries." His designer Kmart jeans were slipping lower and lower down his butt, giving a show in the frozen food aisle that none of those customers had asked for. I rubbed the back of my neck as I started to feel the brain pain, but instead of reaching into my pocket for the Excedrin, I found myself stumbling away, no longer following behind Larry. It's like I was playing Mario Kart on the old Nintendo and my car was heading straight for a wall, but no matter how hard I tried, the controllers seemed to be frozen. I just raced closer and closer to one of the glass doors until I *slammed* into it, falling backward and hitting my head on the tile floor. It all went black pretty quickly, but I do remember a middle-aged woman shrieking for the Lord, followed by the sound of Larry yelling for someone to call an ambulance.

When I woke up, Emma's face was practically pressed against mine, as if I were one of those dead-looking fish at the aquarium, and she was staring at me through the glass tank. She was probably jealous that *she* wasn't the one with me when I finally went down—I could just imagine how much she'd *love* to make a scene and yell, "Somebody call 911! My boyfriend has fallen and he can't get up!" Okay, maybe she wouldn't go all Life-Alert on me, but you get the point. Emma's the kind of girl who really does care, but for some reason she feels the need to make a spectacle of caring. She started blabbering immediately about how *worried* she was and described all the tests that the doctors planned on doing, but the whole time I wasn't really listening. I was too focused on the papery fabric covering my body: the hospital gown. It was baby-blue, with these tiny white polka dots and white trim on the edges of the sleeves. I reached behind me and felt around for them: the strings keeping it all in place. My neck suddenly felt itchy—god, it felt like I couldn't *breathe*. The only thing holding me together at that moment seemed to be those two pieces of string.

The docs wouldn't have my test results right away, so they sent me home. Emma had folded up my clothes all nice and neat, the way Ma usually does it, and brought them over. She opened her mouth—probably to ask if I needed any help, like I'm some kind of baby—and I shook my head before she could say a word."Okay, then." Those brown eyes of hers waited for me to change my mind. When she saw that I wouldn't budge, she left the pile on the edge of my bed, and walked backwards toward the door. "I'll let you have some privacy."

It's pretty funny when you think about it; the girl has seen me butt-naked on several occasions, yet she always leaves the room if I need to change. Like, she'll be a riot in bed, and then once it's time to return to the real world, she's suddenly a saint. Once she dragged herself out of the room, I stripped off that god-awful gown, but as I pulled on the jeans, I imagined them being replaced with one of those paper hospital outfits—for *good*. The thought of it all made me want to check out before they even assigned me to their terminal illness of choice. I would be strapped to a hospital bed for god knows how long while another stupid nurse would inject medicine into my bloodstream, and my hair would fall out and I'd be forced to read pathetic get-well cards from the Hallmark store while being fed my lunch through a tube. I don't need anyone's sympathy. No—I couldn't sit through all that. They would have to *kill* me before I put on one those ridiculous outfits again.

When I got the call from Dr. Sheraton a few days later, I let it go to voicemail. The thought of getting my death sentence by phone was just a little *too* personal—I would have preferred if he sent it in the mail, like Ma's subscription to *Woman's Day* Magazine. After all, I think I have a right to decide.

> ☐Yes! Send me a year's supply of chemotherapy, at the low rate of YOUR ENTIRE LIFE SAVINGS!
> ☑ No thanks, I'll wait until I'm 40.

As Emma loved to remind me, however, I didn't have time to wait.

"Put it on speaker, Jake." I'll be honest—if Emma hadn't forced me to listen to the message with her, there's a chance I would have just deleted the thing myself. I located the speaker button, but my hand felt frozen again—almost like my body did in the grocery store during my "episode." I reached for my neck. Hopefully Emma didn't hear my heart beating so loudly.

Oddly enough, Dr. Sheraton had the kind of voice that made you want to cry: it was firm and important, but so goddamn beautiful.

Hello Jacob, this is Dr. Sheraton from West Greenberg Hospital. I am calling to inform you that your test results are in, and I would like to discuss them as soon as possible. Please give us a call back as soon as you get this message. Thank you.

I would have driven there myself, but Ma insisted I bring someone with me, probably in case I passed out or something. She would have come herself, but Ma's the type of person who doesn't like to cry in public—after Dad died, Dennis and I practically had to drag her to his funeral. It wasn't easy, but then Dennis actually *screamed* at her—I had never seen the kid so angry. Ma hates being yelled at more than she hates crying, so eventually she got out of bed and forced herself to say goodbye to Dad for good.

Dennis would have probably agreed to come with me—but would I really want him sitting there, as he learns that his big brother is also leaving him for good? Not only did the kid have to lose a father, but now *me*? I taught him how to make a three-pointer every time, my fool-proof parallel parking method, and how to talk to girls without sounding like an ass. The key is to throw in a lot of compliments—tell them that their hair looks nice, or that you like their scarf (girls are *always* wearing some kind of scarf). If I'm gone, who's gonna help him out? *Larry*? That dipshit kept apologizing after I got home from the hospital—what, did he think that he was the one who caused me to pass out in aisle 9? Larry's about as exciting as a piece of asparagus, but that doesn't mean I'd voluntarily crack my head open out of boredom.

"I'll do it." Emma straightened up on the couch, locking me in with those brown eyes of hers that first got me a year ago. "I'll be the one to take you." She started to tear up a little, like she was auditioning for some sappy *Lifetime* movie. I didn't argue with her—with Emma, there's really no point. The girl may drive me insane sometimes, but she sure as hell knows how to hold her ground.

* * *

The waiting room outside Dr. Sheraton's office makes it kind of hard for me to breathe. The air almost *feels* sick, and not a single face looks up when Emma and I walk in. Guess I'm just another dude joining the terminally ill club.

There's a row of frames on the back wall, and in them are motivational phrases written in that flowery Hallmark font. One says, "Every day is a second chance" and another one says, "The struggle you're in today is developing the strength you need for tomorrow." How do they know what my "struggle" is like? Plus, I can't even think about what's going to happen in a few hours, let alone tomorrow.

Aside from the offensive wall décor, the waiting room itself isn't terrible. There are rows of chairs with brown leather seats on the far ends of both sides, with a rectangular coffee table placed in front of each row. Funny thing is, I don't see any of those typical waiting room magazines sitting on them. Not even *Women's Day*—good thing Ma's not here, I guess. Maybe they really do just want us to sit here and wait.

In the middle of the room are couches, in that same brown leather, just two of them placed back to back. There are two little plants placed near the armrests on both sides, and they're actually pretty ugly—green and leafy with big yellow spots. They probably did that on purpose—the yellow spots are almost the same color as the yellowish walls trapping us all in here. It's not a happy yellow at all—more like the phlegm that Larry coughs up into the sink and "forgets" to rinse off. That's one thing I won't miss if I'm stuck in the hospital for good.

"Let's check you in," Emma announces, hoping that someone will look up and notice that we have arrived. I let her tug my hand and lead me to the check-in desk on the right side of the room, right next to the door that reads, "William P. Sheraton, M.D. Neuro-Oncology."

"Name?" The woman behind the desk asks the computer, as if I'm actually behind the monitor and not standing directly in front of her. While Emma starts handing over all my information, I lean my elbow on the desk and look around. Bad mistake.

You've got these patients, see, who are sitting on the couches, on the chairs, or standing up by the windows. They're all staring off somewhere, like their minds are itching to get out, but their bodies have already given up. And then next to each sickly person is "the one" who was forced to bring them to this appointment. Okay, "forced" may be too harsh. Obviously no one wants to be here, but at least the ones are trying. Someone needs to try.

After Emma checks me in, she grabs my hand again and pulls me to the opposite side of the room, beelining for the two empty chairs at the end of the row. I was kinda hoping to pop a squat on one of those couches, but leave it to Emma to strip me of any freedom I thought I had left. Emma takes the chair at the end of the row, closest to the restroom. Emma doesn't like to tell many people this, but she has some bladder issues, especially when she's nervous. I remember on our first date at Maria's Trattoria, she got up a total of seven times to "wash her hands" or "ask for more napkins" or "call Mom to feed the cat." No matter how many times Mother Nature called, she always had an excuse ready. It's part of the reason why I asked her on a second date.

My ass barely touches the seat and Emma's already up, making her way to the bathroom door. With her gone, I look down the row of faces next to me. There's a tall man at the far end, probably in his 30s, with his elbows on his knees and his head bending down, like he's praying or something. He has a pretty good-looking woman next to him—wavy blondish hair, not much makeup (she doesn't need it)—and she's got her hand resting on his back. And you won't believe this—she's pregnant. Not only does she have to be "the one" for him, but she's gonna be a single mom soon. Jesus Christ.

Next to the pregnant lady are twin boys, identical, and I honestly can't tell who's the patient and who's "the one." They're pretty pale, and they've got their eyes closed. From here, it looks like they're holding hands.

There's an old woman sitting to my right—she's got this tan skin that's wrinkled, like a paper bag, and a nice and colorful scarf. She's not wearing it around her neck like all those chicks at school; she's got it wrapped around her head, maybe to cover the baldness. But the seat next to her is empty. Where's "the one" for her?

"He killed himself when I got my diagnosis."

I jump in my seat; Emma's back from the bathroom, smoothing out her leggings and tucking them into her Ugg boots for the fiftieth time today. I turn back to the woman, but she's not even looking at me. Her eyes—this turquoise color, matches her scarf—are just staring straight ahead.

"I knew he was gonna do it eventually, but I thought he'd at least wait until *I* died first." She grabs the back of her neck and breathes out. "That bastard always had to beat me at everything."

For some reason, I feel my eyes starting to water a little bit. This woman's husband just killed himself and left her alone? I mean, Dad did the same thing to Ma, but at least *she* wasn't dying of cancer. At least she had a second chance.

"What's your diagnosis? How long do you have? Have you even *tried* the hospital food?" They cross my mind all at once; I'm not even sure which one I say out loud. "Doesn't matter." She looks at me for the first time—she's old, no doubt about it, and she looks like she wants something. "I'm gonna tell the Doc that I don't wanna do his treatment. If I'm gonna die, let it be in my own goddamn bed." She pauses, and looks slightly behind me. "That your girlfriend?"

I turn around. Emma's still sitting there, looking at me like I'm back in that hospital bed, waiting for me to wake up. I look back at the older woman and nod. She nods in return, making sure I understand that yes, Emma is my girlfriend.

"Jacob Manning?" A nurse is standing outside Dr. Sheraton's office with a clipboard in her hands, wearing baby blue scrubs and tapping her New Balance sneaker impatiently. Emma's up on her feet before I can even blink, and for some reason I can't get myself to move. The thought of getting up and leaving this woman sitting next to not one, but two empty seats is just too much.

The old woman looks up at me, probably wondering if

I'm deaf or too stupid to know my own name. Like an idiot, I just keep staring at her, opening my mouth to say something, but nothing comes out.

"Jake, come *on*." Emma's not tugging at my arm this time, but I think she's as freaked out by this person as I am. I get up and look at the woman one last time. Her head is down, but I'm pretty sure she's smiling.

I lift my hand to rub my neck, but somehow I end up taking Emma's hand instead. It's the first time I think she might actually cry.

"It's fine," I mutter. "Imagine being *that* woman."

"What woman?"

Emma stops and looks behind her, as if she's expecting someone to be following us. I roll my eyes—now is *not* the time to be dramatic.

"You know, the woman who was just next to me." I turn around to point at her.

The old woman's chair is empty. There's not one, not two, but three empty seats in a row, waiting to be filled.

AUTHOR'S NOTE

I would like to thank Professor Suzanne Berne for encouraging me to publish this piece, and for all of her help in the revision process. Additionally, thank you to all of my classmates in Professor Berne's Fiction Writing workshop. Your insights and advice were truly appreciated, and I have become a better writer as a result.

WATER BIRTH

SOPHIA VALESCA GÖRGENS

The possibility of infant death
did not scare her. She knew her baby would be born
with swimmer's lungs like the father,
webbed digits from early fetal development
transforming into raw-fingered dexterity in the water.

Her midwife had come with the first contractions,
helping her ease into the warmth.
With the due-date on the paperwork two weeks prior,
the collapsible bathtub had arrived disinfected.
In a small bottle, the enzyme purifiers for the well

sloshed the sides gently, waiting. She'd applied them herself,
morning mist rising from water siphoned from the sides
of a mountain. It rose behind her house, austere.
Yes, her baby would be born with lungs like the father,
forged from highland billows.

The water calmed her, lapped her with support
while the midwife crooned, strung notes
into the strands of a lullaby. She listened, her head
lolling back, cushioned by matronly hands.
The air writhed with impatience.

FIFTEEEN-YEAR-OLD CONTRACTS HIV FROM UNSUPPORTIVE COMMUNITY

ISAAC AKERS

"A 30-year-old man [from Sunrise, Florida] is charged with attempted second-degree murder and criminal transmission of the AIDS virus, along with five other charges involving sex with a 15-year-old boy, according to Pembroke Pines police.

Keith "Keyoko" Sumlin was arrested Wednesday [9.5.12] after the boy told his mother the two had sex and that he later heard the older man was HIV positive, according to a police report.The mother took her son to Memorial Regional Hospital in Hollywood for an HIV test. The preliminary result was positive, according to the report.

Before they had sex, Sumlin said he was 21 and asked the boy, "Are you really 18 years old?" according to the police report.

From the report: "The def asked 'Are you really 18 years old,' and the victim replied 'no.' The def then asked, 'Are you 17,' at which point the victim replied, 'Younger.'"

The teen later told a friend that he had met Sumlin via a mobile phone app and that he had invited the man to his home in Pembroke Pines, where they had sex without condoms.
The friend told the boy that Sumlin was HIV positive and "has a secret Facebook page wherein he posts videos of himself engaging in anal sex with males that appear to be under the age of 18," according to the police report.

Pembroke Pines police detective Michael Silver wrote in his report that during the investigation he viewed a video of Sumlin posted on a social networking website.

"I f---ed this little boy, videotaped it and added it to the online group," Sumlin said in the video, according to the police report. "And I don't use condoms when I have sex and you call me sick, don't worry about me, worry about who gave it to them."

Sumlin, who is being held at the Broward County Jail on $280,000 bond, told police he had sex with the teenager but wore a condom, the report states."[1]

The case of Keith "Keyoto" Sumlin and his infection of the fifteen year-old boy is startling at first glance. The young boy, unidentified in the case because he was a minor but whom we will call Michael to remove him from the abstract, is one of a relatively small population of young black men who have sex with men (MSM) in the USA. The MSM population in the US is estimated to be 2% of the population, and there were only 10,600 new cases nationally among black MSM in 2010. In the most basic and literal sense, unprotected sex was the cause of Michael's infection.[2] The availability of antiretroviral regimens to achieve both viral suppression and a relatively unaltered life means Michael can seek treatment for HIV. Unfortunately the realistic question is: "Will he?" Only about half of black MSM in the USA receive proper treatment, and only about a third of them achieve viral suppression. However, the spread of HIV goes far beyond viral suppression and treatment. Michael (and Sumlin not too long ago) is a member of one of the most at-risk populations for HIV infection in the United States: young black MSM. This case not only raises the question of what life will be like for an HIV positive black MSM, but more importantly, what factors led to his infection in the first place, and why so many other young black MSM end up with the same diagnosis.

> AIDS, in many ways, is like every other health, social, and economic crisis that black people have faced for generations. What is alarmingly different about AIDS is the severity of the infection and the particularly repressive political timing of the emergence of the disease. The combined effect of all of these elements leaves the black community in an extremely vulnerable position. AIDS has the potential to cripple black people in a way that few other health or social forces have since slavery.[3]

Beth Richie wrote these words about AIDS in 1990, but in 2011 African Americans accounted for over 46 percent of all HIV diagnoses, despite making up 12 percent of the population of the USA.[4] HIV transmission and infection rates have increased in the black community, due to intravenous drug use as well as heterosexual contact. However, one of the most dramatic increases in HIV infection rates in the USA has occurred in black MSM aged 13-24, according to the CDC.[5] The CDC estimates that almost two-thirds (29,800) of new HIV cases in the USA are by MSM transmission, and that *more than a third of those new cases (10,600) are within the black MSM population*.[6] They further estimate that within only the black MSM population aged 13-24, approximately 4,800 new cases of HIV occurred in 2010, leading the CDC to state that "In fact, young black MSM now account for more new infections than any other subgroup by race/ethnicity, age, and sex."[7] While some rest content that HIV rates are declining in the USA and that increasingly effective treatments for viral suppression have become more widely available, many acknowledge that "Poor Black and Hispanic Men Are the Face of H.I.V."[8] This is a positive step, but it is only a first step in addressing the myriad of social, economic, health, and other factors that have forced young black MSM into the most ignored and unstable corners of American living.

The questions, "What will be Michael's future?" and "Why were he and so many other young black MSM diagnosed HIV positive in 2012?" are in fact not two different questions at all. The answers lie in unstable home and community environments, a media that associates "gayness" with whiteness and femininity, economic barriers for racial and gender minorities, educational inequality for the impoverished, and the troubling place that black MSM hold within the black community. To better understand the community of young black MSM, is it useful to study the story of Michael, a fifteen-year old MSM who was in the process of introducing himself to this community. We do not know Michael's identity, but we can examine analogous cases of young black men introducing their identities and sexual preferences to others in the black community and beyond, and come to understand Michael's past, present, and future challenges.

African Americans are burdened by their historical representations: "Blacks have been portrayed in the United States … as immoral, promiscuous, deviant sexual beings."[9] This is only the beginning of the stigma and shame that is associated with black MSM. Decades of association of gayness with whiteness in both white and black culture often make personal identity and community identification diverge for black MSM. There is a broad spectrum of black MSM, including those who are homosexual and identify openly as gay, those who are "closeted", those who are bisexual, and increasingly, those within the black community who identify as Down Low, or DL. "Rejecting a gay culture they perceive as white and effeminate, many black men have settled on a new identity, with its own vocabulary and customs and its own name: Down Low."[10] Beyond securing a distinct name for themselves, separate from the label "gay," black MSM have shaped the DL culture into something wholly different from the stereotypical gay culture today. The powerful trend today in gay culture is "coming out," which represents an enormously positive step towards recognition, pride, and self-identification. However the trend in Down Low culture is exactly what the name implies: secretive and anonymous. It disassociates itself from gay, and even GLBTQ culture, rejecting the idea of a closet, and dismissing the idea that there is anything to 'come out' about.

This is particularly because of the strongly negative reaction to those black men who identify as GLBTQ, from both other black MSM who are on the DL, and from the wider black community. In a New York Times piece entitled Double Lives On The Down Low, a black MSM on the DL told the Times:

> If you're white, you can come out as an openly gay skier or actor or whatever. It might hurt you some, but it's not like if you're black and gay, because then it's like you've let down the whole black community, black women, black history, black pride. You don't hear black people say 'Oh yeah, he's gay, but he's still a real man, and he still takes care of all his responsibilities.' What you hear is, 'Look at that sissy faggot.' [11]

If Michael were to come out, he would presumably face incredibly negative consequences regarding his status in this community, his social well-being, his network of support, and even his physical well-being.

An analogous story of "coming out" was recounted by a young man named Roderick. Roderick lived with his aunt and cousins after his parents were incarcerated on drug charges and came out as gay to his aunt when he was 15. He was mercilessly taunted by both his aunt and by his cousins, who called him "an "Oreo" and other offensive names. He said, "It got to where I felt I was going to snap, and kill myself or kill them. I didn't want to do either, so one night I took my cousin's bike and I left, and took a train to New York. I'm just basically dead to my family now.""[12] Another young black MSM was beaten at the age of 14 on the street corner by five boys, before he limped "five blocks home with a fractured leg, fractured rib, broken jaw, nose, and finger, black eye, and bruises. [He] walked passed people whom [his] family considered friends, but no one offered any assistance. [He] knew right then and there that [he] was different and not welcomed."[13] Once openly gay, these two boys ended up joining the welcoming and supportive gay communities, one in NYC and the other in Chicago. This security came at the expense of their places in the black community, whose isolation and violence chased them away.

Another avenue available to Michael as a young black MSM is the DL culture. Men on the DL usually have girlfriends, and they don't usually disclose their sexual activities or preferences to their sexual partners—especially not the female partners.

> Gays to me were white men. The brothers that I hung out with, we never called ourselves gay. We just liked men. One brother asked me where my girlfriend was. I told him I didn't have a girlfriend because I'm gay. Yet he was still like, 'So why don't you have a girlfriend?' He thought I should have a girlfriend as a front.
>
> --Blue Buddha, San Francisco Chronicle, 02 May 2006[14]

In addition to promoting secrecy and anonymity, the DL culture promotes and almost requires a strong image of masculinity. This requirement of hypermasculinity serves multiple purposes. The "thug" image is a functional camouflage and defense mechanism; it asserts independence or separation from mainstream gay culture; and it perpetuates a fantasy of power, independence, roughness and toughness. Many men choose to be on the DL to maintain their connections to the family, friends and community, to find partners without "having to explain yourself, or your sexuality, to anyone," and to assert their power.[15]

For a community that has been deprived of economic, sexual, and social agency for centuries, the DL culture is on the surface a move to reclaim that agency from a history of black oppression, and a mainstream gay culture that seemingly hijacked the GLBTQ movement for white people. But the downsides of DL culture outweigh its positive effects. William, a black man on the DL explains one of the results of DL masculinity: "Part of the attraction to thugs is that they're careless and carefree. Putting on a condom doesn't fit in with that. A lot of DL guys aren't going to put on a condom, because that ruins the fantasy."[16] Hidden behind anonymous DL thugs are their wives or girlfriends, linked unknowingly to a culture that abandons sexual identities as well as sexual histories.[17]

Let's return to Michael, the fifteen-year-old black MSM from Florida. The structures of Michael's life will be destabilized regardless which of the two major avenues he chooses: being on the DL or identifying as MSM or GLBTQ. The DL culture brings secrecy, paranoia, and promotes a fantasy world of anonymous unsafe sex. The DL culture also closes many, if not all of the avenues for sexual health education to reach young MSM by disassociating itself from mainstream GLBTQ culture. This deprives Michaels everywhere of the education that might have prevented them from becoming HIV positive. On the other hand, identifying openly as GLBTQ would likely destabilize the structures of his cultural and familial life, weakening both his economic and his emotional supports. It would subject him to discrimination for being GLBTQ and black from the broader white population; in addition, the black population would discriminate him for "Oreo" as well as GLBTQ.

It is no wonder that there is such an extensive DL culture in so many cities, like Cleveland or Atlanta.[18] But in choosing to avoid the discrimination and barriers present in being openly GLBTQ, black MSM—particularly young black MSM—have subjected themselves to HIV, a virus that thrives in the kind of secrecy and anonymity promoted in DL culture. However, the high and increasing prevalence of HIV in black MSM is not explained by traditional high risk behaviors, such as intravenous drug use, multiple sex partners, or unprotected anal sex.[19] In fact, the culture itself —with its discrimination and violence—has become a risk factor. Compared to their white counterparts, black MSM live a significantly more unstable life, subjected to the structural violence the United States has perpetrated against the GLBTQ and black communities for centuries.

Lower rates of substance use, lower rates of unprotected sex, and fewer sexual partners in the black MSM community should correlate to lower HIV infection rates. But the rates of infection among black MSM are much higher than among white MSM.[20] Though the traditional risk factors do not explain the heightened HIV rates, there are cultural risk factors that do: Black MSM reported less open identification as gay, less disclosure of same-sex behavior, and a much higher incidence of STDs; these are compounded by lower rates of antiretroviral therapy for those HIV positive black MSM, when compared to HIV positive white MSM.[21] While black MSM may seem to win battles against HIV on the field of personal choices, they are losing terribly on the fields of community, economics, and healthcare. This only underscores that while being on the DL promotes pleasure, independence, and an identity that isn't "gay," it does nothing to address the structural violence that makes MSM everywhere at risk for HIV. What's more, DL culture removes young black MSM from the protection and supports of GLBTQ communities.

Asking "What will happen to Michael now that he is HIV positive?" has led us to the factors that facilitated his infection in 2012. At the age of fifteen, Michael lived in a culture that did not educate him about the health dangers of having unprotected anal sex; at the same time, he was in a Down-Low culture that quietly promoted it. If we consider Sumlin, the pervasive effects of DL Culture in Michael's life become apparent. Sumlin associates with many of the hypermasculine ideals presented in DL culture, despite being open about his MSM status. Sumlin, who goes by the name 'sucker4boyz' on YouTube, posted a video diary. During one these videos, he references an altercation he had while driving and tells the camera, "Fuck how I look, I'm from the ghetto and I will beat yo motha-fuckin' ass, and that's on the real." What exacerbates the anonymity and shame associated with DL culture is the inadequate education on sexual and GLBTQ issues, as evinced by the CDC's National Survey of Family Growth.[22] Together the lack of education and the negative ramifications of DL culture creates an unstable environment for black youth identifying as GLBTQ.

More disturbing than Michael's age when he was infected is the difference between his age and the age of his partner: Michael perceived it to be six years, but in reality it was about fifteen years. This is no anomaly among young black MSM. The community health director at Whitman-Walker Clinic in D.C. observed that "In the black gay community, very young black men tend to have their first sexual experiences and relationships with older black MSM ... It's a very resource-driven situation."[23] Many older men have more economic stability, cultural influence, and the experience and knowledge of having gone through a shared struggle. They also tend to face less stigma than younger black MSM. Nonetheless, having older male partners is a risk factor for HIV transmission in the United States and elsewhere, where economic and social power dynamics deprive the younger partner—whether a young girl in Sub-Saharan Africa or a young black MSM in Chicago—of agency and the ability to protect themselves. While intergenerational sex is a risk behavior for all races and genders, it is much more common among those whose personal, familial, and cultural structures are already compromised. Add to that potent mix the low rates of viral suppression and HIV treatment in black MSM, particularly older black MSM. Not only is intergenerational sex more prevalent among young black MSM, but it is more dangerous for them.[24]

With a deeper understanding of the interplay between the Down Low, black, and mainstream gay cultures, it is possible to compare Michael to his non-MSM black peers. However it is not just black MSM who account for the enormous overrepresentation of African Americans in the HIV-positive population: there is a large incidence of HIV among heterosexual black men and women across the United States.[25] This is indicative of an additional set of barriers and pitfalls for all black men, whether they are MSM or not. Young black MSM are are working to create a space of their own and to reduce their personal risk behaviors, but they are continually failed by national healthcare and education systems that ignore them. They are attacked by an economic system built to take advantage of them. They are assaulted and chained down by centuries of racist and homophobic prejudices. This essay focuses on the issues unique to a young man who is both a MSM and black, but has largely glossed over issues that all African Americans face and all GLBTQ persons face.

To change the culture and experience of young black MSM in the United States, issues of race must first be addressed. For this population, familial, social, economic, cultural structures are inseparable from issues of sex and health. In order to preserve social and cultural ties, black MSM have often sacrificed sexual health; this is evinced by the increased rates of HIV infection in their community. Education and destigmatization of sexual and GLBTQ issues could perhaps empower individuals and eradicate DL culture and its dangerous practices of anonymity and hypermasculinity. In turn, treatment for HIV and other conditions may perhaps be accessible to the black community.

It is the interplay within the subcultures that magnifies the violence—structural, physical, and emotional—that an HIV-positive African American experiences if he is a MSM. For the foreseeable future, black MSM will have higher rates of HIV infection than the larger black community, but to change that we need to remove the magnifying glass. To treat this most neglected and most at-risk population, the larger black community must first be treated with education and healthcare: both to reduce the prevalence of HIV in African Americans overall, but also to provide a culturally safe space for young black MSM. Then perhaps the answer to whether Michael would have contracted

HIV in the first place, and whether or not he will receive treatment now, would not hinge upon Michael's race and sexual orientation.

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SEX ED

CAITLIN KEEFE MORAN

They don't teach us enough about bodies. We learn the systems, the stimuli, the raw red muscles, we learn the diseases, the medicines. The anomalies, all bloated and malformed. Purpled. But they never told us how, exactly, to touch another body, never told us that we must take care, and when I am spread out underneath your microscope, pinned down, curled and slightly pink against your sheets, I do not know the language to tell you to be gentle.

They never told us how embarrassing it is to have a body, how much easier it would be to leave my wobbly, sweat-slicked skin behind, and then I could flow into you like air. I could chafe against your hairline, the undersides of your nails, and release you from your body too. We could float away, leave the sounds and the hot, hard membrane, the closed eyes, the smell of the bed, the hands, the fumbling, the clench and release, the moment of pain. The misunderstandings won't plague us in the air.

But I cannot escape the weight of this hairless sheath, this skin, your breath, I crumble, they don't teach us what it means, the inadvertent bruise under my left arm, the bunched-up sinews between your shoulders, how can I read on your body what I cannot read on my own.

But they won't teach us how to the read the signs. The secret is, they don't know either, and they've long since lost the cipher. Our ancestors fit no better inside their skin than we do. They only offer us this: close your eyes, close your eyes, and you will never be able to say, I wasn't told.

HARDSHIPS IN HEALTHCARE:

THE CHALLENGE OF PROVIDING FOR MEXICO'S POVERTY-STRICKEN YOUTH

ILYSSA TAMLER

Poverty—low income and deprivation of basic necessities and natural resources—is one of the most critical human rights concerns in the developing world. Impoverishment can lead to poor hygiene practices, inability to access clean water, inadequate nutrition, a lack of proper education, and limited access to health care. All of these consequences of poverty have a devastating effect on health.

Mexico is one of many developing countries where the standard of living remains low and the levels of poverty high. In 2014, according to the U.S. Embassy in Mexico City, 45.5% of Mexicans were living in poverty, with Mexico's Gini coefficient at 48.3.1 It was also estimated that three-fourths of Mexicans lack at least one of the eight basic human needs as determined by the National Council for the Evaluation of Social Development Policy (CONEVAL) in Mexico. These include a viable income, access to health care, access to social security programs, housing, basic services in the home such as sanitation, food and water, education, and social cohesion. Inevitably, many Mexicans suffer from poor health as a result of this extreme poverty.

I see it first-hand. I am currently serving as the clinic assistant in Casa San Salvador, Nuestros Pequeños Hermanos (NPH) Mexico, located in Miacatlán, Morelos, Mexico. This organization offers a safe and loving environment for over 500 abandoned and vulnerable children from all over the country. These children are provided with education and health care that would likely be unavailable to them outside the walls of this organization. This is an incredible feat, as it gives so many underprivileged kids a chance to break out of the poverty cycle that afflicts many in developing countries.

Many of the children here at NPH had been living in extreme poverty, to the extent that their parents could longer afford to provide for them. Others arrive malnourished, severely abused, or very ill. Thus, it comes as no surprise that many of the children manifest minor to severe health concerns.

One child in particular illustrates the dire health conditions with which some of our children arrive. This girl, now 15 years old, recounts her story and emphasizes the scarcity of food outside of NPH. She was so skinny that people on the street would sometimes give her a taco or two just to keep her alive. Her parents, however, could not provide her with a lifestyle that promoted her well-being.

Health care is beyond the reach of many of the nation's poor. Before the illness that brought her into NPH, she had received medical care only once. When she was continuously vomiting and bleeding from the nose, her parents finally sought medical help. She was taken to the nearest clinic that would accept her family's seguro popular insurance, which is the cheapest health insurance plan available in Mexico. Even so, this health plan is still beyond the means of many Mexicans. At this point she was quite literally skin and bones, and the doctors feared that she likely had severe anorexia, diabetes, or cancer. She was ultimately diagnosed with severe malnourishment, and as a result of this incident, the state took her from her family and placed her in a safe and healthy environment in which she could be properly cared for.

Now at NPH Mexico, this young woman enjoys good health and leads a relatively normal life. She commends the medical clinic and living community for providing her with the resources necessary to maintain her health. The clinic at NPH Mexico truly is able to help restore the health of the children, and in many ways is a crucial part of their success and well-being within the home. Without this access to care from doctors, nurses, and skilled volunteers, many of these children would not be able to thrive the way that they do. However, even the health care system within NPH has its flaws, which I believe are a direct result of the poverty within Mexico. Oftentimes the clinic runs out of necessary medications, whether for patients who take medications daily or for those who come for something to soothe their headache or sore throat. In this way, the clinic is sometimes plagued with an inability to provide for the children's medical needs. The organization is not necessarily at fault for this, as it relies on donations for many of its medications and supplies, and it must ration the funds that it receives. The equitable and effective distribution of these funds is an urgent concern for the NPH clinic. Furthermore, when the home places an order for a medication purchase, it can take up to two months to receive the shipment, leaving children without medication for prolonged periods of time. Although donated medications are important resources, they do not always align with the treatments that children need.

This is not a problem that is unique to this organization, however. Poverty often directly correlates with a lack of access to crucial medical care, and NPH—like many other global health care organizations—faces this problem daily. Lack of access to medicine is a common theme throughout the world, and thus is a pressing concern addressed by medical ethics.

Inadequate resources, technology, and equipment often contribute to misdiagnoses in the clinic, which is yet another ethical concern. For instance, I had been experiencing severe dizziness with mild back pain, and was diagnosed with a urinary tract infection (UTI). The full dose of antibiotics did not relieve my symptoms, so I was sent to a laboratory that works in conjunction with NPH to provide free laboratory testing. My lab results showed that my white blood cell count was extremely high, suggesting that my infection was still present. This time I was treated with intramuscular antibiotics for 5 days.

When the symptoms had still not subsided a week later, I was sent to the lab once more to determine which antibiotics would be effective and which would be resistant to the bacterial infection. As it turns out, my infection was resistant to all “normal” antibiotics, and I would have to resort to intravenous antibiotics, the strongest and most potent available.

I flew back to the United States to get a second opinion regarding the treatment I had been told I would need. However, after being tested by three different doctors, in two different states, I was told I did not even have a UTI. My dizziness, I was told, was likely the result of constant dehydration, and I had no bacterial infection whatsoever.

This is just one of what I believe to be countless examples of misdiagnoses within the medical clinic at NPH. Laboratory technology had confirmed what the doctor had told me, and yet it still turned out to be incorrect. Furthermore, these inaccurate results led to overmedication, which is another ethical concern.

Overmedication with regard to antibiotics can promote drug-resistant bacteria, making it more difficult to treat bacterial infections over time. Children often come into the clinic with a common cold or with symptoms similar to mine, and they are given antibiotics to treat these illnesses. However, it is likely that most of these infections are in fact viral, as most colds are, or nonexistent, as was the case for me. As a result, the clinic at NPH may be promoting the development of bacteria that will not respond to most basic antibiotic treatments, leading to even greater health concerns.

The dilemma here, however, goes beyond the generation of drug-resistant bacteria. Medications, which can be sparse within the home, are not being rationed effectively because they are being over-utilized. If a bacterial infection actually does occur, the home may not have a supply of the necessary medications because the drugs have been already expended.

NPH Mexico truly is a wonderful place that offers children opportunities and resources to which they would ordinarily have no access. Yet, the organization is not immune to the many ethical concerns that afflict health care delivery in developing countries. It suffers many difficulties in its ability to care for its children simply because of its location.

There is certainly room for NPH to improve, but there many are social issues within Mexico that contribute to NPH’s difficulties. Until medical ethics decidedly addresses the medical implications of dire poverty, medical organizations like NPH will not be able to provide the total care necessary for their patients. Only when it addresses the underlying issues of the greater health concerns will it be able to change the face of health care for the better.

ENDNOTE

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HEART-SHAPED

SAMANTHA RODRIGUEZ

The doctor said it was "heart-shaped." He said it imitated the commonly accepted perfect symmetrical shape formed by two similar curves with a triangle cusp at its base. My sister, Amanda, was fourteen and I was ten, so neither of us could quite understand that"heart-shaped" could be anything but positive. It is used in The Legend of Zelda to inform gamers about the number of lives they have. It is found on our boxes of Cheerios to indicate health and low-cholesterol. It is written in text messages, plastered on cards, and doodled in diaries to indicate love, romance, and affection. But, the iconic shape of the heart actually originated from the shape of the silphium plant seeds once used by Ancient Romans as an herbal contraceptive. So to the ancient Romans of the past and to doctors of the present, "heart-shaped" is associated with infertility and prevention.[1] At fourteen years old, "heart-shaped" went from being the perfect semi-circle borders that surrounded "Amanda loves Jacob" to dented upside-down tear drops falling from her eyes as the doctor used it to describe the shape of her uterus.

My mother had picked up my sister and me early from school one morning after receiving a call that my sister fainted in the lunchroom due to excruciating abdominal pains. From school, we went directly to the family OB/GYN. We entered the pink office, my sister was seen immediately, and we lingered for what felt like days in the seating area, patiently waiting for the doctor's "diagignoskei:" Greek for "thorough knowledge," and the root for diagnosis.[2]

The doctor pulled out a folder from his drawer and juxtaposed two images on the table as he explained, "The image to the left is a normal uterus, and to the right is what your daughter has, a bicornuate uterus." "Would she ever be able to have children?" was the question that my mother painfully asked as her eyes became watery and her hand grazed along her belly, with the other holding my sister's head to her heart. The doctor answered this question with, "I'm sorry to say but from the looks of it, you're daughter will never bear children. Again, I'm so sorry." The definitive adverbial "never" echoed in my ears, saturating his words with certitude, authority and self-assurance. My sister grew cold, her eyes avoiding contact with mine, as she sat upright, staring at the white wall in front of her, embellished with pictures of normal uteri.

According to the gynecologist surgeon, Dr. Vimee Bindra, "a bicornuate uterus is when the uterine cavity is made out of two elongated horns instead of the normal uterine triangular shaped cavity."[3] However, the exact cause for this condition is unknown. Science claims that my sister's heart-shaped uterus developed because one strand of DNA, by a random chance event, had a genetic mutation, leading to irregular uterine development.[4] So, how could this doctor's diagnosis be so rich with confidence and jurisdiction for a condition caused by chance, embedded with unknowns? How could he act like everything he said was entirely true, rational, and scientific when science had yet to logically explain the condition?

His "thorough knowledge" was taken as fact, spoken with the voice of god and so my sister was judged infertile. In a study published in the American Journal of Medical genetics, it was found that only 1.6% of women are diagnosed with a uterine anomaly annually. This condition causes women to struggle with risks of miscarriage, premature labor, birth defects, and not having children, for the rest of their lives. For each of these women, the chances of them
having a successful pregnancy were approximately 60%.[5] However, at the time, these percentages and quantitative analyses had yet to be discovered, and I'm not even sure they would have mattered. At the time, all that mattered was the doctor's diagnosis that forced my sister into this small percentage of unfortunate women.

Growing up with only one sibling, my sister and I used to spend hours dreaming up games we could play if we had more siblings. She would say enthusiastically, "If we had a bunch of brothers we could start our own football team, Sam! Imagine how much fun it would be?". Some times her daydream would turn into a full life plan: "I'll have 10 kids, you have 10 kids, and we could be neighbors some day! But no name-stealing!"

But, years went by after the diagnosis and my sister only grew colder and more distant. The daydreaming about child names and big families stopped—forever halted by the haunting judgment of the medical practitioner. She and I barely spent time together. For a while, seeing the shape of a heart reminded me of wounds, neglect, and sterility. There was no space for love and affection in that dented shape. I blamed medicine and her dented condition for putting a dent in our relationship and a dent in all of our hearts.

For seven years, my sister assumed the dents in her heart-shaped uterus meant there was no room for a child. For seven years, she believed she was infertile and, for seven years, my family believed the doctor's diagnosis was god's truth. As a result, she rebelled sexually, stopped using birth control, and used her diagnosed infertility to defend her sexual promiscuity. But, on the morning of June 10, 2010, my sister's anomaly once again did the unexpected.

"Can you come in here for a minute?" my sister asked, as she directed me into her room. She patted her bed, stared at me for a while, and then finally blurted, "I'm pregnant."

"Are you sure, Amanda? Are you really sure? Did you take a test? This isn't just a 'feeling,' right?" I responded.

With her hand over her tummy, and upside-down hearts gleefully falling from her eyes, she responded with, “Yes. Yes to everything.”

My family was less than thrilled about her being pregnant at only 22. She was a college-drop out, still lived at home, and was unmarried. So of course, the news initially set off cannons —very angry Spanish cannons. But, eventually, the mistake was overshadowed by the fortune of the situation: the doctor had misinformed us, and my sister was having a baby. Now, to my sister and my family, “heart-shaped” not only represented the dents in her uterus, but it also somehow re-adopted the meaning of love and affection.

It is true that the diagnosis incited my sister’s deviant, risky behavior that caused seven years of family devastation. But, in the end, the heartbreak was worth it. Had it not been for the misdiagnosis, my sister would still be on birth control and I would not have my beautiful nephew to whom I come home every holiday season. I wouldn’t have this nephew, with this genetic sequence, with such a unique personality, who calls me “titty” instead of “titi,” who says “I love you” when I cry, who calls me a princess when I put on lipstick.

However, my family, and especially my sister, could not forgive the doctor or medicine. It wasn’t the misdiagnosis that my sister was angry about. She was angry with herself for never getting a second opinion, for viewing the doctor as omniscient and for wholly trusting the doctor’s diagnosis to be “thorough knowledge.” She was angry that she trusted rationality too completely and didn’t leave room for life’s unexpected deviance.

Maybe the misdiagnosis isn’t that the doctor made a claim to the best of his ability. Maybe the real misdiagnosis is in our judgments of medicine, in believing his ability was godly, and in our tendency to neglect that doctors are human, too. This misdiagnosis is something that we are all guilty of. We visit doctors and proceed to check off their symptoms: the doctor speaks authoritatively; he studied in medical school for ten years, memorized a lot of hard books, makes a lot of money, and has the backing of science. So, the doctor is god, right? This is where we place doctors on a pedestal, implicate divinity, hang onto their every word, and rationalize that because they are gods, their diagnoses of the patient must be god’s truth.

If, going forward, we all left room in every diagnosis for some of life’s unknown, then both we and doctors would understand that anything the doctors say is subjective to a certain degree. We would open our eyes to the reality that science and medicine do not know everything, and such awareness would lessen the power that diagnoses have to inflict pain. Maybe this would leave room in medicine for less hate and more forgiveness; less godliness and more humility; less cold and more warmth. This would bring an element of humanity and heart to medicine, revealing that medicine is actually just an art that is based on a science.

The stem “mis” comes from the proto-germanic stem “missa,” which means “divergent, astray.”[6] In this way, the doctor’s misdiagnosis caused my sister to diverge from using birth control, from having healthier relationships, and from seven-years of happiness. Our misdiagnosis of doctors leads us all astray: we leads them away from their humanity and lead ourselves away from making a little room for the irrational and believing in fate. But, it is when these diagnoses reveal themselves as imperfect, when we realize we've made a mistake, that we gain the ability to distinguish the right path from the wrong one.

Misdiagnose also comes from the gothic "misso" or "difference, change."[7] Sometimes being led astray is what is supposed to happen when our lives need resuscitating, when we need more blood pumping through our hearts, when our lives need change. Misdiagnoses can be wake up calls that show us that life doesn't always go our way, that trusting the rational isn't always rational, that medicine and science make mistakes, and that nothing in this world is perfect. My nephew is an indirect product of a misdiagnosis; he was nurtured in a heart-shaped uterus that a doctor claimed wouldn't have the space. He's also a product of a mistake; his birth was unplanned and his mother was not ready. But, he is also responsible for bringing joy to seven years of misery. So, if you ask me, we need "missa," "misso" and "diagignoskei" because, sometimes, what we believe is "thorough knowledge" needs to be "led astray."

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SELLING CLEAN

SAHIL ANGELO

It's rumored that former President Bush, before leaving office, recommended Obama use hand sanitizer as a cold preventative. It seems like a sound suggestion: the President shakes approximately sixty-five thousand hands year, exposing himself to a plethora of germs.[1] Yet, Obama is not the only one at risk. Think about everything you've touched today: your computer, phone, a door handle, a shoelace—all of these objects have millions of microbes that accumulate onto your hands. This icky information might tempt you to also follow President Bush's advice, but he has a history of making broad claims that require more research. In fact, the antimicrobial gels are harmful and are not any more effective than regular soap and water.[2] This begs the question, why is hand sanitizer everywhere, including the White House?

The story begins in Bakersfield, California, a city about 100 miles north of Los Angeles famous for gas, agriculture, and country music. It was there, during the sweltering heat of 1966, where nurse Lupe Hernandez made a discovery: alcohol delivered via gel could clean hands in the absence of soap and water. Alcohol's disinfectant properties have been used for centuries: the Egyptians used it to clean bodies before mummification and doctors during the 19th and 20th century used it as disinfectant. Hernandez's brilliance was the delivery in gel form, making it more effective and easier to use. Stricken by her idea's commercial potential, she called an inventions hotline and began a patent project.[3]

At first, Hernandez's discovery only affected hospitals. In the 1970s, surgeons used antimicrobial scrub to sterilize themselves because it prevented patients from bacterial infections during their procedures. Over time, antibacterial use permeated all regions of the hospital. While useful, the soaps in the 70s were problematic: they were either very greasy or they turned doctors' hands ghost white as if doused in rubbing alcohol, causing skin problems.

In 1988, a family-owned hand soap company, Gojo Industries, developed a new gel-based hand cleaner that protected the skin. Despite its benefits, the company lost money on their product for over a decade. According to Joe Kanfer, the CEO, "it drove the sales guys crazy. They couldn't sell the stuff."[4] The product was called Purell. Sales still stalled despite an endorsement in the mid-90s from Wegmans, a New York supermarket chain who installed Purell dispensers in every store. Gojo Industries needed a market jolt. The SARS epidemic was happy to provide.

SARS was just the beginning of what would become a decade of public health scares. Bird flu, swine flu, and other epidemics have instilled a deep, almost visceral fear of germs. Companies have capitalized on this antimicrobial anxiety, and have spent millions of dollars driving up the demand for their product by further socializing us to be germaphobes. For example, in 2008, Purell launched a campaign called "What You Touch." The ad featured four different hands constructed of a number of images representing different things people touch on a daily basis. One hand is cut into separate sections as if it were a state divided into electoral districts. Everyday objects like laptops, pencils, hammers, and phones each had their own zone. The second hand is divided in the same fashion, but replaces objects with cartoon drawings of various microbes. The third hand features short snippets explaining what dangerous bacteria consumers can pick up from a variety of "everyday objects." The fourth and final hand is free from text, cartoon germs, and objects. It simply coated with Purell as if it were a clear glove protecting it from the world's dangers.

Ads like these have proliferated since the 2000s, and most use rhetoric that plays on the fear and the subsequent need for security that is hardwired into our human psyche. Capitalizing on these two aspects of human nature is risky, and it can have significant consequences. For example, 9/11 generated widespread fear and insecurity in the American public, and much of the rhetoric that drew on these feelings, in part, led to many people demonizing an entire religion, rather than the select extremists who were responsible. In addition, these feelings clouded our collective ability to think critically as a society, which when combined with misinformation, facilitated rash actions – like the invasion of Iraq.

The rhetoric used to describe bacteria produces the same fear-induced phenomena with bacteria. We treat them like tiny terrorists: they are deadly, irrational, and unpredictable. The 2014 Ebola epidemic outbreak illustrates this point perfectly: the U.S. public became hysterical after Thomas Duncan became infected; Ebola headlines dwarfed equally pressing news like ISIS and the crisis in Ukraine, for instance. In an effort to "protect the American people," we have demonized all microbes. (We've all seen the signs on antimicrobial soaps that say "kills 99.99% of all bacteria".) In fact, over ninety percent of bacteria in the world are either harmless, or beneficial. Bacteria help us process our food, regulate our blood pressure, degrade deadly toxins, and the list goes on. Recent studies have also elucidated how the presence (or absence) of certain stomach bacteria can prevent obesity, heart conditions, and other chronic diseases.

Despite these facts, our fear has turned bacteria and its microbial friends into public health enemy number one. Companies like Purell have catalyzed this socialization, driving us into the arms of their products without critically evaluating their safety and efficacy. And it worked: Purell's market research showed one in five people had a hand sanitizer product less than 2 feet away at the time of their questioning.[5]

What most people do not realize is that not all hand sanitizers are safe. There are two classes of products:

one is purely alcohol-based and the other contains either triclosan (TCS) or triclocarban (TCC), two chemicals that have been shown to be harmful to humans. The chemicals in the latter class allow companies to label their products as "antimicrobial." It is a successful marketing gimmick, and now TCC and TCS are everywhere: soaps, detergents, carpets, clothing, toys, paint, and even pacifiers all have antimicrobial properties, and are labeled as such. There are now over 2000 antimicrobial products in the U.S. market alone that generate annual profit margins exceeding 1.4 billion dollars. TCC and TCS are most prevalent in two specific products: antimicrobial soaps and gels. According to Rolf Halden, Founding Director of the Center for Environmental Security and cofounding member of the Center for Water and Health at John's Hopkins University, over ninety-three percent of liquid soaps commercially available contain TCC or TCS.[6]

Scientists can now detect the presence of these chemicals in our body due to overexposure. Halden discovered these chemicals in over ninety-seven percent of women's breast milk while the CDC estimates they are present in the urine of seventy-five percent of the U.S. population. Theoretically, we should know what is floating around in our bodies, or what mothers are transmitting to their children. The unfortunate reality is that we are often uninformed consumers.

My dear friend Kelly exemplifies this insidious consumerism. Kelly is by far one of the smartest people I know: she graduated college Summa Cum Laude and Phi Beta Kappa, and is a medical student.[7] One day, we were venting about people's proclivity to avoid handwashing after using the bathroom, especially among the male population (fun fact, 50 percent of men do not use soap; 78 percent of women do). Kelly ended the conversation by whipping out a small bottle of red pomegranate-mango scented hand sanitizer, proclaiming it was her "solution to the world's filth."

As she squirted a blob out onto her hand, I noticed the active ingredient was "triclosan...0.5%." The hand sanitizer flaunted its antimicrobial prowess, claiming it is "long-lasting clean" because it kills "99.9% of germs." Concerned about her exposure, I asked Kelly if she knew what was in her gel. She nonchalantly shrugged.

"What does it matter? They kill dangerous microbes and that keeps me healthy."

It does matter because antimicrobial compounds like TCC and TCS are double-edged swords. While they kill 99.9% of bacteria, the 0.1% that survives can become resistant and proliferate. This creates a horde of super-bugs that are harder to kill and more pathogenic. Furthermore, TCC and TCS (and pure-alcohol based sanitizers like Purell) have shown to facilitate allergy sensitization because they are not selective – they remove both good and bad bacteria. Beneficent bacteria often process allergens and their absence can cause adverse reactions to our environment. It comes as no surprise the U.S. has the highest prevalence of allergies in the world.

Allergies and super-bugs are not the only health concerns surrounding TCC and TCS. The two compounds are also endocrine disrupters, or compounds that alter hormone levels in our body. For example, TCC and TCS mimic estrogen by binding to their receptors, causing the body to respond as if it had an excess of estrogen. Scientists do not fully understand the impact of estrogen mimics, but they include the creation and spread of breast cancer, over development of female sex organs, and the feminization of men. An excess of TCC and TCS can also blocks thyroid hormones uptake, which regulates our physiological metabolism. Recent studies also show these chemicals cause liver cancer. The endocrinal effects can have devastating consequences for our bodies.[9]

The scope of damage extends beyond humans. James Forester, an environmental sociologist, once wrote that nature, now more than ever before in history, is shaped by humans. TCC and TCS prove his theory. Over 95% of TCC and TCS are disposed of through bathrooms, kitchens, and other residential drains and consequently contaminate our water. A recent study conducted by the Environmental Protection Agency (EPA) found detectible levels of triclosan and triclocarban in over one-third of the U.S. public water facilities.[10,11]

These compounds, when dissolved in water and exposed to sunlight, are converted into a class of highly toxic chemicals called dioxins. According to the World Health Organization 2010 fact sheet, dioxins cause "reproductive and developmental problems, damage the immune system, interfere with hormones, and also cause cancer."[12] This matters because ninety percent of human exposure to dioxins is through fish, shellfish, meat, and dairy. Contaminated water infects fish, crops, cows, chickens, and pretty much anything that consumes or lives in water. Yet the damage does not stop with dioxins. Most public water systems contain chlorine, which combines with TCS and TCC to form chloroform, another carcinogenic.

Unfortunately, the TCChain reaction continues as we expand our ecological viewpoint. Swaths of scientists are finding massive levels of TCC and TCS in plants and algae. Dr. Halden, the aforementioned scientist at Johns Hopkins, shows that TCC and TCS are "100-1,000 times more effective at killing fish and algae than they are killing bacteria."[13] Dumping these chemicals as waste products into our water systems can disrupt the food chain and cause unpredictable damage to our ecosystems.

This shocking information leads us to ask a simple question: why are these compounds still commercially available, especially given the fact that soap and water are more effective? How is it that Kelly, a college educated woman, or the former President do not know what they are putting into their body? What about people less privileged than Kelly and former President Bush? Is the systemic fear-mongering truly this pervasive and oppressive?

A glib economist would retort it is basic supply and demand. I call it predatory market economics. It is wrong to supply a product that harms people when viable, healthy alternatives exist. The unregulated supply and demand capitalizes on the uninformed like Kelly. I just stumbled upon this knowledge because of a college biology class I took in college that had one goal: to transform us into scientifically-literate consumer activists. I am in the minority. Fortunately for the majority, there are federal agencies like the Food and Drug Administration (FDA) and the Environmental Protection Agency (EPA) who have the power to ban these chemicals from the market. Yet, the sheer volume and use of antimicrobial products in stores, hospitals, and schools suggests that these regulatory agencies are not up to snuff.

The FDA is the arm of the U.S. Department of Health and Human Services that ensures drugs, vaccines, and other medical products are safe and effective for humans and animals. They have the regulatory power to stop companies from incorporating TCC and TCS into their products by deeming them unsafe, but how they determine safety is crucial. They begin by selecting a series of scientific studies published about the product. Then, they apparently sift through all scientific studies with a fine-tooth comb. If the study seems sound, they will approve the product.

Their process seems logical, but any scientist will tell you that how research is conducted matters. It is easy to skew studies to yield positive results. Academics circumvent this problem by having others peer-review their work in published journals. This process establishes a degree of trust. Corporations, however, are not required to submit their work in peer reviewed journals and are notorious for conducting flawed research. If the FDA bases their decisions on methodologically flawed studies, it will subsequently create unsound policies that allow innocent people to suffer. Thus, the question is: which studies does the FDA choose and why?

A brief history on FDA policy surrounding TCC and TCS might reveal the answer. Federal regulators first examined the compounds in the 1970s and first sought regulations in 1978. However, very little was actually achieved. The New York Times argues this was because of the "agency's slowness" and "industry lobbying." In other words, the FDA risked the health of U.S citizens either because they were lazy or accepted bribes from profit-motivated businesses. It is absurd to think that an agency whose sole purpose is to protect the health of people will shamelessly neglect its core functions for either money or a 32 year-long break. Lobbyists are the primary cause of the FDA's sluggishness. They acquire political support by donating large sums of money directly to political campaigns, or indirectly through political action committees. If oil conglomerates, pharmaceutical companies, and other corporations control Washington through these means, it is reasonable to expect the 1.4 billion dollar antimicrobial industry to do the same.

It's easy to get frustrated, but recent events gives us hope. In 2010, The Natural Resource Defense Council sued the FDA and forced the agency to make a final decision about TCC and TCS by 2016. Recently, the FDA admitted the chemicals might adversely impact health through antibacterial resistance and endocrine disruption. In December 2013, the FDA finally took action: they gave antimicrobial companies one year to submit data proving TCC and TCS do not harm humans. Even though this is a positive step, this demand should have been made thirty years ago before the chemicals were released commercially. The organization's fundamental purpose is to ensure human safety. The EPA is also to blame when considering the damaged caused by environmental feedback loops. These chemicals harm humans either directly or via the environment. This is a fact confirmed by the scientific community, so why does it need until 2016 to make a decision? Even worse, why does it take a lawsuit for the FDA (and EPA) to act? It is not only absurd, but it undermines the credibility of these regulatory agencies. Fortunately, some frustrated states like Minnesota and Iowa have sidestepped federal regulatory bodies and banned the chemicals in their state.

FDA supporters argue that their response to TCC and TCS is an anomaly, but that simply isn't true. I have a one-litre blue Nalgene bottle that has a giant green "BPA FREE" sticker. Almost all plastic water bottles now sport similar stickers, but this is a recent phenomena. BPA used to be in almost all plastics and was a goldmine for chemical distributors. In 1997, a movement began to eliminate the substance from the market after scientists suggested BPA was an endocrine disruptor. By 2007, there was definitive proof that BPA greatly damaged human health, but there is still controversy today within the FDA whether or not to ban the chemical. TCC, TCS, and BPA are three of hundreds of dangerous compounds that the FDA refuses to ban.

I once went to a lecture about the benefits of chocolate, and there the presenter told me a startling fact. Americans decay at a slower rate than Europeans because we have many more synthetic chemicals in our bodies. The EU has banned over 1100 chemicals due to their toxicity. Of those 1100 chemicals, the FDA has only banned nine. The sheer discrepancy between the two in regulatory power and action is embarrassing. In fact, the lack of consistency in terms of regulation has stalled trade agreements between the U.S. and the EU. Until there is regulatory convergence, some free-trade agreements will continue to stall. It seems the EU is giving our treasured unregulated market the European equivalent the middle finger.

The system that sells clean is a vicious cycle: disease causes public fear of germs, driving the demand for some form of protection. The clean-industrial complex produces antimicrobial compounds that are ineffective and toxic both to humans and the environment; yet they fearmonger via advertisements. The federal regulatory agencies turn a blind eye until forced otherwise by grassroots movements. To make matters worse, federal bans on compounds like TCS or TCC encourages companies to replace them with other potentially harmful compounds in order to maintain their profit margins. The end result is the same: widespread health and environmental problems.

What are we supposed to do in the face of an oppressive and deceitful system that is capable of duping future doctors and former presidents? It is tempting to posit that we, as a society, need to be informed consumers and avoid these products. It is appealing because it puts the onus on us, as individual actors. Unfortunately, that argument does not work for two reasons. The first reason is rooted in inequality: not all consumers have equal access to the same information, nor have the education to understand the impact of chemical like TCS or TCC. It is unfair to expect everyone to be informed in an inherently unequal society. The second reason is practical. We simply do not have time to investigate every object we touch. For example, almost every dye used in clothes is toxic. Investigating our food, clothing, hand sanitizers, etc. are all laborious, time-intensive projects. The clean industrial complex profits from consumer ignorance, so instating real change must come from above.

The FDA and EPA need to have more teeth. Overhauling aspects like their data review process will help, and should be a top priority. In the absence of consumer activism, these federal organizations should be a voice for the voiceless. In doing so, they are automatically empowering us to be smarter, more informed consumers. We are not being sold clean; we are being sold toxins under the guise of cleanliness. It is time to end our war on microbes, and reclaim what we have lost: our capacity to think, our capacity for action, our environment, and our health.

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KNEELING DRUNKARD’S PLEA

CHRISTINE DEGENAARS

Kate, I called you today
but you didn’t answer. I counted
each ring and the seconds it took
for the silences to break into another.
Kate, I counted.

Kate, if you still lived
in Tennessee would you have answered?
Would you have smiled on the phone until
your teeth touched the receiver? Kate, I bet you,
if you still lived here, you would.

Kate, I was calling because I’ve spent
the whole day with Diana and her words—
I feel like her words are swallowing up mine.

It’s like those mornings after we curdled the night
talking, twirling your words up in mine until we didn’t know
who’s was which. Remember how rough our throats felt,
pickled and barmed, don’t you remember?
Kate, I was calling because you have to remember.

Kate, Diana has cinched up my words. Diana’s swallowed
me. Kate, Diana says you’re still here—that your eyes
are in each rosary bead and your smell is in the carpet.
Diana says you smell like my carpet. Kate, tonight,
I’ve found you in the carpet. She’s stolen my words.

Kate, I’m sorry. Tonight, I took my oxycodone
and I didn’t read the label—no, I ripped the label and the pills
pricked and barbed my throat. Kate, when my nose touches
the carpet, will you still kiss me?
I called you today and you didn’t answer.
Kate, I’m sorry.

WHAT NOBODY TELLS YOU ABOUT YOUR MOM'S BREAST CANCER

Nobody tells you that at first your mom will laugh along when you tease her after finding a strand of her hair in the food she cooked because the chemo is making it fall out, but after a while it upsets her and humor loses its comfort.

Nobody tells you how to—or whether you should—tell your friends that she's sick. How hard it is to comfort them, because you feel like you deserve the comfort. If they're too sad, how it is awkward and makes you uncomfortable, and deep down it worries you because should I be more upset? Or if they're not sad enough, how you get angry for their lack of care and understanding. And then you have to do it again when the doctors have decided she's dying.

Nobody tells you that during her last days, your mom isn't your mom anymore. The painkillers have knocked her unconscious, or worse, sleepless and hallucinating. When you realize it's the end, it's too late, because she's been transformed into an incoherent, unrecognizable woman, not the woman who pushed you on the swings or wiped away your tears. The movies show dramatic last words, but you can't remember hers because they didn't make sense or didn't seem like they'd be her last.

Nobody tells you how hard it is to watch your aunt with Breast Cancer at your mom's funeral; you can't even tell her that everything will be okay anymore because it may not be.

Nobody teaches you dead-mom etiquette. What's the correct response to a boy who jokes, "You must not care about Breast Cancer," because you forget to wear pink to an October football game? Some things you can awkwardly laugh off but some leave you angry. Like the classmate who argues that free health care isn't necessary, who obviously has never had a parent die of cancer, so he doesn't know medical bills cost over $1 million. Or a stranger who comments that fundraisers should focus on other types of cancer, because he's "pretty sure Breast Cancer isn't even that deadly anymore."

ISABELLA DUFFY

No one tells you how to control your angry, bitter jealousy. You find yourself heatedly commenting on a Her Campus article titled “My Brave Survivor” because being brave doesn’t always lead to survival, because your mom was the bravest person you’d ever seen and she didn’t survive. You find yourself comparing your tragedy to hers, and you decide yours is more tragic. No one tells you not to compare your pain to others. No one tells you that people handle pain differently, so you can’t compare even if you wanted to, because comparing doesn’t even help you.

But most of all, no one tells you about the love you’ll find yourself surrounded by, the selfless things people will do for you, who then reject your thank you’s. No one could prepare you for when your neighbors and friends coordinated a dinner schedule so your family doesn’t have to cook. Or when you were at the mall or at a restaurant or a park with her when she was sick but still alive, and strangers introduced themselves as survivors, or offered prayers of healing and strength, and even though you’re not religious you appreciated it. Or when after her funeral, cards arrived in the mail from classmates you didn’t know existed, offering condolences or sharing that they’ve been through the same. Or when your friends’ moms offered to take you prom dress shopping, then later shopping for college.

And no one tells you about the feeling of peace that finally comes when you realize how much you look like her in pictures, and you’re proud instead of spooked, or when you hear her favorite band on the radio and you sing along instead of tear up, or when you watch those videos of her that you replayed at night when you couldn’t sleep because you needed to hear her voice but now how they comfort you instead of make you feel worse, and when all the things that made you miss her still make you miss her, but they don’t make you sad anymore.

CONVALESCENT SERUM THERAPY
A DISSENTING VIEWPOINT

ANDREW HAWKINS

The acute outbreak of the Ebola virus in West Africa has been a disturbing event.[1] Ebola is a pathogen for which there is no known treatment.[2] Healthcare professionals are left without adequate clinical infrastructure to combat this high-mortality disease. In response to this reality, the World Health Organization (WHO) has turned to an experimental treatment: convalescent serum therapy. WHO approved its use as a treatment for Africans suffering with Ebola. The organization made this decision without comprehensive consideration of the historical precedent for provision of experimental therapy or scientific evidence for the safety and efficacy of plasma transfusion.

Variolation (cowpox inoculation) was first tested during the smallpox outbreak in Boston in 1721 by Cotton Mather, the famous New England cleric and physician.[3] That epidemic infected nearly half of the population (~12,000 citizens). The mortality rate for the outbreak was 14% for unvariolated individuals and 2% for variolated individuals. Mather's work prefigured the current process of clinical trials, in which scientists perform comparative analyses to determine efficacy. The hallmark of his procedure was controlled, randomized sample groups that featured subjects receiving treatment and subjects receiving the conventional care of the time. Today, drug testing is conducted in three phases.[4] Phase I tests 20-30 subjects to determine drug metabolism and toxicity. Phase II samples a relatively small group to examine effectiveness, short-term side-effects and risks. Phase III establishes effectiveness in a large population. A drug receives approval status only after passing rigorous standards set at each stage.

Problem Undertaking Phase II Trials in Africa

The current challenge in the Ebola epidemic is designing a proper Phase II trial in the African clinical environment. Current vaccine candidates, cAd3-EBOV (cAd3) from GlaxoSmithKline (GSK) and the U.S. National Institute of Allergy and Infectious Diseases (NIAID) and rVSVΔG-EBOV-GP (rVSV) from NewLink Genetics and the Public Health Agency of Canada, are not expected to complete Phase II trials until the first quarter of 2015.[5] Even then, they will most likely be available only to healthcare professionals volunteering for NGOs.[6] According to a recent article in the New England Journal of Medicine, "the design of these proposed trials in exposed populations raises many complex questions that pit issues of scientific rigor against feasibility and acceptability."[7] There is no approved vaccine presently available for Ebola patients.

As with other clinical trials, a randomized, controlled trial generates the most robust data.[8] Subjects enrolled in studies must be asymptomatic but present evidence of early-stage disease progression. For example, patients infected with Ebola would need to be identified before the development of hemorrhagic fever and the diarrhea and vomiting that occur after a mean incubation period of 6.3 days.[9] This identification requires point-of-care detection technology that has not yet been utilized. Although there has been progress on the development of oral swabs for antibody detection and serum confirmation testing, these have not been subject to clinical scrutiny.[10]

Other factors that complicate clinical testing are traditional practices in West Africa that prompt family and friends to come in contact with sick individualws or hide loved ones because of a distrust of government officials.[1] For instance, due to years of armed conflict, Sierra Leone, Guinea and Liberia have a history of instability in their healthcare infrastructure.[11] For a Phase II trial, African patients exposed to Ebola would need to undergo plasma transfusions at the first sign of symptoms to test convalescent serum therapy for symptom reversal and recovery. This treatment could also be tested by prophylactically transfusing uninfected individuals to assess the overall infection rate. Either of these methods may prove to be a difficult undertaking given the current political situation.[12]

Testing for Efficacy

A study of the efficacy of convalescent serum therapy during the 2009 H1N1 influenza epidemic serves as a model for a comparative analysis in Ebola patients.[15] Subjects would be enrolled in a study with informed consent. Confirmation of infection would be established by reverse-transcription polymerase chain reaction (RT-PCR) detection of viral RNA.[10] Patients with contraindications for convalescent serum transfusion such as hypersensitivity to immunoglobulin would be excluded. Recovered patients would need to provide informed consent for donation of convalescent plasma. Whole blood would be drawn through an intravenous catheter and then centrifuged to collect plasma containing desired antibodies in a process called apheresis.[16] Plasma would then be screened for viral particles and Ebola-specific antibodies verified by RT-PCR to ensure adequate serum concentration. Results from convalescent serum transfusion in the H1N1 outbreak showed that treatment reduced mortality and viral load. Timely detection, informed consent, RT-PCR analysis and proper apheresis technique, though potentially effective, would be complicated procedures in resource-constrained Ebola Treatment Units (ETU).

WHO Proposal

A WHO meeting of medical ethicists in August 2014 concluded that the compassionate use of experimental therapies in regard to the Ebola outbreak is ethical.[17] Scientific research protocols demand a more nuanced approach. Rigorous protocols also arrive at a different conclusion with regard to the administration of unproven drug therapies. A decision by the United States Circuit Court of Appeals for the District of Colombia in Abigail Alliance for Better Access to Experimental Drugs vs. von Eschenbach summarizes the issues of access to Phase II experimental drugs. In the case of a terminally-ill Ebola patient, once all approved treatment options such as hemodynamic monitoring and supportive care have been exhausted, there would be no further capacity to access experimental drugs. In the opinion of Abigail Aliance, a "broad right would harm terminally ill patients by endangering clinical research enrollment and the collection of reliable safety and effectiveness data".[18]

Convalescent serum therapy underwent a Phase I trial during the H1N1 outbreak. That trial established that plasma transfusions do not cause toxic reactions in patients. No complete Phase II trial on effectiveness of proposed Ebola treatments has been undertaken. Under the standards adopted by the scientific community, without evidence of effectiveness, the West African Ebola patient ought not be subjected to unproven therapies. The decision by the panel of medical ethicists convened by the WHO failed to meet this scientific standard.

Evidence of Efficacy of Convalescent Therapy

Evidence supporting the efficacy of convalescent therapy for Ebola is sparse. The scientific literature on efficacy has consistently determined that passive immunization of non-human primates that include the use of high-titer anti-EBOV equine immunoglobulin and the passive transfer of neutralizing human monoclonal antibody has resulted in no therapeutic utility.[19] A primate study published in 2009 extended these findings. It showed that transfusion of convalescent-phase blood from rhesus macaques to the Zaire Ebola Virus (ZEBOV) into 3 ZEBOV challenged monkeys resulted in no overall decrease in mortality.[20] Jahrling and colleagues urged caution in using convalescent serum therapy as a shortcut to a solution for Ebola and suggested further investment in more promising medications.

Most of the interest by WHO for convalescent serum therapy is based on a 1997 case study of patients in the Democratic Republic of Congo, which observed that there was a decrease in mortality after transfusions.[21] The authors, however, acknowledge that factors other than convalescent serum therapy that may have enhanced survival rates. Patients received supportive treatment that was markedly better than the that of normal patients during the 1997 epidemic. This complicates their findings on the effectiveness of convalescent serum therapy. It was concluded that survival after 5 days of Ebola symptoms and supportive care quality are predictors of overall mortality.[22]

An assessment of Ebola released by the WHO on September 26, 2014 outlined the apparent gaps in relevant clinical evidence. It also addressed concerns with the distribution of an interim guidance report for the National Health Authorities and Blood Transfusion Services.[23] In consideration of various treatment modalities, WHO observed that convalescent serum therapy "could be biologically plausible" and provided a detailed clinical guide. WHO deviated further from established scientific protocols in its approval of convalescent serum therapy when it noted that even if the therapy is non-effective the "byproducts of investment would be beneficial."[23] Among the potential benefits it included: "improvement of blood donation infrastructure and supportive care capacity."

Additional Concern with the WHO Approach

One of the concerns regarding the feasibility of plasma transfusions is the possibility for transmission of secondary viruses such as HIV and Hepatitis A/C.[24] With the current disparity in blood screening protocols in the afflicted West African nations, increased plasma donations and transfusions may lead to greater rates of HIV infection. The amount of convalescent serum required for a large-scale transfusion would be prohibitive, given the current pool of Ebola survivors.[25] It is also doubtful that these countries have the capability of maintaining high standards for infection control to protect the healthcare workers who will need to conduct these donations. Lastly, these countries will not have widespread access to apheresis machines to filter blood donations. Consequently, they most likely will rely on primitive sifting and settling techniques. The remaining toxins, circulating immune complexes and soluble mediators of inflammatory that remain from sifting and settling may increase medical complications in recipients. Given a realistic assessment of current healthcare infrastructure in the effected areas of West Africa, the ability for convalescent serum therapy to provide a short-term solution seems improbable.

Conclusion

Amidst the hysteria associated with the current outbreak, healthcare professionals are being pressured to provide an answer—fast. The medical ethicists who agreed that providing experimental therapies as an effective means to satisfy these demands overlooked the importance of maintaining the standards of clinical research. The Director of the Center for Disease Control in Atlanta, in a recent podcast on the JAMA website, noted that decisions "are based on data."[26] In the United States, policy makers ultimately concluded that the public interest as well as the interest of terminally-ill patients is best protected by allowing access only to drugs of proven efficacy. Given the dearth of evidence for the efficacy of convalescent serum therapy, WHO ought not endorse this unproven therapy. WHO asserts that, should convalescent serum therapy not be effective, the secondary benefits of investment in the African healthcare infrastructure would be significantly constructive; this claim is wildly speculative. Desperately grasping for a solution to the Ebola crisis without credible evidence of the treatment's efficacy will not only fail the patients affected by Ebola in West Africa, but will delay the resolution of a lethal epidemic.

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Nalma-9 Health Post, Lamjung, Nepal - This health post serves hundreds of families living in nine villages in the mountainous Nalma region of the Lamjung district of central Nepal. The health post provides five pounds of iodized salt and six pounds of soap for each child under the age of five who is brought to the clinic for a monthly wellness check-up. This young child was brought by her grandmother to the clinic while her mother worked to cultivate rice paddies during the day.

HEALTH CARE IN THE HIMALAYAS

KELLY DISTEFANO

“WRIT ON WATER IN WASTE”
INGESTION AND EXCRETION IN SHARON OLDS’ *THE FATHER*

EMILY SIMON

“When the nurses empty his catheter,
pouring the pale, amber fluid
into the hospital measuring cup, it is
neither good nor bad, it is only
the body.” – Sharon Olds, “Death and Morality”

Elizabeth Bronfen’s *Over Her Dead Body: Death, Femininity, and the Aesthetic* poses discomforting questions: both for its macabre subject matter, and for the possible limits of representation it bespeaks. Though Bronfen’s study deals explicitly with the female corpse, the issues she raises are generally applicable to death and its depictions. Namely, the apparent polarity between the reality of death and its representation, which seem to be mutually exclusive. In imaging art, Bronfen contends, one must choose between these evident polarities: “Do we see the real, while denying the representation or do we see the representation, thus putting the real under erasure?”.[1] In aesthetic representations of death, its brute reality is elided by the language or art of its figuration; to render it is thus to “‘exteriorise’ [the] real by transferring it on to an image/signifier.”[2] Conversely, artless death remains unsayable, inexpressible, and insists upon its singularity, its knowability. Images of mortality thus present a tricky opposition of proximity and distance: one is either too far from or too close to the body at hand, and as soon as one term is privileged, the other is always submerged. Bronfen wonders if this binary is irreconcilably exclusionary, or if it is possible to approach aesthetically the reality of dying without absenting the body under its scrutiny. The fraught relationship between seeing and saying is one that has long occupied the medical field, in which mortality is always close at hand. Though aestheticism seems antithetical to the antiseptic halls of a hospital ward, it is unexpectedly instantiated by Michel Foucault’s medical-clinical gaze. He limns this particular way of seeing in *The Birth of The Clinic*, in which illness is described in surprisingly aesthetic terms: “Disease is perceived fundamentally in a space of projection without depth of coincidence without development…The form in which truth is originally shown is the surface in which relief is both manifested and abolished—the portrait.”[3] In order to read the inscription of illness, then, the doctor’s gaze must bracket the immediacy of human suffering and level his corporeity to a two-dimensional, visual surface. There are evident parallels between Foucault’s claim and the mimetic/figurative tension explained by Bronfren; in her explication of the clinical gaze, Laura Tanner seems to restate Bronfen’s key opposition: “In order to render the disease visible, the medical gaze must factor out the person with illness; seeing the patient as an embodied subject emerges as not only inconsequential but counterproductive.”[4] Again, it is a question of representation: to map the patient’s illness, the medical gaze must consider the suffering body an “external fact,” while to see the human is to elide precisely the ailment the doctor intends to cure.[5]

Recent trends in medical and cultural theory have attempted to resolve this antinomy by deconstructing it, as emerging disciplines like narrative medicine aim to synthesize observation and representation. In "The Problems of Seeing and Saying in Medicine and Poetry," Richard Sobel and Gerda Elata locate an analogue between the kinds of problems posed by Foucault and Bronfen, as "Both physician and poet experience similar intensity the problem of seeing and saying," of bearing witness to the world before them.[6] In fact, the task of poetry can inform medicine by conditioning a specific kind of attention to the patient at hand; in engendering identification, rather than distance, poetry bridges the gap that intervenes to problematize both seeing and representing by opening a "space of negotiation…which is closed off by the precise discourse of medicine."[7] This created space is one of empathy, which translates the medical gaze into language that facilitates identification, rather than elision. Such compassion—what Jack Coulehan calls "compassionate solidarity"[8] in his essay on suffering, poetry, and medicine—recuperates language, saving it from its inevitable fate of "losing the real…to the needs of a representational unity."[9] In its most intense forms, loving compassion "allow[s] for the possibility of a gaze that dissolves the distance between the two": not only between dying patient and healthy observer, but also between death and its figurative representation.[10]

The paternal body at the heart of Sharon Olds' *The Father* occupies a peculiar midpoint between the polarities outlined above. Olds' poetry is an arguably beautiful, lyric representation of death, but at the same time, it presents illness in brutal, unflinchingly real terms. Since its publication in 1992, the 51-poem elegy has been subject to much critical scrutiny for its graphic imagery, as Kristin Lindgren explains,

> Olds insists that the reader confront the concrete and often repellent physical details that accompany disease and death. Her unflinching descriptions of body fluids and bodily processes—descriptions that many readers find uncomfortable—transgress literary and cultural codes that have worked to distance and aestheticize the dying body.[11]

Precisely this question of discomfort, and of the reactions of readers to Olds' ground-breaking poetics, has divided critics of her work. Lindgren insists that Olds' imagery "demand[s] intimate engagement, not distanced assessment.[12] Conversely, Terri Brown-Davidson contends that "emotion run amuck tends to alienate a reader," and that Olds "has pumped up her experience to such a heightened level it no longer resembles any reality a reader wants to participate in."[13] These dynamic of response function on two registers: the reaction of readers to the text, but also the reaction of the speaker to her father's dying body. Olds' speaker may be classified as a speaker-spectator, insofar as she bears both visual and verbal witness to his illness.* Her response to her father's death and dying shapes the conditions of our reactions as readers, which will be limned here; particularly, the fraught opposition between disgust and engagement is one to which we will return throughout this analysis.

Critics and readers alike also bristle at the blatant eroticism of *The Father*, in which Olds is a hyper-sexed Electra figure, mourning the ailing object of her erotic cathexis. In "Sentencing Eros," Calvin Bedient calls the volume "A sequence of fifty-one poems on the poet's ghoulish, erotic death-watch of her father, who was hospitalized for cancer, and the grieving aftermath. His dying both steps up and makes safe (unrealizable) her lust to be him and to have him."[14] Despite their vast and obvious dissimilarities, illness and eroticism are comparable in their promise of merger; as the body's borders dissolve—psychically, as in intimacy, or physically, as in illness—their increasing permeability poise the subject for integration with another. As such, the father's terminal illness seems to intensify incestuous desire because its corporeal effects reproduce the structures of sexual unity as an intensification of the "compassionate solidarity" invoked earlier. Though Sobel and Elata insist that "neither physician or poet peep for perverted pleasure—indeed, few sights are less erotic than a body being examined for signs of disease," Olds' poetry endues the medical gaze with a revelatory eroticism that creates its uncomfortable closeness.[15] These terms invoke "The Lifting," in which Olds' father reveals his naked body to her, raising "the cotton of the gown as it / rises the way we were promised at death it would rise, / the veils would fall from our eyes, we would know everything" ("The Lifting" 31-33). This denuding is thus epistemophilic in its unveiling, bound up with the desire to discover and know.

In combining eroticism and illness, Olds taps into an ancient element of medical care now eradicated by the stark clinicism of contemporary biomedical practice. Though Hippocratic rationalism has come to dominate the medical field, he was once rivaled by Asclepius, cult deity of dream, desire, and healing.[16] In "Unforgetting Asclepius: An Erotics of Illness," David Morris calls for the depathologization and explicit reintegration of Eros into a discipline clandestinely subtended by desire: the desire to know, to see the patient's body. Asclepian erotics would function as the antidote to the medical gaze by registering, rather than submerging, the body; it would "reinterpret eros as a power that invokes desire (as distinct from knowledge) that credits intersubjective experience (as distinct from objective data), and that values bodily presence (as distinct from meaning)".[17] If Hippocratic *logos* and Asclepian *eros* are reconfigured such that they are paired equally and oppositely, then the word may be capable of bearing commensurate witness to the desired body. As averred by proponents of narrative medicine, poetry is one of the most appropriate and effective mediums for speaking the unspeakable body, and *The Father* stages precisely this kind of reintegration, this reunion of Hippocrates and Ascelpius. It is not Eros simply for the sake of shock value, but instead for assimilation and reconciliation of two surprisingly analogous experiences of embodiment.

As such, unification and integration are manifest structurally in the trope of analogy. Sharon Olds' work is suffused with metaphor, so much so that it has been identified as one of her characteristic poetic devices.* *The Father*, despite its frank look at illness, is no exception; though her graphic renderings have a kind of directness, she does not practice the representation voice advocated by Susan Sontag in her famous "Illness as Metaphor," which claims that "the most truthful way of regarding illness—and the healthiest way of being ill—is the one most purified of, resistant to, metaphoric thinking."[18] As we have seen, however, poetic metaphors—when constructed carefully, specifically, and individually, as Olds' are—actually resolve the problematic gap between seeing and saying identified by both Bronfen and Foucault. If the motion to "reassert the health of metaphor thinking" proposed by Kenneth Pitchford may be borne out, and extricated from the trite analogies endemic to medical thought, then Olds' poetry stands in support of that recuperation and renegotiation.[19] The kind of aestheticization lamented by Sontag adheres to "the standard account of epidemics," which "are mainly of the devastating effects of disease upon character," while Olds' poetics assaults not character, but the body.[20]

Not least of all, this is facilitated by "the erotic potential of *likeness*" identified by Alicia Ostriker in her study of Bishop, Olds, and Stevens.[21] Eroticism inheres in the structure of metaphor itself, since it dissolves boundaries and distinctions; "to assert connection over difference, to want to blur rather than reify categories," as in metaphoric figures, "is to engage in erotic discourse.[22] By pairing similar but distinct things, metaphor privileges integration of separate terms, as Roman Jakobson explains in his famous distinction between the linguistic function of combination and selection: selection, which is represented by metaphor and proper to poetry, occurs by dint of substitution made on the basis of equivalencies.[23] "Similarity connects a metaphoric term with a term for which it is substituted," so that good metaphors do not elide the thing itself, but instead draw upon and draw out its characteristics by likening it to something that shares them.[24] As such, metaphor encourages an identification and near-erotic fusion, which is exaggerated and heightened by illness, in which corporeal borders are already permeable, subject to "the fragmentation of embodied identity."[25]

In this context, Olds' poetry pushes merger to the point of consumption, as one critic argues, "Olds would like to gobble life whole, to swallow the entire thrust of human experience with such gusto that no dust particle escapes her attention."[26] Scholarship has paid some attention to what is incorporated, swallowed, or assimilated in *The Father*, since it is situated at the intersection of illness and desire outlined above; however, little to no work has been done to read the images of emission and ejection that appear in equal and opposite measure in Olds' poetry. When Swiontkowski claims that "Olds learns to feast on [her father's] body" and describes her father's death as "food for Olds,'" she neglects to attend to what is spit back up or expelled, both by Olds and by the paternal body.[27] Because Olds' father suffers from esophageal cancer, he has painful difficulty swallowing and regurgitates bile and mucus, as we read in "The Glass": "My father has to gargle, cough, / spit a mouthful of thick stuff / into the glass every ten minutes or so" ("The Glass" 7-9). Excretions seep through the pages of *The Father*, as waste products like spit, urine, sputum, and feces register the deterioration of the father's cancerous body, and the developing identities of both father and daughter. The painful death of the speaker's father occasions also a re-drawing of her own subjectivity, and her own corporeal limits. If there is not traceable "a plot, a linear progression" in what is sustained by Olds' poetry, then perhaps a narrative emerges in what is sloughed off and discarded in it. [28]

After all, the dissolution and integration of bodies occasioned by illness and erotic relations means, most fundamentally, that something is falling off. Some boundary, whether psychical or physical, has been disposed of, some skin has been shed, to afford this kind of union. In eroticism, "There is the fact that since disgust signals the violation of the borders of the self, it must be overcome by love in order for sexual intimacy to be welcome.[29] In exhibiting this integration, *The Father* thus also details disintegration; the collection turns on the parataxis of ingestion and expulsion, which explores the simultaneous movements of attraction and repulsion subtending disgust. As assimilation and incorporation, a poetics of metaphor is a poetics of consumption, and it is both a bodily and structural fact: consumption always produces waste.

We may formulate this question after the Derridean model of the "*parergon*" as proposed in "Economimesis." In any given work—Derrida employs Kantian aesthetics as his example, crucial for its opposition to disgust—the *parergon* frames what may be included, thereby implying what is excluded. An inside always depends on a discarded outside, but Olds' poetry confronts us with both aspects. Moreover, what is purged—explicitly, in *The Father*, implicitly in Kant's Third Critique—is the same: "What this very work excludes, is what does not allow itself to be digested, or represented, or stated…It is an irreducible heterogeneity which cannot be eaten either sensibly or ideally, and which—this is the tautology—by never letting itself be swallowed must therefore *cause itself to be vomited*."[30] As *The Father* limns this act of exclusion, even that which is not spit back up in Olds' poems is transformed and discharged in some evocative way.

Derrida's paradigm is complicated by the elegiac form of Olds' collection, as "What the word *disgusting* de-nominates is what one cannot resign oneself to mourn…And if the work of mourning always consists in biting off the bit, the disgusting can only be vomited."[31] If mourning is accomplished by consumption, then how is mourning precluded, problematized, or revised by the images of vomit and expulsion that populate *The Father*? At the same time as substances are expelled by the characters at the level of plot, they are incorporated into the body of work as a whole, so any reading of these poems must negotiate seeming contradiction because that which seems impervious to bodily assimilation and yet has proven itself representable. Is Olds' elegy in some way itself a byproduct of consumption—an assumption which would require reworking of our understanding of waste? We must also negotiate the contrary impulses we have identified thus far: on the one hand, metaphors that dissolve the distance between healthy and sick, lover and beloved, and on the other, the disgusting and distasteful that resist permanent incorporation and threaten to push us away.

These oppositions staged by closely reading images of the body in *The Father* enable us to register their ramifications on the body of the text at large, and its paradoxical production by waste. The contrary motions of the text limn the opposing reactions elicited by waste and leaky body matter: aversion and attraction, or what Carolyn Korsmeyer calls its "paradoxical magnetism."[32] In fact, she even allows for "a response that, no matter how unpleasant, can rivet attention to the point where one may actually be said to savor the feeling. In virtue of this savoring, this dwelling on the encounter, the emotion constitutes a singular comprehension of the value and significance of its objects."[33] Such fascination, termed "aesthetic disgust," is certainly at work in Olds' poetry, as this fixation structures reader reception in such a way that it reproduces the simultaneous push-pull that inheres in regarding the ailing body.

We would be remiss to analyze such substances without engaging Julia Kristeva, whose theory of the *abject* illuminates our understanding. She defines the abject as such:

> A massive and sudden emergence of uncaniness, which, familiar as it might have been in an opaque and forgotten life, now harries me as radically separate, loathsome. Not me. Not that. But not nothing, either. A 'something' that I do not recognize as a thing. A weight of meaninglessness, about which there is nothing insignificant, and which crushes me.[34]

Like hair that has fallen from one's head or fingernail clippings in the trash bin, the abject unsettles because it is recognizably familiar as having once belonged to me, or bearing similarities to me, and yet is no longer a part of me or of my kind. Something that is mine or like me is no longer a part of me, destabilizing the security of my bodily borders and contesting my conviction in my subjectivity; the abject is not "lack of cleanliness or health…but what disturbs identity systems, order. What does not respect borders, positions, rules. The in-between, the ambiguous, the composite."[35] It is this same threat that subtends the emotion of disgust, as its composite terms—revulsion, abhorrence, revolt—"convey a strong sense of aversion to something perceived as dangerous because of its powers to contaminate, infect, or pollute by proximity, contact, or ingestion."[36]* At the same time as the abject threatens, however, it also "protects the individual…protects us because we are able to expel the abject through various means."[37] As such, Kristeva employs as examples of abjection "an item of food, a piece of filth, waste, or dung," vomit, or a corpse, all of which have purchase on the images of *The Father*.[38]

As an "in-between," the abject occupies a liminal position between subject and object, since it no longer belongs to the "I" but is also a "jettisoned object" that "is radically excluded and draws me to the place where meaning collapses."[39] Abjection is thus the site where non-meaning collects, as Allan Lloyd-Smith explains in his reading of the abject in the post-modern, linguistic landscape. He classifies the current human situation as one of "abjection": "the oppositional production of an antithesis to colonized and cleaned-up meaning structures."[40] As "an affront to the symbolic system" of discourse, the abject testifies to the unsayable, something outside of language.[41] Olds' explicit terms—"I love the terms of foulness," she proclaims in "Waste Sonata" ("Waste Sonata" 36)—certainly indulge linguistic abjection, as Suzanne Matson contends, "She disarms the words as inherited metaphors themselves, metaphors that have phallocentrically created special 'dirty' vocabularies for the private use of men, or just as exclusively, clinical vocabularies for the use of controlling medical figures."[42] Yet they are still incorporated into the "refined" art of poetry like the "Brit Art" described in "Abjection/abjectivism"—they still lend themselves to consumption.[43] At the same time as *The Father* sustains these categories of abjection and representation, we will soon see that it pushes back against them.

Though "the disgusting" is a classification that has expanded to contain other sensory and extra-sensory phenomena, its etymology is grounded in an understanding of oral revulsion.* As we saw in Derrida, the most literal understanding of disgusting is that which refuses incorporation, and thus must be spit back out, vomited: it is dis-taste, that which repulses taste. The father's esophageal cancer renders hyperbolically this oral rejection, as it makes everything that passes through the mouth something hard to swallow; the irony, of course, of his cancer is that it was brought on by his alcoholism, something that could perhaps be swallowed too easily. Heavy drinking began the process of dismantling his body, of exteriorizing the interior, as "he had removed his own / liver and brain and put them on the table, small / organ of the bourbon, large organ of the chaser" ("Parent Visiting Day" 19-21) In "The Waiting," Olds describes her father's difficulty drinking even diluted coffee: "He tried to swallow an eighth of a teaspoon / of coffee, he would have his child to give him / the cup to spit into, his child to empty it" ("The Waiting 24-26). This image constructs a reciprocal relationship between the two, as his spit fills the cup metonymically extending Olds' hand. His expulsion is continuous with and enables her ingestion; his lack is her fullness. In "Sharon Olds and the Taming of the Patriach," Gale Swiontkowski identifies this inversely related father-daughter pairing, as Olds seems to "[transform] the father-imago into an agent of nurture."[44]

The father-god unmakes himself in his gagging, expelling not just foreign, abject bile, but the body itself. Recalling the pain of her father's last months in "I Wanted to Be There When My Father Died," Olds writes, "All summer he had gagged, as if trying / to cough his whole esophagus out" ("I Wanted" 7-8). He attempts to turn his insides out, to unburden himself of the organ of his discomfort; of course, his imagined liberation from unmaking occurs at the price of his own bodily undoing, and he himself stages the assault on his body undertaken by illness. Olds' recognizes his decomposition as an inversion of her own, as she had once been "pummelled" and "mauled" but the brute, felt presence of his alcoholism (20, 21). Metaphor reverses Biblical creation:

> I was an Eve
> he took and pressed back into clay,
> casual thumbs undoing the cheekbone
> eyesocket rib pelvis ankle of the child
> and now I watched him be undone and
> someone in me gloried in it. (21-26).

The generative power is transferred from the father to Olds, whose subjectivity is reinforced by his concurrent dissolution. Decomposition and composition are thus contiguous actions, just as Olds' figurative move makes her into a character at the same time as it disavows her substance. The prosody also registers this parataxis, for as the poem is composed, its syntax simultaneously discomposes into a litany of scattered body parts.

As the father's capacity for consumption is compromised, his other modes of sensory access to the world are reconfigured: primarily, the distal (sight, hearing) usually privileged by Lloyd-Smith's "colonized and cleaned-up meaning structures," are usurped by the proximate senses of touch, smell, and taste. If "vision takes on an almost physical quality," a tactility, then it is also worth considering the intervention of the gustatory.[45] In fact, the poem entitled "The Look" is not about vision at all, but instead initiates bodily contact, fixing upon the father's expulsion of sputum in time with the back rub she gives him. The retrospective look of "The Present Moment" recalls, while at the same time eliding, his pre-cancerous eating habits:

> I have
> long forgotten the man who ate food—
> not dense, earthen food, like liver, but
> things like pineapple, wedges of light,
> the skeiny nature of light made visible.
> ("The Present Moment" 9-13)

He had previously supplanted the gustatory sense with the distance of vision—food incorporated through sight like "wedges of light"—but his chronic reflux forces an immediate confrontation with taste. The liver stands in as synecdoche for the body racked by alcoholism, which the father cannot consume but is also no longer able to jettison. He is brought back to the "dense" earth in this moment, grounded in the felt immediacy of the body in the same way the thickly layered commas foreground the felt quality of the lines. In Carolyn Korsmeyer's exegesis of what Aurel Kolnai calls "the eroticism of disgust," she explains the intensified perceptual texture of moments of repulsion: "When one is disgusted one is almost wholly occupied with the sensory presentation or appearance of the intentional object rather than with its existential status."[46]

"The Request" intensifies and complicates the shifting sensory dynamic of illness. Sunk "down / so deep inside himself," like the line break that buries us deeper in the poem, the father can no longer project himself outward through the sensorium ("The Request" 12). His body's failure materializes in the liquefaction of his eyes, "his irises made of some boiled-down, viscous / satiny matter, undiscovered"; appropriate states of matter accord with proper functions, and as soon as one breaks down, the other follows. ("Wonder" 13-14). Made blind and mute by his dying, the father cannot have interactive purchase from the object world. Unable to take in or process the world at hand, he is horribly estranged from it, and yet inexorably present, becoming Kristeva's abject corpse-in-life. As Laura Tanner contends, the ailing body both exaggerates and problematizes the threat of abjection, since "such a person often exhibits the bodily signs of impending death while yet resisting the inanimate coldness that helps us to classify the corpse as Other."[47] In this liminal arrest, the father can neither vomit nor swallow: "the fluid stood / in the back of his throat," stagnant as the intervening line break that halts reader progress ("The Request" 8-9). This suspension of matter persists, unchanging, from life into death, as "The Exact Moment of his Death" reproduces this language of stasis: "We could see the fluid / risen into the back of his mouth" ("Exact Moment" 10-11). Even in its arrest, the body refuses to incorporate liquid into solidity, insisting on an inside/outside dichotomy that can no longer be maintained by the gag reflex. Readers, too, are suspended, unable to swallow easily Olds' graphic imagery, but helpless also to refuse it.

A possible exception to the father's compromised gustatory sense occurs in the moments that he receives the sacrament of Communion from visiting priests. This should occasion a spiritual transcendence of the material body, but, as in Olds' other theological metaphors, the doctrine of transubstantiation is taken literally: bread, in fact, becomes body. When, in "His Terror," "He opens his mouth for the porous disc / to be laid on the tongue," ("His Terror" 10-11) a linguistic identity is created between the Body of Christ and the father's sputum: "The sides of the tongue were dotted with / ovals of mucus like discs of soft ivory" ("The Last Day" 28-29). Though divergent bodily products, waste and nutrition are here tantamount, becoming, like the language of her poetry, "layered, like flesh upon bone."[48] Later, Olds engages her father's body in this same irreverent sacrament: "a compound disc / of sweat, I brought it off on my lips" ("His Smell" 29-30). The apparent debasement of the Eucharist further contests the kind of theological morality of body and spirit continually undercut by her poems, especially "Death and Morality" and "The Feelings." If "the body on earth is all we got," ("I Wanted" 15) then we are beholden to failings, bewitched by "the trance of matter" ("The Swimmer" 22). As Kristen Lindgren explains, "In *The Father* there is no religious or moral framework through which to perceive and makes sense of death; there is only the embodied self's transmutation to pure matter."[49] These images of gustatory ingestion neutralize the category of the divine, not by opposing it to the body, but by assimilating it. What is spit out as mucus is reincorporated by the poetic function as nutrition, generating a combinatory circle of abject, turned object, turned subject.

Sputum thus threatens to destabilize boundaries of selfhood, especially when it "dries like ivory clay from the side of his mouth" ("Death and Morality 18). The sudden solidification of matter upsets expectations, and threatens disgust, for it is the rule of repulsion that "Dry will usually be less contaminating than wet, except when the benchmark expectation is of moistness or suppleness."[50] When the father expels mucus in "The Glass," the eponymous receptacle remaps the surrounding space like a "solar system" ("The Glass" 32). "The old earth that used to / lie at the center of the universe," the father's central power, outmoded by his illness, has revealed itself to be as pretentious as the geocentric model (34-35). Instead, he "[turns] with the rest of us / around his death, bright glass of / spit on the table, these last mouthfuls," and his abjection becomes the gravitational center of this space and of their lives (36-8). As with the Copernican Revolution, it is not that the central body itself has changed (the solar system never revolved around the earth, always the sun), but that its reality was made unavoidably present, transparent like its glass container. This resistance to discovery of the putrefaction at the core, rather than outside of, human life, is what subtends our repulsion: "Ultimately the basis for all disgust is us—that we live and die and that the process is a messy one emitting substances and odors that make us doubt ourselves and fear our neighbors."[51] As constitutive, the abject substance does not upset boundaries but only reconfigures them, creating its own solar pull.

As the father's condition worsens, the externalization of the abject is visibly mapped on the body itself. The bodily borders—the corporeal *parergon*—that sustain stable subjectivity become permeable; even the epidermal boundary is disposable, as "Every hour, now, he is changing, / shedding some new ability" ("The Pulling" 1-2). As his bodily fluids dry up, solidify, the body itself liquefies: where "his solid ruddy stomach had been" there are now "loose / soft hairy rippled folds / lying in a pool of folds" ("The Lifting" 8-10). As the abject is traditionally female-gendered, the father is feminized by his disintegration, nested within labial folds of skin; soon after, Olds explicitly identifies his physical similarity to her and her daughter. Swiontkowski cites this imagistic trans-gendering as an exchange of power, for "In feminizing her father-imago, Olds in run assumes for herself certain masculine qualities of will, ambition, and self-realization."[52] More than a figurative imposition from the outside in, however, this poem, collapsing in upon itself through repetition, testifies to the body's revolt against itself from the inside out. As the cancer proliferates through division, the body tries but fails to rid itself of dead cells, which cluster in tumors protruding from, but not rupturing, the skin's surface. As William Ian Miller writes in *The Anatomy of Disgust*, "If skin cover[s] the disgusting matter inside, the festering inside might write itself large upon the skin, desecrating it by erupting to the surface."[53] This violently failed disposal texturally inscribes the father, on whom "you can see some of the larger lumps / pressing out at his throat and chest, / he is like a stocking stuffed with things" ("The Picture I Want" 6-8). Through this simile, the father's body is turned into an inanimate vessel, pressured to bursting by an internal force both self and not-self. The blood transfusions to keep him alive continue this process of internal alienation, for "They have drained / the blood out of his body and replaced it / with fresh blood from the people of Redwood City" ("The Lumens" 6-8).

At the same time as abject fluids are discarded and cordoned off, then, they are also invited back into the body. Through our own act of incorporation, which marries the merger and consumption inexorably present both literally and stylistically in Olds' poems, we are able to expand upon Kristeva's understanding of the abject by making ingestion and expulsion two sides of the same coin. As we saw in "The Glass," any belief in a rigid inside/outside distinction is always a fiction. In truth, "Social and cognitive structures create dirt less by assigning something to play that role than as a consequence of categorization itself."[54] Borders are always already permeable and porous, and situations like illness and desire simply make these conditions visible, precisely by subordinating vision to the proximate senses. When understood in this light, the give-and-take created by these equal and opposite functions does not engender inequality, in which the body must be possessed or a held onto, but rather constructs a cyclical space of reciprocity that welcomes permeation and disintegration. In this way, Olds eventually, though gradually, accustoms herself to cremation as the proper method of disposal for her father's body. The idea originally repulses her because she considers it flagrant disrespect for the integrity of the body, informed by the material spirituality limned by earlier poems on the Eucharist: "I hated / the way we were treating him like garbage, we would burn him, as if / only the soul mattered," she laments ("The Dead Body" 8-10). Cremation instantiates Kristen Lindgren's claim that "While depicting his body in fragments, however, the daughter resists the actual fragmentation of his body," citing "The Dead Body" as proof positive:[55]

> I wanted this man
> burned whole, don't
> let me see that arm on anyone in
> Redwood City tomorrow, don't take that
> tongue in transplant or that unwilling eye.
> ("The Dead Body" 17-19)

If cremation disintegrates the body, then she wants this disintegration to be at once complete, integrate, to save it from enacting the partial abjection wreaked upon the body by illness. "This man" instead remains wholly subject, even as he is turned into objectified subject. Olds clings to the incorruptible virtue of the cremated body, belied by the fractured, convoluted syntax:

> I am glad we burned my father before
> the bloom of mold could grow from him,
> maybe it had begun in his bowels but we burned his bowels,
> cleansing them with fire.
> ("The Mortal One" 7-10)

The crematory fire neutralizes the body's ability to produce the abject, to empty itself and proliferate like its cancerous tumors. When she holds his urn, she focuses on the material weight of its containment, "the smooth, square box…soldered up," which she wants to assume into herself ("The Urn" 5, 7). She is going to swallow him, like people "swallow / whole cars," swallow without masticating to maintain the coherence of the urn, and the blessed "pressure of [its] weight" that has come to metonymize his body (13-14, 25). Here, she exhibits the greed earlier pilloried by Terri Brown-Davidson, as the voice of the poet who "like Kronos…would like to gobble life whole."[56]

However, "The Urn" is immediately followed by "His Ashes," a titular shift that supplants the illusion of wholeness with the fragmentation at its center. As Olds cradles the urn, its weight evokes an image of expulsion, when the father urinated, "got the fluid out crackling / and sputtering like a wet fire" ("His Ashes" 9-10). Despite the urn's containment, the father's body leaks, both physically and imaginatively, from the narrative space accorded it. Olds attempts to reconstruct him imaginatively from his pieces; she converts "the jumble / of shards," shattered as the line break, to "a bone of his wrist…the elegant knee he bent…his jaw…his skull that at birth was / flexible yet" (33-34, 35-38). This recuperation of his image remains only hypothetical, couched in interrogative constructions that cannot be grounded in material confirmation. Her musings are punctuated by a dash, which interrupts his reintegration and returns and reconciles her to the ephemerality of his now-dissolute substance: "bone and the ash it lay in, silvery / white as the shimmering coils of dust / the earth leaves behind it" (39-41).

When she visits her father's grave a year after his death, she accepts the previously repulsive mold clinging to the surface of his headstone. She incorporates abjection—thereby voiding the term—into the material and poetic texture of "One Year," when "the first dots of lichen were appearing /

like stars in early evening" ("One Year" 20-21). Again, she is overcome by a desire to ingest his being: "When I kissed his stone it was not enough / when I licked it my tongued went dry a moment, I / ate his dust, I tasted my dirt host" (38-40). This time, however, she accepts it in disperse form, and she sacrifices something of herself in the process; the fluid of her mouth is lost to the gravestone, and the self is dependent on this digestion, just as the subject "I" depends syntactically on the line buried beneath. Following this exchange, her identification with her father mounts, and she declares in "The Swimmer," "I am like those elements my father turned into, / smoke, bone, salt" ("The Swimmer" 16-17). The line break actualizes this material transformation staged by the simile, as they become alike in their sublimation from solid body to residual vapor. Presenting herself as a swimmer, Olds here has adopted the earlier image of her father as "a Channel Swimmer," though she no longer feels the prohibition against touching him, and has in fact absorbed him ("The Present Moment" 28). As such, he seems more troublingly abject in life, while in death, he actually reaffirms and strengthens her subjectivity.

When she goes in for a breast exam, the procedure confirms their likeness and even enables her to inhabit her father's body through its failing:

> I feel like my father in the hospital bed
> ……………………………………..
> I don't know when he found the lump,
> rising above his clavicle. But when I
> go down and get ready to die,
> prepare to find a sphere hard as a
> pea-seed buried in my breast,
> I can feel myself
> slip into my father.
> ("The Exam" 2, 7-13)

Her corporeality has begun now to reproduce the obtrusions of his. In mirroring the abject—submitting it to identificatory assimilation through its poetic restaging—she has purged it of its horrifying unfamiliarity. She is at home in his body, not troubled by the "uncanniness" (literally, "un-homely-ness") identified by Kristeva; not "radically separate,"[57] she is instead joined with him "wholly, deep inside of," inhabiting, "his flesh" ("The Exam" 14).

So far we have illustrated the work of mourning, of "biting off the bit," so deeply troubling to Derrida as anathema to the disgusting.[58] Derrida's assertion is obviously informed by the Freudian paradigm explicated in "Mourning and Melancholia," though he refers specifically to mourning's extreme variant, melancholia, in which "The ego wants to incorporate this object into itself, and, in accordance with the oral or cannibalistic phase of libidinal development in which it is, it wants to do so by devouring it."[59] To be true, *The Father* exhibits this extremity of consumption, but to claim that this is all Olds does is as myopic as arguing that her poetry swallows life whole without expulsion. If the body of her work is a digestive one, as I have argued, then it is both a biological and poetic fact that something must be discharged. This contiguity of consumption and excretion actually inheres, despite Derrida's reticence to the fact, in the gradual structure of mourning, by which "each single one of the memories and expectations in which the libido is bound to the object is brought up and hyper-cathected, and detachment of the libido is accomplished in respect of it."[60] The self does absorb attributes from the loved object, but it does so in order to decathect them, to let them go.

Olds completes this work of mourning in "To My Father," which finds her "hip-deep" in a pond, where she writes,

> I peed,
> I looked down my naked body,
> greenish with maple shade, and saw
> the pee curl, oily and amber, in the
> pewter spring-born water. Bourbon
> down to icy crystal—I am with you.
> ("To My Father" 3-8)

What Olds has assimilated of her father, she here discharges—not through the forcible removal of vomit, but through the natural phase transition of urination. Metaphor converts urine, “oily and amber,” to “bourbon,” thereby returning it to her father’s body. The corporeal system of excrement literalizes the process of decathexis, finally successful. She invokes her father apart from her self, reading his substance on the mercurial surface of the water and subsequently declaring herself separate: “I have seen your gorgeous name / writ on water in waste, and pulled to the / dam and dashed over it” (24-26). This moment saves Olds from descending into hysterical melancholia, which is facilitated by unrelenting narcissistic identification.[61]

The Father, too, is “writ on water in waste,” in the language of abjectivism parsed by Lloyd-Smith. If “abject and abjection are my safe-guards. The primers of my culture,” which enable artistic production precisely through their exclusion by the parergon, then Olds’ poetry foregrounds the disgusting that usually only implicitly subtends everyday life.[62] Olds presents another model of poetic creation, one that does not depend upon the elision of the abject body (this is, fundamentally, what is at stake in Bronfen’s analysis), but which instead presents the body in all of its stinking putrefaction; the “healthy metaphors” solicited by Richard Pitchford in fact appear to be the unhealthiest of all. Like the “waste foetuses” that move through the father in “Waste Sonata,” waste has a paradoxically generative power; the act of decomposition is actually an act of composition (“Waste Sonata” 46). Though the disgusting is most commonly associated with death, life, too, inheres in it, as “Disgusting objects are those that endure the cycle of birth, growth, and death, after which they disintegrate and provide the material that generates and supports other life forms.”[63] Writing in the stinking ink of blood, sweat, and bile, Olds explodes the aesthetic parergon, neutralizing precisely the border between inside and outside that mobilizes our revulsion towards what is excluded from our bodies and our cultures. As such, she makes room for the contradictory and ambivalent responses of readers to her poetry, uncomfortable detachment and incorporative engagement, since the boundary that effects them is only illusory, and may be manipulated at will. The Father thus neglects the process of sublimation—both in the psychoanalytic sense of redirecting impulses to higher pathways and in the scientific sense of a phase transition from palpable solid to invisible gas—as waste is materially present throughout the elegiac trajectory of Olds’ work. Like the familial cosmos depicted in “The Glass,” Olds’ constellation of poetry turns about the material stuff at the core of being; to believe we can vomit it up cleanly, without consequence, is simply benighted objectification of our own corporeity.

ENDNOTES

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29 Carolyn Korsmeyer, *Savoring Disgust: The Foul and Fair in Aesthetics* (Oxford: Oxford University Press: 2011), 33.

30 Derrida, "Economimesis," *Diacritics* (11: 3 – 25, June 1981), 21.

31 Ibid., 23.

32 Korsmeyer 3.

33 Ibid.

34 Julia Kristeva, "Approaching Abjection," *Powers of Horror: An Essay on Abjection*, trans. Leon S. Roudiez (New York: Columbia University Press: 1982), 2.

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47 Tanner, 107.

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59 Freud, "Mourning and Melancholia," *The Standard Edition of the Complete Works of Sigmund Freud*, trans. James Strachey (London: The Hogarth Press: 1916), 249 – 50.

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*** AUTHOR'S NOTES**

All internal citations refer to poems in Sharon Olds's *The Father.* Sharon Olds, *The Father* (New York: Alfred A. Knopf, 1992).

***p69** At the risk of committing the insidious misdeed of conflating poet and speaker, I will from now on refer to the speaker of The Father as "Olds." As this volume is confirmed to be autobiographical, most scholarship on it has done the same thing.

***p70** In "Talking to Our Father: The Political and Mythical Appropriations of Adrienne Rich and Sharon Olds," Suzanne Matson cites "dramatically prolific and unapologetic as a crucial means of empowering the self" in Sharon Olds' poetry (Matson 40). Moreover, in Alicia Ostriker's "I am (Not) this: Erotic Discourse in Bishop, Olds, and Stevens" engages metaphor as one of the most outstanding devices in her poetry.

***p72** For a more thorough understanding of the overlap and disparity between the categories of the abject and the disgusting, consult Chapter 1 of Rina Arya's book Abjection and Representation: An Exploration of Abjection in the Visual Arts, Film and Literature. Here, they will be considered as roughly synonymous.

***p73** The word "disgust" combines the privative prefix "dis" with "gusto," or "taste" (from the OED). For more information on and an expansion of the term, see Chapter 1 of William Ian Miller's The Anatomy of Disgust, "Darwin's Disgust."

HAVE A DRINK OF WATER

CHRISTINE DEGENAARS

Dark hair, almost black and a scar
like a fingernail along her chin. He caught her
by surprise with the flash of his Kodak
on a trip they had taken to Savannah.

It's his favorite picture of her, before she became
too thin and before she left Tennessee
for good for some place out west.
He has her sitting by the sofa on a low wooden stand
and I wonder how often he looks at her. Pretty girl.

Bernard's in the kitchen and I can hear him shuffling
his papers on the kitchen table. He isn't having a good day.
He won't hold his coffee cup and his bones are shaking
under his skin, dry and pallid as Elmer's Glue.

I ask him what he's looking for and I can feel my voice
echo and bounce off each door frame and window until
it meets him and funnels into his ear. I'm fine,
he says, but I'm not sure he believes that.

There are no other pictures of Kate in this place
and eleven bottles of pills. His doctors say he needs one
of each in the mornings. I help him count them out:
rilpivirine, tenovir, emtricitabine to start.

He'll only take them in the kitchen, at the table that hides
behind the refrigerator and the wall.
White and pink and yellow pills in hand,
he swallows them, invisible from view.

TAWLI

MARIA ASDOURIAN

Before my grandpa died of Alzheimer's, he was a master strategist at backgammon. We had been playing since I was six. According to my grandmother, the only time he lost a game—to a terribly loud walrus-mustached man—was in the winter of 1970 when he drank too much arak at a friend's house one evening. He was a humble man, and he didn't like to talk about himself. But when we set up the backgammon board, I fished some stories from him. They were mostly stories of triumphs and mishaps. He always seemed to be in a quarrel with someone when he was younger: his neighbors, the butcher across town, his cousin's brother-in-law's uncle. This surprised me because he always seemed like such a quiet and introspective man.

I visited him almost every weekend, eager to fill up on bouregs and namoora and kunafeh and other treats that I could never find in my school cafeteria. We read through old fables like Nasreddin Hodja and played a lot of games, but my favorite was backgammon. Tawli was what he called it in Arabic. I remember spending the day at my grandparents' house a few weeks before Easter. I was rummaging through some boxes and found a drawer full of old trinkets he and my grandma brought with them from Lebanon decades ago. In that drawer were dusty piles of photographs, black and white and yellowed with age, small alabaster figurines and long silver chains worn to a dark rusty maroon color. At the bottom in an old box I seized an ornate and worn-looking backgammon game board, much larger than the one we'd always used for playing. I rushed to the living room where he was leafing through my grandma's recipe book. On Sundays, it was our united task to choose our favorite thing from the book for her to make us. I nearly knocked the book out of his hands waving the game board in front of him, and we quickly set up our checkerboard wicker chairs and coffee table—near the entrance of the kitchen, of course, where the smells of the olive oil and lentils wafted out at us. From our important workstation, I could see my grandma moving around in the kitchen, walking back and forth, mincing fresh garlic, stirring the boiling pot on the stove, chopping onions. The television downstairs was playing one of her favorite soap operas, *El Mehteleh*, with a rowdy mix of Arabic syllables darting their way up the stairs. Although I wasn't able to visit them everyday, their home felt so familiar to me, as if time would stand still in between our sessions and pick right back up again on Sundays.

The game set was beautiful, but old: mahogany, splintered along the edges of the board, with a pair of crooked dice carved out of ivory inside a grey velvet pouch with an inscription on it. Each side of the game board had twelve long isosceles triangles, alternating beige and auburn colors that had faded in some spots. I knew that old things were usually valuable and fragile, so I had to be delicate when I handled the game pieces. Just imagining chipping or breaking a piece of the game made me almost not want to play, but I couldn't resist. My grandpa set everything up quickly after dusting the game pieces and set his cup of Turkish coffee on the table next to him. He was ready for business, and I was too.

My grandpa let me start. I reached out to pick up the dice, and I dropped them with such force that one rolled off the table onto the floor. Thankfully it didn't chip. Then it was my grandpa's turn. He moved with such careful deliberation, even when just rolling a pair of dice. He was superstitious, and first blew into the dice, making a show of it, juggling them in his hand and taking pains to find just the right angle from which to throw them. They landed perfectly, right in the center of the board. It went on like that. His creased fingers, worn from years of tailoring, quickly moved the checker pieces, then pausing for a moment before hovering over the board, as he changed his mind and moved them elsewhere. I'm not sure why, usually he never second-guessed himself. But I beat my grandpa that day. I thought that's how clever I was, more clever than that walrus-mustached man. I guess my grandpa thought so as well. Maybe that's why he had a mischievous grin on his face the rest of the day and winked to my grandma when I bragged about my victory during dinner.

We still played after he was diagnosed with mild cognitive impairment, at least in the beginning. I heard lots of strange new scientific terms being used almost everyday at my house, and no one really explained them much to me. But I knew they were all about my grandpa. Everyone was worried about him. Everyone except him, at least. I asked him what was wrong, and all he told me was not to worry. At the time I believed him. He laughed it off, said it was nothing to make a fuss about, that he was already a bit scatterbrained to begin with so it couldn't get much worse. But it did. Over time, he started forgetting simple things, like which buttons to press when using the microwave, where the sock drawer was, when it was his turn to roll the dice during our games. Once, when he was backing up from his driveway in his grey Volkswagen Rabbit, he forgot to take his foot off the gas pedal and crashed right into the row of maple trees across the street. Luckily, he was fine. The car made it out with only minor damage and no one else was hurt. But after that, he got much worse very quickly. My parents took me to see him less and less, and when I asked about it, they said that grandpa wasn't feeling well and needed some rest. In the beginning I whined about it. After all, my weekends at their house were always so fun. But after some time, I got used to it and only brought visiting up occasionally. I thought that a game of backgammon might cheer him up. But when I was finally able to visit, their house looked different. It was less colorful, somehow, there was a heaviness in the air, and the electric outlets had all been covered with plastic cases. When I asked my grandpa about it, he sighed and rolled his eyes. “I know, I never thought I’d have to live in a house covered in plastic. What am I, a child? I wasn’t planning on sticking a metal rod in any outlet…”

I wasn’t sure how to respond, so I slowly slinked away. I’d never seen him so upset before. My grandfather took great pride in his independence, in his ability to forge a new and better life for himself and his family from very humble beginnings, and I think realizing he was losing this made him despondent. I remember he used to apologize, over and over again to my grandmother, every chance he got. One day he broke one of her vases, one with a blue and golden yellow floral pattern. He lost his balance when he was getting up and bumped into the table it was on as he was trying to steady himself. I was downstairs watching *The Wild Thornberries* on television when I heard the crash. I ran to see what happened, but stopped halfway up the staircase when I heard my grandpa yelling and my grandma trying to pacify him. She said she didn’t mind, that she never even liked that vase. It had been a gift from her sister-in-law. But he was so upset at himself for being clumsy and careless, he was yelling in Armenian and Arabic and I heard a lot of words that I knew were “bad.” I was scared then, and over the next several weeks, I was met only with a disheartened “not this time” when I asked him to play some backgammon with me. I thought I had done something to upset him, but my grandma caught me one day before I left their house and whispered that he didn’t want me to see his hands trembling during the game. She told me that he was sick, that his brain wasn’t working well and that was affecting his memory and even his muscles. It was getting harder and harder to control. “What?” I asked, “but what’s really wrong with him?” She looked at me and shook her head. “I wish I knew… they call it Alzheimer’s. He’s losing his memory, but his trembling may be because of another disease, Parkinson’s. Whatever it is, they can’t fix it.” I couldn’t believe that something like this was happening to him. People got sick. I knew that. But losing your memory, slowly forgetting your past and the experiences that give your life its substance… I couldn’t imagine anything worse. Would he forget about the walrus-mustached man? Would he forget my grandma? Would he forget me?

His condition progressed very quickly. By the time I was twelve, my grandpa had been diagnosed with late-stage dementia and looked lost and wandering in his own world. On good days he would hum to himself during the day, otherwise he remained silent. But my grandma tried to maintain as much normalcy as she could in their home. She still cooked, always my grandpa’s favorite meals, and would sit with him for an hour or two just to get him to finish a quarter of his plate. A home health nurse visited him on a daily basis, but I only got to see him once every week or two. Most of his time was spent flipping through an old deck of cards or shuffling around the room. He became very agitated if he sat down for too long. My grandma laughed when he made a fuss; she said that it was very typical of him, that he had always been stubborn and even that didn't change. No matter where he was in his mind, his face would always light up for a quick second when he heard her laugh. It was easily missed, if you weren't looking hard enough.

One day during my visiting time, there wasn't anything good on television and nothing much else to do. My grandma was in the kitchen at the time, preparing Turkish coffee on the stovetop for my grandpa. It gave the room a pleasant aroma, a quiet reminder of a once bustling home. I was tip-toeing up and down the stairs, pretending the floor was lava and jumping from chair to couch to table. But I was bored and tired, and my mom wasn't going to be back to pick me up until the evening. I wandered into the kitchen to look for some snacks. There wasn't anything good in the refrigerator, so I scoured through the pantry, but all there was to eat was an expired box of Nabisco crackers and some jellybeans. I filled a Tupperware bowl to the brim with jellybeans and went back to the living room where my grandpa was sitting, trying to balance the beans in one hand and a glass of milk in the other without spilling anything. I asked him if he wanted to watch anything on the television, but he didn't respond, so I settled on the Disney Channel. I wasn't sure if he was in the mood for jellybeans himself, but I grabbed a small handful from the bowl and placed them in front of him, remembering how much he used to love the sour green flavor. But he didn't eat them. Instead he began shuffling them around on his plate.

I pointed at one of the piles on the table, and slowly started lining them up in a pattern. I started pushing them into little piles, then messing them up and starting over again. My grandpa was looking at the table, a puzzled look on his face. I asked him if he would like to try. He grabbed a jellybean—slowly, hesitantly—like he was frightened that it would suddenly jump up, and would place it, first, where I pointed. His hand was trembling as he did so. After a while, I stopped pointing, and he continued the same rhythmic pattern of movements. Pick up red, place next to green, pick up blue, place next to red. Then I asked him to count them, one by one, and he did that, too. It was difficult to hear him, as his voice was barely audible, a whisper. And he sometimes stopped counting and just shuffled the beans around. I was getting tired, but I wanted to keep playing with him. After a while I decided to start cleaning up and put everything away. Out of the corner of my eye, I saw him grab a small handful of the green jellybeans he had just sorted and throw them into his mouth. And there it was, that mischievous grin I thought I would never see again.

Maybe I thought then that he would make a miraculous recovery, that he would defy the odds and start remembering again. I knew my grandpa was still there. But he didn't. After he was taken to the nursing home, he only got worse. We kept hearing from the doctors that this was to be expected, that he didn't have a lot of time left, so all we could hope for was to make him as comfortable as possible for the inevitable. I remember visiting him one day with my mom and dad. My grandma was there as well. He grinned at us blankly as we walked inside, but he remained silent for the remainder of the day. I didn't know where to sit, so I stood to the side and tried to half-crouch on the windowsill. The room was rather large, cloaked with varying shades of beige and grey, with a picture of a large red tulip on the wall. We were there for several hours, and I had been excited to get to meet the doctors. But during the day no one came in, except for one young nurse who handed him a cup filled with pills and a glass of water. My grandma cleared her throat every few minutes between her attempts at conversation. I kept glancing at my grandpa. I wanted to ask him something, but didn't know what. Whenever I opened my mouth, I just couldn't. He wasn't there with us in the room. He was someplace else.

We still visited him once or twice a week. When I got out of the car and walked towards the building, I always hoped that things would be different that day, but it never was. It was the same, spending a few hours staring at that blotch of red on the wall, glancing at the clock, waiting for something to happen. What changed were the smells of the facility, strange and unwelcoming ones that would permeate out of the automatic front door as we stepped inside. There were two televisions in the common area near the front of the building, but my grandpa became agitated when the nurses tried to take him out of his room, so he never got to watch them. He just sat in his uncomfortable looking chair, and when we visited him we had to sit there as well, unable to talk to him or to each other because there wasn't anything left to say. It never sat right with me that one area of his mind could be fine. While his prognosis was still so hopeless, he could still count out jelly beans—admittedly small, but still a form of mathematical reasoning. The diagnosis itself was more like a premature death sentence. I just felt sad and frustrated that he was written off while still here. I wished they could do something to help him. If someone broke a bone, doctors could put a cast on it to make it better and then help them with other sorts of physical therapy. Wasn't there some kind of brain therapy that could do the same for him?

It was December, a few weeks before my birthday. We had just gotten back from Roche Bros., where I had picked up a few coloring sheets that were part of those store-wide contests that promised the winner and their family an all-expense paid vacation to Disneyland. In the car I had been so excited, dreaming up these different coloring palettes I would use to impress the judges. It was like one of those coloring book pages. There was already an outline of a holiday scene with reindeer and snowmen and a jolly-looking Santa, and I just had to be meticulous and color within the lines. I had no doubt in my mind that I would win. I'd set up a little station for myself on the floor, organized all my crayons, colored pencils, and markers into neat and orderly rows. Things felt so monumental back then, being able to totally immerse yourself into what you were doing, imagining yourself as whatever you wanted to be. Monumentally good, and bad. I heard the phone ring from the other room, a message from the nursing facility. My dad picked up the phone, and I could tell from the look on his face that it was the news he'd been dreading the most. I didn't think it would happen so abruptly. I thought that we would be with him on his last day, sitting around his bed, that I would be holding his hand and in his last breath, he would tell us that he still remembers. But it had been more than a week since I last saw him. Suddenly, I didn't feel like coloring the picture anymore.

I wish I'd played more backgammon with him. I wish I'd known him better. I wish I didn't feel so relieved when I heard the news.

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