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.

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The Medical Humanities, Health, and Culture Minor

INTRODUCTORY NOTE

For a publication dedicated to representing the work of undergraduate students, it's worth considering why so many of the works featured in this second issue of *The Medical Humanities Journal of Boston College* reflect on age. Our collegiate years—our best years, we're so often told—are oddities on the lifespan, located somewhere between childhood and adulthood; our bodies seem out of time, almost without age. Growing up and growing old are processes intimately linked with embodiment, but the collegiate years—a tentative middle ground between development and decline—seem to erase embodiment altogether. We might even say college students seem ageless, insofar as they are assumed to be healthy and able-bodied. We know these assumptions are problematic, and students and faculty here at Boston College are engaging in worthwhile conversations about ability, chronic illness, and mental health in the student body. This issue of the journal aims to become part of those vital conversations.

Medical humanities, insofar as it focalizes health, illness, health care, and the body through a humanistic lens, asks us to reconsider dominant narratives and problematic assumptions. For college students, a pressing matter might then be: What does it mean to come of age? In her memoir essay "Weight," Claire Stauffer, in sharp and lyrical prose, captures a moment with her mother during which age distinctions blur and their relationship deepens. Matthew BeDugnis, in his memoir "Blackbird," negotiates both coming of age with Cerebral Palsy and his mother's illness through an automobile.

In the alumni guest folio to this issue, Maureen Josephsen '04 shares her experience of living with chronic Lyme disease. From her diagnosis during her junior year at Boston College to the present, Maureen spins a story as complex as it is powerful. Intertwining her personal narrative with the history of Lyme and its political and medical implications, Maureen offers a thoughtful reflection on chronic illness. In the other folio piece, Matthew DiOrio '14 analyzes the patient-provider relationship and clinician language choices in a thorough and accessible research paper. We are grateful to Maureen and Matthew for sharing their work with us.

This issue is not only concerned with coming of age, but also with experiences across the lifespan. Maria Jose Cordova's short story "The Cut" captures a tender and complex moment between a mother and her baby. In a pair of photographs of hands, Marilyn Smith asks to us consider what it means to accompany someone at the beginning and toward the end of life. Amelie Champagne Lyons, in her sestina "Watching My Grandmother Fade," represents the aftermath of Alzheimer's in her own family. The cover of this issue—"In Passing" by Cate McAnulty—represents an elderly subject in arrested motion, evoking memory and the passage of time. These works call us to contemplate what it means to age, to give care, and to bear witness.

Putting these pieces into conversation with other works in this issue reveals what's at the heart of medical humanities: What it means to have a body, to be human. Russell Simon's case study of HIV/AIDS in the United States, "The Color of HIV" considers how structural inequalities relate to transmission. Guy Guenthner and Theresa Rager each pen an op-ed on a contemporary public health issue: Adderall abuse and childhood vaccinations, respectively. In "Waounan Woman's Prayer," Colleen Brady explores the cultural and humanistic impact of medical service through poetry.

Along with the work mentioned above, we are honored to feature an impressive range of work in the medical humanities. As always, we are grateful for your continued readership and support of this publication. The warm responses and outpouring of support following the inaugural issue sustained the work on this second issue. To our editorial board, advisors, and supporters we extend the most sincere thanks. We hope this second issue becomes part of conversations around medical humanities occurring both here at Boston College and beyond.

All our gratitude,

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

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WEIGHT

Claire Stauffer is a senior in the Morrissey College of Arts and Sciences, double majoring in Biology and English. She shared this piece during the Boston College and Harvard College Collaboration on Medical Humanities.

It was quiet that afternoon. Weekday afternoons were always quiet in our house. Dreamy, lazy, languid in the heat of summer, resting on the downstairs couch I heard you calling me from upstairs. Your voice had that same timber, will always have that same timber every time you call me upstairs. I rose, hesitant to leave that sunlit couch, but your voice again *Claire, come up just a moment!* there again beckoned me up, up into that bathroom. I entered the room and met eyes with you and you said *I just need your help for a moment* in that hushed way, in that way that made me know it was ME who needed to help you, and it couldn't be Jill. That hushed language between parents and older siblings is one you learn from the moment that second child is born. Out on the smooth countertop sat Dad's old electric razor. I lifted it, felt it weigh in my hands. I knew what was coming, God we all knew it was coming. It had been coming since April, since that hushed conversation, that same hushed language in the car on a same sunny afternoon, that same *don't tell Jill* had weighed the same as this razor weighed now. You sat in that chair and stared back at me from the mirror, but your eyes weren't meeting mine, not really, and mine weren't meeting yours, not really.

You looked like a child then, like I did when I was five and waiting for Dad to comb my hair, and you looked up at me, your child, in that same way. Waiting for me to comb your hair. The razor felt heavier now, the weight of that hush felt heavier now, everything was heavier now the moment you looked up at me like that.

I turned the razor on.

It became real then.

I fumbled my way through the already thinning patches of your scalp. I felt unsure, unready, wielding that razor. Shouldn't I know how to do this, shouldn't everyone know from the movies? They do this all the time in movies, this moment right here. But they don't tell you about how heavy that razor is in movies, they don't tell you how much steel can weigh when you look at me like that.

You made a joke like you always do - that Irish bleak humor never turns off, not even for a second. I laughed. I appreciated it.

You could tell how hard this was, I could tell how hard this was, but we just kept staring and not seeing, not actually. But we knew, and we kept that secret, you and me, between ourselves and the hushes and that heavy, heavy razor.

I finished and cleared some stray hairs from your crown, and you sat (admiring yourself, I liked to imagine). Seeing yourself, that terrifying feeling of seeing yourself, and while you were seeing yourself so was I. I was seeing you, actually. For the first time, maybe.

You were thinner now, medications already starting to wear on you. But you looked determined. But you looked scared. But you looked at me and I knew you were looking at me as equal now, because I was seeing you for the first time. How is it that after sixteen years I am only now seeing you for the first time?

We'll be okay you said. That 'we'. The 'we' that meant we were in this together, as partners, as equals, that 'we' that made up that hushed language, that 'we' that had been weighing down on me since you pulled over that car on that sunny afternoon in April and you told me that you had breast cancer.

Yes, that same 'we' that made me know we - you, and me, and Jill - we would all be okay.

REEVALUATING MEDICAL RECORDS IN A DIGITAL WORLD

Theresa Rager is a junior Biology major and Medical Humanities, Health, and Culture minor in the Morrissey College of Arts and Science. Theresa's first piece in this issue of the journal—"Reevaluating Medical Records in a Digital World"—is an adaptation of a paper written for Sara Moorman's course "Sociology of Health and Illness."

With the 21st century well underway and technology abounding, the health care systems of many nations are catching up. In an effort to increase efficiency and lower administrative costs, many countries are introducing smart cards in their healthcare systems. However, several critics of smart cards have claimed the technology has not yet advanced to the United States' security standards, requires too steep of a cost, and can only be effective in a national health insurance program. Nevertheless, health smart cards have proven effective in France, Germany, and Taiwan as a means of keeping electronic medical records (EMRs) and have the potential to be adopted in the United States.

France is consistently ranked as having one of the premier healthcare systems in the world, in part because of the *carte vitale.*[1] The smart card keeps patients' EMRs dating back to 1998 and carries information including doctor's visits, referrals, vaccinations, operations, diagnostic tests and imaging, prescriptions, and billing and insurance records. Doctors only need to swipe the card through a reader to view and update a patient's medical records.[2] Overall, France spends 10% of its GDP on healthcare while the United States expends approximately 17% of its GDP on such costs. In other words, the French save approximately $600 billion annually compared to the United States.[3] Many of these savings can be attributed to a reduction in administrative costs from the *carte vitale*. The French require 67% fewer administrative workers than Americans, an efficiency that leads to fewer waiting lines and payment delays that prevent patients from receiving treatment and doctors from receiving paychecks.[4] Germany, with one of the most expensive healthcare systems in the world, held similar concerns regarding administrative costs. Therefore, they turned to a universal health smart card system, or *die elektronischen Gesundheitkarte*, in 2008.[5] Because the patient's insurance information is kept on the card, payment is automatic, allowing insurance companies to pay doctors within three days and allowing doctors to save the expense of denial management companies. In that same year, Taiwan gained autonomy and had the privilege of designing its own healthcare system. To keep spending costs low, the Taiwanese decided to adopt the health smart card system as a means of documenting patients' medical and billing information.[6] France, Germany and Taiwan have discovered the benefits of a health smart card system as a means of reducing the cost of spending and increasing efficiency.

While health smart card systems have proven their efficacy in several countries, there are several critiques of enacting such a system in the United States. One valid reproach of smart cards is security. For one, in a nation that highly values patient privacy and security of medical records, it is questionable how organizations could demonstrate HIPAA compliance in an electronic system that lacks standardization. Additionally, there is always a concern the system could crash, leaving the healthcare industry in a state of panic.[7] From technology experts, it has been noted that smart cards have slower performance in encrypting and messaging information than Pentium-based PCs, which increases the ability of malicious users to intercept and hack EMRs.[8] In an attempt to study medical staff and patient perceptions of health smart cards, a research group from Melbourne, Australia conducted a study surveying both emergency department (ED) staff and patients. The study found the majority of staff and approximately half of the patients had concerns regarding security, confidentiality, and privacy of EMRs with a smart card system.[9]

ED Staff and Patient Perceptions of Health Smart Card Issues

Concern	No. of ED Staff (%)	No. of Patients (%)
Security Issues	68.5	49.3
Confidentiality Issues	71.7	48.2
Privacy Issues	73.9	55.6

Data from Rosli, Reizal Mohd, et. Al

While this data only provides staff members' and patients' perceptions of potential security issues, such perceptions could be critical to the industry's adoption of and compliance with smart cards.

Although a health smart card system could provide many cost-saving benefits, the cost of implementation could inhibit the adoption of such a system. One case study had to spend $86,000 to install a smart card system within one organization for 12,000 people.[10] A simple card reader with minimal security features can cost upwards of $250 in addition to the price of individual cards, ranging from $10 to $30 and a $100 software-licensing fee. In total, the initial investment for an organization could be over $100,000, an expenditure that could prove exorbitant.[11] When the "public healthcare sector is chronically short of cash…the costs of using the next feature-rich component outweigh the benefits" of potential future cost reduction.[12]

Furthermore, smart card systems tend to work best in a setting of universality, yet the United States healthcare system remains fragmented. These systems tend to excel in a national health insurance program as a system that works in every medical facility.[13] The key potential benefit of a smart card system is the transferability of information between insurers and HMOs; in a system with numerous plans varying from citizen to citizen, such transferability would be virtually impossible.[14] Because several healthcare systems are already in place between providers and insurers, the advent of several electronic card systems does not allow for user mobility but adds to system complexity.[15] Moreover, the study of ED staff and patients found that 52.8% of staff and 60.0% of patients wanted the card system to be optional. With only certain citizens opting to use the smart cards, administrative costs would not be reduced and two record systems would exist. [16] Additionally, a 2001 Canadian study published in *Social Science & Medicine* found that "professionals would not adopt health smart cards in their practice if their use was optional to patients."[17] Clearly, the universality of the smart card system is key to its implementation in the medical sector.

The high expenditure on healthcare in the United States must be addressed, and cutting administrative costs would be a proficient first step. While the price of implementation may be high, the continuation of a paper records increases the cost of programs such as Medicare by 1% each year after 2015.[18] EMRs would also reduce "duplicate records—estimated to cost $60 to $100 per patient."[19] Furthermore, a card system could be a step toward making the American healthcare system more cohesive, particularly in programs such as Medicare or Veterans' Affairs. There are reasonable concerns that such a system could lack security, have a high implementation cost, and fail in the United States' fragmented healthcare system, but the benefits of EMRs have the potential to greatly advance the American healthcare system through a reduction in administrative costs and an increase in efficiency.

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WAOUNAN WOMAN'S PRAYER

Colleen Brady is a senior English and Biology major in the Morrissey College of Arts and Sciences. Her featured work was originally written for Professor Allison Adair's poetry workshop, and in the future, Colleen hopes to become a physician and work with marginalized and underrepresented populations.

Embera and Waounan women,
The brown girls, whose bodies and faces
are carefully lined with black henna, generously
painted, whose hair shines, women who
wear river washed *palomas*,
those brightly beautiful dyes, easy on the
eyes, women whose chests are bare
in the heat, no shame
living in homes made of bark with straw
devouring dinners of corn and plantains,
malnourished bodies resting after a sweltering
span of work,

Strong and sick women
concerned for their babies, who will
work and walk hours and hours to find
a makeshift clinic, where gratefully and gracefully
they receive ointments and antibiotics and creams
from *gringos* in blue, saying *dónde duele*? while
there's more than physical sickness here, watching those
angel-aliens so easily make their girls smile—even
after decayed teeth are ripped
from their mouths with silver tools
and little local anesthetic—with just a touch,
a word of care, *chocas en las manos,*
pegatinas, latex glove balloons: souvenirs
the tooth fairy can't bring,

Ever indebted women,
whose with high hopes for future
lies in mothers sending their
girls from Darién to the city, where
their tattoos are wiped clean,
dressed with chests concealed, where
they'll marry a Hispanic city man, a mother
who hopes her girls will always remember
home, the dances she taught
them, how to make their hair
shine, make their skin glow,
her hope they won't work
as hard, or have to walk
and wait only
to fall through
cracks instead of care: that will make
their mother proud of sending
her daughters away.

THREE-QUARTER HOMES:
A COMPLICATED POLICY DEBATE & ETHICAL CROSSROADS

Andrew Hawkins is a senior Biology major and Medical Humanities, Health, and Culture minor in the Morrissey College of Arts and Sciences. Andrew is a staff writer for *Voices in Bioethics*, an online journal affiliated with the Masters in Bioethics program at Columbia University. Through his work, he intends to expand scholarly ethics discussion to populations and identify essential principles. To do so, he focuses on clarifying legal precedent and analyzing scientific evidence to address how we shape public health policy.

> *Bunk beds with dirty, cigarette scarred mattresses blocked windows. Mold stained the ceiling of a bathroom at New Lots… Some homes had broken sinks, holes in the wall… bed bugs crawling on walls and beds.*[1]

Yury Baumblit and his company Back on Track Group featured in a recent exposé by *The New York Times* violated the central tenet of medicine and patient care: do no harm. It may be easy to view the current investigation as a microcosm of exploitation and corruption—a law enforcement issue not indicative of a flaw in the larger system. In reality, there has been a recent epidemic of kickback schemes and assistance program fraud.[2,3] A larger issue is at stake with shifts in healthcare administration to outpatient settings. Ascension Health, a Catholic healthcare provider, reported that Medicaid's outpatient care revenue growth has outpaced inpatient care revenue growth under the New Affordable Care Act (ACA), suggesting increased Medicaid outpatient demand.[4] The estimated 30 million newly insured people under the ACA are expected to increase outpatient visits by 2.6% nationwide under the ACA, while the overall volume of Medicaid beneficiaries increased by 15% from July through September 2013.[5,6] The dominant trend in health care delivery is decentralization into primary care clinics, extended-care facilities, nursing homes and specialized treatment facilities (such as Mr. Baumblit's New Lot homes).

Less attention has been paid to ethical challenges in these settings because the cases often lack the drama and urgency common to inpatient care. Ethics consultations are infrequent and the moral questions are minute: requests for unneeded services, non-compliance etc. Clinical ethics, known for addressing flashy cases, arose in the moral vacuum of the 1970s. The alliance between patients and physicians had been weakened and trust in the medical guild eroded due to entrenched paternalism. Hard-fought mandates protecting patient autonomy and novel ethical principles (non-malevolence, beneficence, etc.) stood to prevent abuses. The hospital setting served as the primary incubator for the norms of bioethics. These practices, however, did not translate to the outpatient setting.[7] Structural constraints and lack of ethics resources make traditional ethics board review and legal intervention seem cumbersome and costly. Thus, a lack of regulatory oversight coupled with an absence of an ethical framework left a void to be filled by unscrupulous entrepreneurs. Rather than attending to the impoverished, the current system incentivizes waste and encourages treating patients as commodities.

Kim Barker's investigation deals with the most invisible, vulnerable population in the United States: patients suffering from drug addiction. She uncovers a slue of ineffective bureaucracy and a network of scammers associated with Mr. Baumblit involved in Medicaid and disability fraud. The unregulated, "hands-off" environment, contributing to the development of the private, for-profit residences known as "three-quarter houses" (a term derived from being in between a halfway home and the street), has a long history. In the fall of 2008, Mayor Michael Bloomberg announced a 51% reduction in overnight shelter capacity.[8] Options for individuals struggling with homelessness was drastically reduced, which forced many to exchange their "shelter allowance" paid for by the NYC Human Resource Administration for bunk space in three-quarter homes. Operators of these houses profit by neglecting maintenance; almost 90% of suspect addresses had a building code complaint between 2005 and 2012 resulting in a violation.[9] Mind you; these statistics include only documented cases. Three-quarter homes are also allegedly responsible for flagrant violation of tenant rights. According to patient testimonial, landlords illegally evict inhabitants who do not report to mandatory substance abuse treatment. Drug users are among the most socially despised members of society. Their illicit activity, however, does not justify obviating their right to informed consent.

The essential moral function of outpatient addiction treatment facilities should be reintegration of outcasts into society rather than subjecting them to a continuous cycle of relapse for the sake of profit. Christopher Vogt, a Professor of Theology at St. John's University, argues that society has a moral imperative to participate in harm-reduction and ought to view the addict as a 'neighbor.'[10] The issue of funding outpatient facilities or even properly regulating addiction treatment with taxpayer dollars is politically tenuous. Since the 1980s, New York City has undergone substantial changes in legislation leading to the promulgation of three-quarter houses. Patients in public mental health facilities were deinstitutionalized and the City phased out Single Room Occupancy Hotels while prison populations expanded significantly.[11] Until 2009, the Department of Homeless Services responded by outsourcing to unregulated homes by offering rent vouchers.[12] Government officials are reluctant to expand the already taxed shelter system because of its dangerous reputation. The policy hurdles are apparent and the situation seems bleak—only after *The New York Times* published an investigation did Mayor de Blasio follow-up with his own.

In order to shape an appropriate solution an ethics for outpatient care must be envisioned. The crucial issue for further scholarly discussion is whether clinical ethics can be adapted to the outpatient setting. Bioethics is best designed to resolve conflict and address questions in a resource-rich environment. How will our moral considerations need to change to create ethical policy for vulnerable populations? Caregiver disloyalty, for-profit care and the consequences of outsourcing are just a sampling of the problems that will need to be addressed in the coming years.

Fraud arises when the system allows for it and can be prevented by restructuring incentives. In 2011, the Centers for Medicare & Medicaid Services (CMS) announced that it would be phasing out the "pay and chase" model: claims are paid within 30 days before investigating for inappropriate billing.[13] If providers' claims are analyzed and audited before payment is made for services, revenue flow to physicians or treatment facilities involved in fraud and abuse can be preemptively detected. This may imply even greater compliance issues for outpatient facilities with greater scrutiny and larger costs. However, the economics are more complex. The Obama Administration reported that for every dollar spent investigating health care fraud and abuse from 2011-2013 resulted in a recovery of $8.10.[14] A comprehensive law enforcement action lead by Mayor DeBlasio against three-quarter homes might prove to have latent economic benefits for the City.

Public assistance programs must be given the proper funding to implement treatment for stabilization and reintegration. Successful programs do exist. Utah has reduced chronic homelessness by 72% since 2005 through extensive collaboration between community service partners and by providing permanent supportive housing.[15] In-home counseling for drug addiction and unemployment has been highly effective. New York City ought to take note and respond to the exploitation of three-quarter homes with an ethics of care and empathy.

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RECLINE/DECLINE

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I DIDN'T KNOW YOU B4

Gabby Aquino is a senior Biology major and Theology minor in the Morrissey College of Arts and Sciences. Gabby's featured piece was written for a class with Professor Amy Boesky and came as a result of personal reflections on her hospice volunteer experiences. Additionally, she is Editor-in-Chief of *ASIAM* literary magazine

Mr. Salisbury was 95 years old. He would fall asleep every 20 minutes and forget what he was doing every 15. The first day I met him, we watched *The Sixth Sense*. He fell asleep for most of it, but woke up for the ending. I turned to him, "Is this your first time watching this movie?" "Yes!" he replied. "Did you like it?" "Yes!" "Do you understand the ending?" "No, I don't," he answered, looking confused. I was surprised he had never seen the movie. It was possible he just forgot. "Bruce Willis was dead the whole time," I explained. He didn't hear me. "He was dead the whole time!" "Come again?" "HE WAS DEAD THE WHOLE TIME!" Mr. Salisbury made an understanding face and nodded. I gave away the ending to all the residents of the home, but then again, I'm sure they've all seen it. Thus began my attempts to find the best way to communicate with Mr. Salisbury. His left ear was better than his right, and he didn't mind if you held his arm to keep his attention. And like that, we were able to start our relationship.

The next time I visited Mr. Salisbury, I walked to security to sign into his visitor's log. Even though a whole week has passed, my name was the last name that had been checked in. I went to his room, but it was empty. I suddenly became nervous that he had already passed. I approached the nurse station and asked where Mr. Salisbury was. "Salisbury?" the nurse replied, "He goes to Bingo an hour early to get his favorite spot. The rec room." I headed over to see Mr. Salisbury in his motorized chair with two Bingo boards in front of him. I reminded him who I was. He immediately welcomed me to the table and introduced me to his best friends, both in wheelchairs. Lou was a charming grayed man and Bernie was a middle-aged man who can no longer speak coherently after having a devastating and paralyzing stroke. The Bingo caller started the game and everyone gave undivided attention. This was quite a serious activity, except for whenever B4 was called. At least one resident would always shout "B4 what?" followed by laughter. This happened every game, every week. The joke never got old.

We played Bingo each time I visited. Between games, we talked about his service in the air force and his family. He spoke highly of his children, but I never asked where they were now. I didn't meet his family, but Mr. Salisbury and I had fun on our own. Very quickly, my company became an expectation, something we both looked forward to. Soon I was one of the voices cracking the "B4 what" joke. It was guaranteed a laugh.

But time kept passing. One day during Bingo, Mr. Salisbury fell asleep in his motorized chair. His arm pushed the joystick forward and he sped into our table, causing a commotion. He woke up panicked, but I knew I had to have a cheerful attitude. I calmly moved the chairs and tables back to where they were. He relaxed with a smile. "Silly me. Can't stay awake for nothin'." The signs were increasing over the weeks. I was reminded of a sentence from my training, *"Patients in hospice service acknowledge that they are in their last six months of life and do not want to be resuscitated or kept alive by any extraordinary means*". By the end of three months, he was sleeping for most of my visit. I tried to memorize his face and the wrinkles in his hands. My training instructed I should start giving a countdown until my last visits. I came in more often to avoid the lower numbers.

The dreaded day came when I told Mr. Salisbury that this would be our final visit. I stood up, taller than him in his chair. He grabbed my hand, looked me in the eyes and said, "I wish you all the best. Thank you so much for seeing me." I assured him it was my pleasure and I will miss spending time with him. We took in each other's faces and smiled with sadness, knowing.

FIRST, DO NO HARM

Michaela Simoneau is a sophomore in the Morrissey College of Arts and Sciences majoring in Biology and International Studies with a focus area of ethics and international social justice. Michaela is heavily interested in public health, particularly the social determinants of health and the larger systems that establish this socialization. Her featured piece, in which she explores medical malpractice and potential remedies, was originally written for the First Year Writing Seminar with Professor Brian Sousa.

First, do no harm. It is an adage that has been associated with medicine for centuries. As a physician takes a patient's life into their hands, their skills providing the best hope of recovery, this saying guides their moves: "First, do no harm". Yet for a physician, such high stakes makes infallibility simply impossible. No matter the scale, mistakes can happen; the consequence of having physicians is that we have to live with the all too real shortcomings of humanity's imperfection. Ultimately, doctors must be held accountable for their mistakes, just as they are responsible for ensuring exemplary standards of care for their patients. However, medical malpractice litigation as it exists today is deeply flawed: failing to protect doctors and physicians appropriately; hindering the way medical care is provided; and poorly outlining the guidelines for the adjudication of the cases which do arise. In order to create a more balanced system of patient and physician protection, a clearer system of standards and fair malpractice litigation must be adopted in order to evolve health care into a more transparent and effective system.

Malpractice occurs when a professional breaks a standard of care or conduct, resulting in client injury or damage.[1] Particularly, medical malpractice is "improper, unskilled, or negligent treatment of a patient."[2] In civil litigation, these proceedings typically fall under the subset of TORT law, which deals with damages resulting from the wrongful acts of others.[3] Under this law, there are four criteria for determining whether a physician is truly negligent, and whether they are truly culpable: Did the physician provide the care he or she was supposed to? Was the expected care standard met?; Did the patient sustain any compensable injuries?; and Were the injuries caused by substandard care?[4] These questions lack simple answers, especially when situations vary so wildly and when proving fault is so difficult in actuality.

It is not as if these questions are just starting to be considered; malpractice suits have been a matter of debate for centuries. The first malpractice case is recorded as *Stratton vs. Swanlond*, in 1374, and was handled by a local "Court of Common Pleas."[5, 6] Yet this local battle over malpractice did not extend into a national debate over patient and physician protection until around the nineteenth century. In 1852 *The Boston Medical and Surgical Journal* noted that "one case after another shows that the best operators in New England expose themselves to the hazard of a vexatious lawsuit... [to the end of] the ruin of the defendant's professional influence . . . even if his last dollar is not taken."[7] This debate gained further hold in the 1960s and 1970s, as it became clear how medical practices and standards of care were being affected.[8] Over time, it has become more evident that medicine is entrenched in a world increasingly focused on technology, economics, and law, and that these forces will only have a larger influence on the bureaucracy and policy behind medicine.[9] The debate has not been resolved, but has instead only escalated.

Today there are some measures in place to govern malpractice suits, but they remain vague. A standard of conduct attempts to regulate the expected level of care from physicians across the nation, yet such standards are exceptionally difficult to judge across areas with such dramatically different resources.[10] A "respectable minority rule" in theory protects physicians who are performing riskier surgeries and techniques which only a small number of respected doctors use, preventing their liability should something go wrong.[11] Yet again, it is extremely difficult to establish what that vague parameter of exclusivity includes. An "error in judgment" rule is effective by mandating that medical professionals are not at risk of malpractice if they err in judgment when choosing a treatment or diagnosis from a set of feasible conditions or tactics.[12] Nevertheless, it is difficult to apply these laws, and such provisions do little to project physicians in court.

As a result, *liability* is less of a question; rather, litigation is used more frequently to determine the *amount* of compensation a patient will receive.[13] This goes beyond physical or emotional injury to punitive damages—extra-monetary compensation won in court cases that serves more as revenge on the physician than payment for pain and suffering.[14] In 1975, the California Medical Injury Compensation Reform Act limited noneconomic damages to $250,000, and also limited lawyer fees to eliminate some punitive damages.[15] Yet there is still an unsettling potential for unnecessarily enormous settlements. Patients must be compensated, but the terms of such compensation must be regulated on more than a case-by-case basis.

This lack of protection has caused many physicians to distrust the legal system, and a fear of litigation along with a desire to maintain their careers and good standing has led to dishonesty with regard to medical errors. In a recent study by the Archives of Internal Medicine, 98% of doctors acknowledged the need to disclose serious issues to patients, particularly after a physician's mistake, but that statistic fell to 33 percent when it was described as full disclosure, with a full, explicit apology.[16] Furthermore, physicians admitted they would be far less likely to report errors if they were sure the patient would never find out.[17] This distrust for the handling of malpractice and mistakes and the wariness it imposes have created a new layer of distrust between doctor and patient, and a wholly undesirable lack of transparency. These lies by omission create a horrific barrier to care—one that is completely unnecessary and potentially avoidable without such a fear of litigation.

This fear of failure imposed by the courts has led to a costly and impractical era of defensive medicine. Defensive medicine terms the unnecessary measures doctors often take to avoid the chance of making mistakes or missing something, and being sued as a result. As President Obama stated in his June 2009 speech to the American Medical Association, "too many doctors order unnecessary tests and treatments only because they believe it will protect them from a lawsuit."[18] One study said that 79% of doctors acknowledge ordering more medical tests than they think are needed; 74% refer patients to specialists more often than needed; 61% are reluctant to make humane choices for terminally ill patients; and 83% of physicians and 72% of hospital administrators do not trust that the justice system will be reasonable in lawsuit results.[19] This could be beneficial, an extra safety net might prevent any overlooked issues. These tests were *beyond* what the physicians believed necessary, consuming unnecessary time and resources. Such tests purposelessly funnel away tens of billions of dollars every year.[20] With a continued culture of corrupted malpractice, defensive medicine has become expected, the new standard of care, ingrained into the routines of physicians for decades.[21, 22] This standardization is clear in the reluctance of medical professionals to change their ways after minimal malpractice reform; changes in Texas, South Carolina, and Georgia, for example, did not produce significant change in the number of MRI or CT scans ordered.[23]

Beyond the cost of defensive medicine, corruption in the legal system is further using malpractice as a means to increase the cost of health care and insurance. A 2010 statement by the president of the American Medical Association clearly highlights the dysfunction with which the system impedes the true wishes of doctors and patients: "The litigation lottery invites abuse, inefficiency and persecution of the blameless … Unfortunately, the liability system has failed patients, but it is extremely lucrative for trial lawyers…"[24] With huge premiums, physicians are forced to pay exorbitant amounts for insurance, especially in New York and Florida where they pay $100,000 annually for one million in coverage.[25] Newt Gingrich explains, "the system subsidizes lawyers instead of improving health care."[26] As George W. Bush said in his 2003 speech before the American Medical Association, "There are too many frivolous lawsuits against good doctors, and the patients are paying the price."[27] They pay this price through higher defensive medicine bills, lack of doctor transparency, and falling confidence of medical professionals. The entangled, ineffective system must change.

Effective reform has been negligible so far. While there are plenty of policies condemning doctor mistakes, there are few endorsing or incentivizing desirable practices. As President Obama explained in his June 2009 speech to the American Medical Association, "We need to explore a range of ideas about how to put patient safety first, let doctors focus on practicing medicine and encourage broader use of evidence-based guidelines."[28] Establishing such protocols will help to eliminate some malpractice risk. The reform that has been passed by Congress is largely in the form of small pilot projects that do little in terms of enforcement; Congress has failed to provide the proper funding required for implementation and development of better tactics.[29] Only with more large-scale, broad-based reform will there be real change that does not impede the work of doctors or the safety of patients.

A possible remedy to some of the aggravation within the system could occur through technocratization and separation of the medical malpractice suits from the larger court of civil litigation. Oftentimes, the jury handling a malpractice suit is not a panel of experts, unable to appropriately judge the situations at hand, even with an expert testimony. Two-thirds of such cases end in settlement because of the expectation that physicians will "accept liability even in cases of inevitable deterioration following due and proper treatment."[30] With biased, uninformed juries, physicians rarely have a chance. Newt Gingrich—with the group "Common Good, " a reform-minded group of politicians—suggested a special court in order to eliminate such poorly informed decisions.[31] It is challenging to have litigation without any bias, yet this new system may eliminate some of the distrust that obscures clear reason in determining fault. Perhaps the delegation of malpractice suits to a separate court will begin a new era of more informed, fair decisions for all parties, such that truth and accountability are both upheld.

Beyond all of the legal reforms and the technical aspects that must be implemented to solve this issue, a larger emphasis must be placed on maintaining the human connections between physicians and patients as a reminder of why we do not simply use robots for care and diagnostics. Malcolm Gladwell explains that "the overwhelming number of people who suffer an injury due to negligence from a physician never file a malpractice suit at all. Patients don't file lawsuits because they've been harmed by shoddy medical care. Patients file lawsuits because they've been harmed by shoddy medical care and ... they were rushed or ignored or treated poorly."[32] Take Dr. Wendy Levinson, MD, from the University of Toronto, who found that doctors who had never been sued had spent on average an extra three minutes with patients, compared to those who had been sued.[33] This basic level of communication and humanization establishes patient-physician trust and connects the patient and doctor, leading to more understanding, open communication, and less animosity should something go wrong. It is a shame that more physicians still adhere to the stereotype of being cold and distant. Simply increasing this basic communication correlates to better outcomes, better patient behavior, and fewer malpractice cases. Perhaps the remedy to this issue of lawsuits is simply a change in the way of approaching these relationships.

Ultimately, physicians are not Gods, not infallible, yet with each life they take into their hands they are inspired to try to solve a new problem and to save a life. It is their job, their duty undertaken from the moment they swear the Hippocratic Oath. The empathy and care for human beings to which they swear—drawing on humanity, vulnerability and imperfection—create better caretakers. "There is art to medicine as well as science… warmth, sympathy, and understanding may outweigh the surgeon's knife or the chemist's drug."[34] Giving up that empathy, the ability to understand a patient, is not a cost that should be paid for ultimate perfection. Thus, physicians cannot avoid these mistakes, but must learn how to handle them.

Transparency is the key. The debate is far from over, the balance not yet achieved; systematic reform must include some elimination of tension and fear. This ultimately requires a more universal understanding of the grounds for malpractice suits, a standardized system of care and justice. It requires a restructuring of court procedures to eliminate bias. Beyond this, humanity has to be brought back into health care. Patient-provider communication must reestablish that physicians are fallible and patients deserve full disclosure. Only then can trust be reestablished. Only then can physicians perform at their highest standard. Only then will patients feel that their needs will be fully met. Communication is the future of health care, and lack of reform will only serve to entrench the system in bureaucracy and litigation.

A system such as that will heal no one.

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HIGH-LOW SEED

Rusty Cosino is an undergraduate student in the Morrissey College of Arts and Sciences, pursuing a major in Film Studies. Rusty also intends to study Medical Humanities, Health, and Culture. He writes short stories and poetry, performs spoken words, makes films, and engages in creative collaborations.

I finally caught up with my schoolwork,
& then I woke up.
In my twin size bed & I read the clock
timed at 5:18, remembering that this
was the week everyone would be
worrying about housing & their living
space & here I was all drowsy in
my bed living inside my head.
You see I used to believe that I
was bred to be ready for anything & everything
but it's been so hard to remember
simple things like getting my ass to
class. But time has been moving so
fast but slow at the same time & I
don't know how I should go about
the situation & I'm not patient
enough to plan it out and it leaves
me just shouting out "help."
But you see I have just been yelling
at myself in my head hurting myself
with words of resentment. & I'm behind because
I fail to be patient in class and
even if I'm physically present, I'm not
present because my head is spinning
and I'm beginning to lack belief
in myself & it's selfish of me
to wallow in sadness but I would
drive myself towards madness if I'm
not kind to my health so …
(breathe) breathe.
I'm trying to see the bigger picture
but the pictures that hang in my room
make it challenging to resume my life here
& now & even though my vision
is cloudy & I feel so drowsy
all the time I know it will work
out. But only if I put in the
work & have faith, remember to take
breaks, & never give up. & I am
too damn stubborn to be defeated
& I want to look back at this
in the future & realize that all
I needed were my loved ones. The ones
like my family, friends, & mentors.
Loved ones near and far,
The ones that fill my life with
joy are fun to talk to &
ones that teach me new things.
& Now I am beginning to see
a brighter side so …
(breathe) breathe ….
& remember you have so much
still ahead of you
so keep your chin up
look high up into the sky
& soar side by side
with the other eagles.

THROUGH THE LOOKING GLASS

Nick Raposo is a sophomore in the Connell School of Nursing, pursuing a minor in Medical Humanities, Health, and Culture. Nick is particularly interested in global and public health, and hopes to incorporate these focuses into his nursing career. Outside of his academics, Nick is a volunteer for the Student Admissions Program and a freshman Resident Assistant.

"There are times in the lives of most of us, when we would have given all the world to be as we were but yesterday, though that yesterday had passed over us unappreciated and unenjoyed." – William Edward Hartpole Lecky

When my dad passed away last July, it was tough. It was halfway through the summer, I had just graduated from high school, and I was preparing to embark on the exciting and nerve-wracking journey that is college. All the while, I was living life in my own little world, detached and disconnected from those closest to me. Most of my days consisted of working one job or another (at the time I was juggling three, for no justifiable reason), and my days off consisted of sleeping in, spending lazy afternoons by the pool, evenings by the fire with friends, and late nights of Netflix. But I got lost in that little world. I forgot to be present, mindful, and – most of all – appreciative. So when my dad, who was neither sick nor ill, didn't wake up from his sleep one morning, Reality didn't just bring me back down to earth. It hit me. Hard.

During the first few nights after my dad passed away, I couldn't sleep. During the day, I couldn't eat. In the mornings, I would step into the shower, curl into a ball, and hope that the sound of the water running would muffle my wailing and sobbing. In the face of it all, I had the misconception that it was my responsibility and duty to never shed a tear around others, to always maintain an optimistic tone, and to attempt to live each day just as normal. But after such a painful experience, life doesn't just go back to 'normal,' and I would be mistaken to pretend that accepting my dad's passing as a part of my own life experience has been a simple exercise in resilience and soul-searching. It *was* tough, and it's *still* tough.

But I've grown from this experience. (I know what you might be thinking: How can one possibly find any positivity or room for growth in such an experience as death? But that's *exactly* the point.) At the beginning of my freshman year here at BC, I didn't even mention my dad. I figured that if I didn't talk about Dad, then my new friends wouldn't ask about Dad and, as a result, we would all be spared the off-putting response that I would be obliged to give. I was wrong for two reasons: (1) similar to how telling a child not to touch something only encourages the child to disobey, not talking about my dad meant that people had more questions about him; and (2) attempting to sweep my dust under a rug so that people - including myself – wouldn't realize the reality of my life was a *very* poor coping strategy. Only two people on campus knew what I was going through: my incomparable roommate and one of the nuns on campus. With their encouragement and support (the power of which I'm sure they underestimated), I eventually was able to share my experience with my friends. I shared with a roomful of strangers during my 48HOURS retreat. By the end of this past school year, I was able to tell stories about my dad without regret, remorse, or tears, and now here I am writing about my experience.

Part of this growth experience for me has been a profound attention to life lessons ("Give reminders of love and appreciation," and "Smile often," to name a couple of my own). One of the simplest, yet most important lessons that I've learned from my dad's passing is that happiness goes a long way in making people, myself and others included, feel good. My dad was always happy and always loving. "Hate is such a strong word," he would say to me as I complained about the bits of onion in my spaghetti sauce or the pigeons waddling too close for comfort. Reflecting on his happiness and love has been a way for me to continue learning about my dad and his values and motives. Understanding my dad's life lessons has been a way for me to develop my own, a way to keep positive about the experience that I have endured, and a way to learn and grow in the face of adversity.

This summer, I decided not to work at all. (The reader, briefly scanning this piece while on break at his/her on-campus job, gasps at this shocking violation of "How to Make Yourself Stand Out to Potential Post-Grad Employers" and "How to Be a Good College Student 101".) Instead, I opted for one of my life lessons: do what makes you happy. Now, that's not to say that work can't bring happiness. In fact, I've experience some of the happiness that meaningful work can provide. But after last summer – when I lost myself in an attempt to juggle three jobs and some form of social life and was subsequently plucked out of a fog by the loss of a loved one – I vowed never to become so immersed in work that I would disengage or disconnect from myself, from those around me, or from the present moment. Rather, I wanted to spend this summer doing things that I like: reading, cooking, spending meaningful time with friends and family, smiling, enjoying the little things, listening to Motown or jazz, taking naps, deep-breathing for thirty seconds. And that's what I've done.

Just this afternoon I was reading Lewis Carroll's T*hrough the Looking-Glass*. In Chapter III, Alice comes to a forest, and immediately forgets what a tree is called. She then realizes that she's also forgotten her own name. In despair, Alice seeks the help of a fawn grazing nearby:

> *"What do you call yourself?" the Fawn said at last. Such a soft sweet voice it had!*
> *"I wish I knew!" thought poor Alice. She answered, rather sadly, "Nothing, just now."*
> *"Think again," it said: "that won't do."*
> *Alice thought, but nothing came of it. "Please, would you tell me what you call yourself?" she said timidly. "I think that might help a little."*
> *"I'll tell you, if you'll move a little further on," the Fawn said. "I can't remember here."*
> *So they walked on together through the wood, Alice with her arms clasped lovingly round the soft neck of the Fawn, till they*

came out into another open field, and here the Fawn gave a sudden bound into the air, and shook itself free from Alice's arms. "I'm a Fawn!" it cried out in a voice of delight, "and, dear me! you're a human child!" A sudden look of alarm came into its beautiful brown eyes, and in another moment it had darted away at full speed.

Alice stood looking after it, almost ready to cry with vexation at having lost her dear little fellow-traveller so suddenly. "However, I know my name now," she said, "that's some comfort. Alice – Alice – I won't forget it again. And now, which of these finger-posts ought I to follow, I wonder?"

(So what? Why is this important? What is it about this single scene in a children's book that motivated me to reflect and write about the experience of my dad's passing?) What I find so striking about this scene is the experience of loss and growth that it traces, and how much my own experience over the past year mirrors the one that Carroll creates. Alice is at first lost, innocent, naïve, and clueless. She is lucky enough to run into a fawn who is willing to guide her through the thicket of the forest and into a clearing. When the girl and fawn emerge onto the field, Alice remembers her name, but loses the companionship of the friend that helped her to remember it. Teary-eyed and anguished at the loss, Alice nonetheless realizes that she has gained something profound from the brief encounter. "'I know my name now… that's some comfort… I won't forget it again.'" My experience has been a lot like Alice's journey through the forest. I was once naïve and clueless, just like the girl. But I was lucky to have my dad to guide me through some of the thicket of life. I was lucky to have my dad to help me remember my own name. Loss is difficult, it's tough, and it's something that I will live with. But I also get to live with the luck, joy, and blessing of having had someone to guide me through the thicket of life, to remind me of my name, and to teach me something about who I am as a person. The life lessons that I have gained from my stroll through the forest of life with my dad are some of the most important that I have learned, and I know that—just like Alice—I won't forget them as I continue my adventures through the looking-glass.

Alumni Guest Folio

CLINICIAN LANGUAGE CHOICES:

AN ANALYSIS OF AGENGY IN PATIENT-PROVIDER INTERACTION THROUGH UNCERTAINTY MANAGEMENT FRAMEWORK

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Introduction

Though there has been substantial research in the relatively new field of uncertainty management theory, very little analysis has been done with respect to the patient-provider relationship that is fundamental to the field of health communication. Perhaps the most common binary relationship in healthcare, it is remarkable that uncertainty management theory has been mainly focused on other social fronts: romantic partnerships and family decision making processes.

The goal of this paper is to explore the rationale behind altering agency choices in patient-provider interactions. Notably, this is distinct from previous applications insofar as the information provider will be the focus of discussion as opposed to the information seeker, historically the more common source of analysis in uncertainty management research. Ultimately, the Theory of Motivated Information Management (TMIM),[1] and subsequent adaptations that integrate appraisal theory,[2] will be adapted to explain altering the source of agency in delivering primarily negative diagnoses or news to a patient.

Ultimately, the paper will define four categories in which agency can be shifted from the provider to other sources as mechanisms. Through an examination of these categories and specific examples of each, shifts in agency will be concluded to have one of two goals: (1) preserve provider safety/distance from liability and (2) manipulate or coerce the patient into a making a decision favorable to the provider.

Patient-Provider Interaction Overview

To premise, it is important to understand the complexity of the patient-provider relationship as distinct from other binaries. The relationship between a patient and provider is necessarily asymmetrical, that is, it is controlled by the physician, typically through asking questions.[3] Resultantly, the flow of information between provider and patient is also controlled by the physician. Doctors can restrict the flow of information to patients, often withholding critical facts about their diagnosis and treatment.[4] Additionally, the medical interview is shaped by the context in which it takes place; cultural assumptions about the patient, the logic of differential diagnosis, and the demands of bureaucratic organizations combine to constraint doctor-patient communications.[5] Notably, this would include legal liability and malpractice, to be discussed in greater detail later on in the paper, as well as assumptions about a patient based on appearance that may make deflecting agency to another source easier (for example, an overweight patient).

Regarding the actual medical interview, it inherently subordinates the patient's concerns, beliefs, and life world to the demands of medical discourse.[6] It can thus become a form of repressive communication that ultimately and severely compromises the quality of patient care.[7] The structure of the medical interview is likely one such cause of these results. Roter and Hall suggest that there are five parts that take place in each medical visit: opening, history, the physical exam, patient education and counseling, and a closing. Notably, patients are most verbally active in the history section where communication is almost equivocal between provider and patient (52% in favor of physician). However, physicians are very quick to redirect patients from presenting the entirety of their concerns in the history segment of their visit, which has the effect of limiting the full disclosure of all of the patient's concerns.[8] Many times interruptions are made to redirect patients to closed-ended questions, possibly to facilitate transition to the later segments of the medical encounter.

Negative talk is rare from physicians during the medical encounter. Physicians often find other, indirect ways to express displeasure. Reprimands may be expressed as forceful counseling or imperatives on the need to follow recommendations better.[9] One such example is a deflection of agency, where the provider distances themselves from the patient and replaces another agent in place of him/herself. Notably, this would not be considered negative talk, instead, a way to communicate a message indirectly to the patient.

Defining Agency in Medical Encounters

First, I provide a definition of agency, "an autonomous organization that adaptively regulates its coupling with its environment and contributes to sustaining itself as a consequence."[10] Importantly, there is an active component to the definition provided, making inanimate objects incapable of functioning as an agent. By this logic, neither procedures nor technology can present as permissible agents in medical encounters.

It is important to provide an explanation for how to locate agency, and how it exists in medical interactions. For the sake of this paper, two criteria will be required in order to determine the source of actual agency in any given relationship:

The system must define its own individuality, and
It must be the active source of activity in its environment.[11]

To clarify, I provide an example of finding the source of agency in a typical (and perhaps, ideal) medical scenario in which a patient visits a provider for an annual, regular physical examination. The system is necessarily *individualized*, the patient and his/her scenario and relationship to the provider is unique. The *active source of activity* is that of the physician conducting the actual physical examination on the patient. Thus, the agent in this interaction can be concluded to be the physician.

Often times the agency in certain interactions can be convoluted. However, in a medical discourse, there are necessarily two parties and therefore an agent is by definition present in the provider that is delivering the message. Yet there are examples of physicians skirting around being the agent in delivering diagnoses, particularly in delivering news of chronic or terminal illness or other potentially detrimental news.

Context and Types of Agency Deflection

This section of the paper will focus on defining four categories in which agency can be deflected to another party or object through language and patient delivery. Through application and several examples, the alternative agent presented will be examined and analyzed for permissibility as an agent per the previous definition.

The four types of agency deflection to be examined are not mutu-

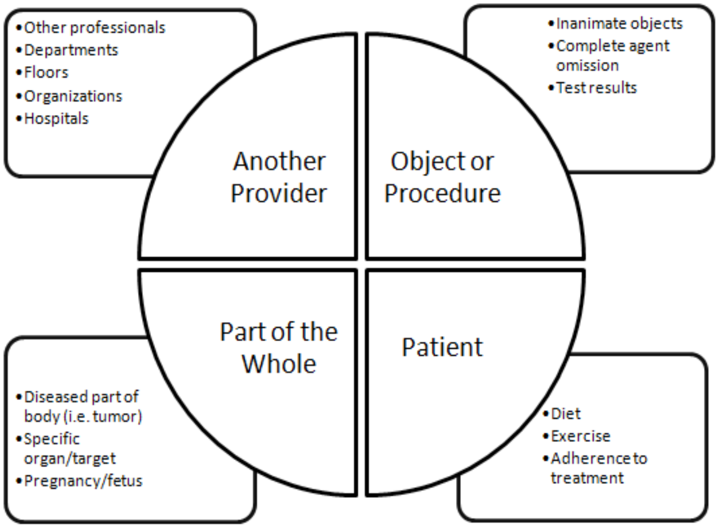

Figure 1. Proposed mechanisms of agency deflection and examples

ally exclusive yet most examples can be located in one of the four strata (Figure 1).

Deflection of Agency to Another Healthcare Provider

There are several ways in which a provider can deflect agency to another provider or organization. The first and perhaps most common is a deflection to a specific healthcare provider. This is frequently accompanied by language choices from a nurse saying, "the doctor will be with you shortly," or as a physician, "the radiologist will be in with your results." This often results in a vicious cycle of several cascades of agency shifts. The nurse can shift to the physician, the physician to the diagnostic test interpreter, the interpreter to a surgeon and so on. This can lead to compounding anxiety about test results, confusion for the patient, and a delay in patient care. Though each of these people is a viable source of agency according to the proposed criteria, a deflection of agency nonetheless occurs.

An alternative to deflecting agency to an individual provider is a deflection to an organization, department, floor, or another hospital. I provide an example to clarify: a newborn girl was transferred from a community hospital to a city hospital to rule out a GI bleed with the goal of increasing her quality of care received. Several days into her treatment, a nurse noted an IV slough with a darkened area at her IV site. The patient was subsequently transferred to the ICU and the parents came to visit. Alarmed by the extent of the injury, they consulted several floor clinicians and received a multitude of different responses, some of which claimed the problem originated in the community hospital, others blamed the general medical floor nurses where she was first admitted, and only one physician assumed accountability for the complication and admitted something should have been done sooner.[12] Significant it is that the quality of patient care was in fact compromised in failing to immediately transfer the patient to the ICU for fear of repercussion. Additionally, while a nurse can serve as the agent responsible for the complication, shifting agency to the entire community hospital or the medical floor in which the patient was transferred is not justified, as neither can qualify as active agents and instead serve as overly generalized safety nets employed by the information providers.

Deflection of Agency to Objects or Procedures

Another mechanism in which providers are able to deflect and distance themselves from personal involvement is through utilizing an object or procedure as a faux agent. As previously discussed, neither fits the criterion for admissible agency. These types of language choices are common both in written and spoken language. For example, in a review of several physician case presentations, Renee Anspach cites several examples where either a process, test result, or machine is utilized as the source of action in case presentations:[13]

i. "Auscultation of the head revealed… and angiography showed…" [processes]
ii. "Follow-up CT-scans have showed…" [object/machine]
iii. "The arteriogram showed that this AVM was fed…" [process]
iv. "The EEG showed…" [test result]
v. "The path revealed…" [test result]

Notably, in each of these examples, the agent is entirely omitted. None of these processes can be performed without a human presence; for example, auscultation requires human interpretation of sounds. In personifying a process as a machine, procedure, or results of a test, a provider effectively distances themselves from the patient. Should blame or guilt be a resultant effect of the information provided, perhaps the hope is that the patient will exert their frustrations on the machine/object rather than the provider.

Additionally, the verb choice in each of these examples appears redundant, frequenting neutral verbs such as "revealed" or "showed" that are purely technological in nature. Anspach notes that in these choices of verbs, a provider takes an active human process and converts it to a mechanic, fail-proof method, limiting any room for human error.[14] The usage of the agentless voice can be particularly significant when the decisions are controversial, problematic, or questionable, she notes. Citing an example of a newborn baby who did not receive betamethasone, a drug that could have helped alleviate or prolong the child's life, the physician notes on an official record that "No betamethasone was given," a sharp contrast to adopting responsibility for their actions, perhaps more accurately stated as "The doctors at St. Mary's did not give betamethasone.[15] This is certainly an example of how in retrospect, language can be used as a defensive mechanism to protect doctors.

Arguably, omission of the agent and failure to acknowledge the true source of agency can also be detrimental to the quality of care received throughout the treatment of a patient as well. "Dr. Smith noted a lesion on an X-Ray," as opposed to "an X-ray revealed a lesion" would allow the party charged with patient care, or reading the patient's chart easier access to contacting the diagnosing physician if uncertainty or complications should arise.

Deflection of Agency to a Part of the Whole

This mechanism of agency deflection can occur in one of two ways. The first and more common is when clinicians refer to a very specific part of the patient in an attempt to dehumanize the part of the body. For instance, it occurs when clinicians narrow in on a part of the body such as a specific organ or a tumor. Often times this type of agency deflection is accompanied with overly scientific vocabulary that can easily confuse a patient. Multiple research avenues have shown health literacy and patient understanding of the complexities of their disease to be significant to their adherence and ultimately health outcome.[16] Examples of this type of mechanism may include "the tumor is growing," or "the inflammation of the liver has not reduced," in both cases the patient is ignored and loses the individuality of their illness and is generalized to the function of a part of themselves.

A second example that offers a slightly different comparison is that of a fetus of a pregnant woman. *The Business of Being Born*, a documentary on home birthing as an alternative to hospital births describes an elaborate drug cascade that women in hospitals go through in giving birth. If the patient isn't progressing through the birthing process at a fast enough pace, physicians administer a drug called Pitocin, which is designed to increase strength and rate of contractions. However, the increased strength of contraction results in significantly more pain, thus requiring administration of additional epidurals. In a contrasting manner to the way that Pitocin speeds up the contraction process, the epidural contains chemical properties that slow contraction rate. The cycle of administering Pitocin and epidurals continues, often giving cause for additional interventions such as vacuum-assisted deliveries or cesarean sections. Patients in the documentaries are quoted describing the process as a "domino effect" and physicians using delivery techniques such as claiming that "it's necessary for your baby." The physicians interviewed in the documentary describe a strong association between the induction of labor and increased cesarean deliveries, and thus this process is detrimental to the quality of care that both the mother and child receive.[18] Though the physician is necessarily the agent in this interaction, by honing in to the health of the unborn child, the interaction between mother and clinician is lost. Additionally, because the child is not yet autonomous from the mother, it is unable to be a recipient of agency.

Deflection of Agency to Fault the Patient

The final mechanism of agency deflection occurs when the provider deflects blame directly to the patient in which he/she is interacting with. This is perhaps the bluntest type of agency deflection discussed because it can turn physician fault onto the patient. As an example, a theoretical case of an elderly gentleman who unexpectedly passed away amidst a heart surgery is offered. In consoling the patient's family following the operation, the surgeon offers that due to the patient's lack of exercise and poor diet, there was a buildup of plaque in his arteries and he suffered from a sudden heart block. These types of deflections where a physician places blame on the patient in areas such as diet, habits, exercise, smoking, etc. can again be used as a defensive explanation to later provide rationale for physician error.

Previously discussed in Patient-provider interaction overview, cultural expectations and physical observations about the patient were said to shape the context of the medical interaction between a patient and provider.[19] Notably, issues such as smoking and weight/diet would be discussed here. By providing explanations in charts and patient records that "patient reports regularly smoking" or "patient unable to adhere to previously provided diet regimen," the physician is again employing defensive tactics. Notably, both of these explanations put the fault on the patient in a preemptive safety net for the clinician, which contrasts sharply with previously discussed events of physician error, such as in the administration of betamethasone provided.

Roter and Hall discuss that these areas are typically where physicians are actually inclined to express discontent with their patients.[20] Findings indicate that physicians often reprimand patients through forceful counseling or imperatives on the needs to follow recommendations better. "For the unsuccessful dieter, for instance, this could mean exhortation for the patient to do better on his diet and follow a prescribed regimen," (p. 120). The physician may also express discontent in tone of voice or by cutting the patient off in various ways.

Summary of Mechanisms

Though some of the mechanisms discussed function through providing a viable alternative agent, the detrimental effects of deflecting agency are evident in each of the provided mechanisms. Notably, patient outcome suffers in many regards: delay in receiving information or care, patient adherence to prescribed

treatment methods, patient understanding of the complexity of a diagnosis, or feeling at fault for their current state of being.
The primary effects of deflection of agency appear to be enacted for two purposes, one defensively as to protect from liability and, alternatively, to manipulate and or coerce a patient into a particular decision.

Defensive Medicine

The Congressional Office of Technology Assessment [21] provides the following definition of defensive medicine: "Defensive medicine occurs when doctors order tests, procedures, or visits, or avoid high risk patients or procedures, primarily (but not necessarily or solely) to reduce their exposure to malpractice liability." Some medical practices have become so routine that physicians are unaware that liability concerns originally motivated their use. This is evident in the training of both new and old physicians who simply follow organizational protocol.

The prevalence of defensive medicine, especially in the United States is particularly alarming. A 2007 survey of 300 physicians, 100 nurses, and 100 hospital administrators found that more than 76% of physicians responded that malpractice litigation had hurt their ability to provide quality care to a patient. Additionally, 79% of the surveyed responded that they had ordered more tests than necessary, 74% referred patients to specialists more than necessary, 51% recommended invasive procedures more than necessary, and 41% prescribed excessive medications such as antibiotics than they typically would have based on professional judgment.[22] It is clear that defensive medicine is deeply ingrained into modern medical practice, spanning well beyond the previously discussed language implications.

Defensive medicine is harming to both physicians and to their patients. Moore, Adler, and Robertson note, "There exists a direct, causal effect of the doctor-patient relationship on medical patients' treatment perceptions and malpractice claim intentions in the event of an adverse medical outcome."[23] By deflecting agency, a physician effectively distances themselves from the situation, largely in fear of liability. Physicians' anxiety about malpractice lawsuits may drive defensive medicine more than the actual risk of a lawsuit.[23] A malpractice suit is described as a personally and professionally devastating experience.[25]

Manipulative or Coercive Medicine

On the opposite end of the spectrum, physicians may employ these agency shifting tactics for self-benefit as opposed to self-preservation. Returning to the Pitocin-epidural cycle discussed earlier, a patient describes coercive techniques employed by physicians, "That's one of the great manipulative techniques that are used, is when a woman starts to question, Why do we need to do this? The first thing you turn to is, oh, it's for the good of the baby." She continues that, "It was very easy for them to do things that we hadn't really wanted them to do," and that at the end of the intervention, "Everybody says, "Thank God, we were able to do all these interventions to save your baby…the fact of the matter is, if they didn't start the cascade of interventions, none of that would have been necessary."[26]

There is also research that may support the claim made in Epstein's documentary describing the manipulative nature of OB-GYN physicians. Brown explores the relationship between time of day and rate of cesarean sections performed.[27] In his discussion of "physician demand for leisure," he notes that the most common times of day for cesareans are between 4-8p.m., and shortly before midnight. Epstein furthers this claim by suggesting that physicians tend to coerce patients into cesareans in self-interest before dinner time and so that they can have an uninterrupted night of sleep.[28]

But physician manipulation and coercion are not limited to OB-

GYN physicians. Scare tactics are often similarly implored in an attempt for patients to adopt a certain treatment regimen. This idea is so fundamentally ingrained in us that it seems almost natural; from the time we can walk a pediatrician is telling us to eat vegetables and drink lots of milk in order to grow tall and strong. Similar campaigns about smoking, drug use, and exercise are plentiful both in and out of the doctor's office.

Additionally, clinicians may employ some of the previously discussed objects as manipulative devices. For example, upon the return of blood work from a patient, a physician might suggest, "Your lab results may be an indicator that you are at risk for diabetes," in a preemptive attempt to persuade a patient into adopting healthier eating and exercise habits.

Theory of Motivated Information Management

Theory Background

The remaining segment of this paper will adapt the Theory of Motivated Information Management (TMIM) to fit the proposed mechanisms of agency deflection described.[29] Historically, TMIM has been used to evaluate social relationships. For example, prior implications have discussed the drives behind seeking sexual health information from partners,[30] discussion of listing as an organ donor among family,[31] conversations between parents and children of divorced or divorcing parents concerning relationship status[32] and discourse surrounding enrollment and options surrounding eldercare.[33]

First, it is important to qualify the patient-provider relationship as applicable to TMIM. TMIM is a theory framed within interpersonal contexts.[34] Additionally, Afifi and Weiner frame TMIM with several examples of relationships that it can encompass: employees and managers, students and instructors, romantic partners, and notably, individuals seeking health information from physicians. The theory is rooted in dyads, with "at least two communicators; intentionally orienting towards each other; as both subject and object".[35] Though there has been minimal published content that pertains to the patient-provider relationship, the interpersonal nature of the provider-patient interaction qualifies it for TMIM framing.

Historically, information sharing was minimal in medicine. Davis addressed ways in which physicians manage information with patients' families in order to "allow them to remain optimistically uncertain for a long time". He continued to note that "long after the doctor was no longer in doubt about the outcome, the perpetuation of uncertainty in doctor-to-family communication, although perhaps neither premeditated nor intended, can nonetheless best be understood in terms of its functions in the treatment systems."[37] Afifi and Weiner explain that these varying levels of uncertainty are what TMIM aims to explore. Individuals may desire to either increase or decrease their uncertainty.[38]

Theory Framework

The theory proposes a three-phase process of information management that information seekers go through in deciding a course of action to resolve an uncertainty discrepancy. The original theoretical framework proposed that this discrepancy would arise when anxiety motivated seeking of additional information.[39] Subsequently, the theory was expanded to account for a broader range of emotions rather than just anxiety through its adoption of appraisal theory.[40]

The framework begins with individuals becoming aware that they desire more or less uncertainty than they currently have, the uncertainty discrepancy.[41] Resultantly, they experience an emotion. Some of these emotions include anxiety, anger, fear, disgust, jealousy, envy and hope.[42] The realization of emotion concludes the interpretation phase of the theory.[43]

The evaluation phase is next in the framework and consists of two assessments: outcome expectancies and efficacy.[44] Outcome expectancies reflect beliefs about the outcome of an information management strategy, essentially weighing the costs and benefits of seeking information.[45] These costs and benefits are said then to influence a set of three efficacy assessments: communication efficacy, coping efficacy, and target efficacy. Communication efficacy involves the ability to engage competently and understand the information management action. Coping efficacy evaluates whether the resources to handle the information are met. Target efficacy addresses the belief of whether the target has access to the information and is likely to be honest in their transmission of the information.[46]

The decision phase involves a selection of three information management options: seek information, avoid information, or engage in cognitive reassessments, thereby resolving or reinitiating the information management process.[47] Notably, the entire process is iterative, the evaluation phase affects the decision phase, etc.[48]

Though the above depiction of the process is typical for an information seeker (in a patient-provider relationship, the patient), the process is slightly altered for the information provider, discussed in less detail. The provider cycles only through the evaluation and decision phases that begin when they become aware of another's desire for information. While the information provider engages an identical process of outcome and efficacy evaluations, the specific content level is altered. During the evaluation phase there are three considerations made: the overall outcome of revealing the sought-after information, the importance of that outcome, and the probability that the information will yield the outcome they expect. These evaluations lead to a similar decision phase in which the information provider has identical options in conveying the information.[49]

However, the strategic decisions in this phase involve "the amount and veracity of information that the information provider choose to provide, the directness which the information is conveyed, and the preferred channel for interpersonal transmission (e.g. face-to-face, vs. e-mail). Ultimately, the information providers' feedback affects the entire process for the information seeker both at the time of the interaction and in subsequent assessments in information management strategies.[50]

Context-Theory Integration

There is strong overlap between the evaluation process described in the TMIM framework and the rationale for deflecting agency in patient-provider interactions. Specifically, the outcome and efficacy evaluations likely account for both the previously discussed intentions of defensive and manipulative medicine. The overall outcome (OE) of revealing the information is defined as the most important aspect in making a decision.[51] Thus, if a physician is aware that he/she may be liable following a decision, it will likely affect their phrasing and delivery of the message. Similarly, in considering physician leisure as a factor in manipulative medicine, language choices can be used to alter decision-making processes in the patient to better serve the needs of the physician.

In expanding on the current TMIM framework, I propose three additional criteria that are significant in consideration of the evaluation phase: conflict avoidance, a surrender of subjectivity, and mitigation of responsibility. Conflict avoidance is a frequented topic in interpersonal communication, but is more commonly discussed among romantic partners. However, proposed rationale for conflict avoidance are certainly relevant. Roloff and Wright propose that delaying discourse may stem from a desire to avoid confronting someone until a person has a clear notion of what to do.[52] This is particularly evident in cases of delayed patient care due to fear of liability and confrontation, specifically in the case of the newborn transferred from the community hospital to the city hospital where treatment was delayed in that the adverse event at her IV site went unreported for several hours.

A surrender of subjectivity is particularly relevant to the object/procedure as an agent mechanism proposed. Leder proposes that a loss of subjectivity is a dire threat that modern medicine faces: in seeking to escape all interpretive subjectivity, medicine has threatened to expunge its primary subject—the living, experiencing patient.[53] Thus, in addition to the clauses provided concerning communication efficacy, the presentation of a message necessarily considers the objective versus the subjective. In understanding that diagnostic technology is most highly valued in medicine, followed in descending order by the physicians' observations and finally by the patients' account, the physician evaluates presentation method, particularly in that the state of medical culture that is data driven and scientific.[54]

Finally, a mitigation of responsibility is a necessary sub-clause to the outcome evaluations proposed in the current framework. As an enormous factor in provider decision making processes, mitigating responsibility allows for the minimization of the physician's role in producing findings and observations, and minimizes the physician's role in medical decision making.[55] Though the latter can be countered through manipulative medicine, both serve as factors in providing clinician security through defensive medicine.

Discussion

In contrast to the rather grim nature that constitutes the deflection of agency, it would be an interesting analysis to compare these mechanisms to those that occur in the delivery of positive news, such as a physician delivering news that a treatment method is working or a patient is now cancer free. Afifi and Morse propose that while individuals in bad moods make pessimistic outcome expectancies, those in good moods make rose-colored assessments of outcomes.[56] Does agency return to the physician in delivering good news? Does the provider take responsibility, proud of their actions?

Additional language and diction choices in patient-provider relationships have yet to be evaluated. An analysis of pronoun choice, for example, would also be appropriate for examination. Do the same criteria that drive agency choices also dictate whether the physician uses the plural "we" and credits his/her medical team or the singular "I?"

An examination of the prevalence of agency deflection would be a valuable step in future research. Specifically, do areas of the world where defensive medicine and fear of malpractice suits is minimal see less frequented shifts in sources of agency? A data-driven study could better pinpoint the roots of the issue and perhaps provide way to a mechanism of resolution.

Furthermore, a large area of research with regards to TMIM with and to agency choices is the role of emotions in the information provider's response.[57] Though several emotions have been examined in detail with regards to the information seeker, the emotions of the provider go unexamined. Notably, the emotions of the information provider do not necessarily fit the appraisal framework of requiring a negative emotion. Certainly a physician does not always feel negatively in delivering diagnosis in a similar manner that a patient does, entering the doctor's office with a particular concern. How can emotions like confidence or compassion be molded to the revised TMIM emotion-appraisal theory?

Agency choices may be subconscious considerations that physicians employ without actually cognizant thought. However, their effects on patient outcome make claim that intention effort to provide a legitimate source of agency is necessary. Through deflecting agency to other sources an uncertainty dilemma is unnecessarily prolonged. Consideration of diagnosis presentation needs to be a priority for healthcare providers in order to avoid these subtle yet significant intricacies that appear in message delivery.

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LIFE WITH A TWIST OF LYME

Maureen Josephsen is a reading specialist and teacher. Maureen graduated *summa cum laude* from the Honors Program in Boston College's Morrissey College of Arts and Sciences in 2004 with a Bachelor of Arts in Biology. While at Boston College, she was elected to Phi Beta Kappa and served as a 4Boston volunteer at Franciscan Hospital for Children. She also was a resident assistant and campus tour guide. Maureen holds a Master's of Science in Education from the University of Pennsylvania, with a specialization in reading, writing, and literacy education. At Penn, she was awarded the Lawrence J. Fink Award for Urban Education and the Master's Program Award for an Exemplary Portfolio. She and her husband reside in New Jersey.

I was a Resident Assistant during my senior year at BC. Sitting in a circle during team-building training, my Resident Director encouraged us to get to know one another by responding to questions: "Tell us the story of a trip you took this summer." "Tell us your favorite thing to do in Boston." Then she mentioned the elephant in the room. "Or you can tell us the story of a scar you have." I tried to pull down my t-shirt sleeve to cover it more, but the unusual scar was still visible on my arm. You could see the hole where the tube went in, the four dotted corners where it was sewn into me. I stared at the floor. While I was at BC, I was not ready to tell the story of my scar, my most visible mark of Lyme disease. But now I am.

When I was a junior in the fall of 2002, I lived in 90 St. Thomas More Hall. I woke up one October morning with an inexplicable stabbing pain in the fingers of my left hand, so I popped some Advil to get through that morning's classes. In the days that followed, joint pain became my constant companion. In the span of a minute, the pain moved around, and I could feel joints throbbing in a rhythm. Ankle, ankle, ankle, finger, finger, finger, shoulder, shoulder, shoulder - it was as if I had a new heartbeat. Pangs thumped and pierced through me, each joint an instrument in a symphony of transient pain. At the same time, I felt a little tired. I found myself irritable, crying. I thought it was just stress. When the pain wouldn't go away after a few days, I realized it wasn't just a cold or the flu. I scheduled an appointment at University Health Services. I remember the physician asked me, "What's your top complaint?" I couldn't name just one; there was this odd arthritis that pulsed through my body, some tiredness, some irritability. I named the joint pain, and the doctor said they would run some tests.

I returned to Health Services a week or so later, still undiagnosed but symptomatic, to be told that all of my tests came back negative. I did not show signs of an autoimmune disease like rheumatoid arthritis; my blood work looked normal. I wasn't sure what was happening but mentioned the possibility of Lyme disease, with which my relative had recently been diagnosed. "Do your knees hurt?" asked the doctor. I shifted in place, the white paper crinkling beneath me. "No," I replied. It was usually a shooting pain in my left hand, my fingers, that kept me awake at night, that stabbed through me when I was studying in Bapst or trying to do genetics research in Dr. O'Connor's lab. "It's just this arthritis that moves around, I've never had it before, it hurts so much," I trailed off, unable to better explain the strange sensations. The doctor shook his head. "If your knees don't hurt, then you don't have Lyme," the doctor said matter-of-factly. "And your Lyme bloodwork was negative." I was happy to hear that. I had never hiked or camped, so I felt that Lyme would be an unlikely diagnosis for me, anyway. I had no idea what Lyme disease was; I only knew it was caused by a tick bite. Content, but still puzzled as to why I was hurting, I didn't know enough to ask to look at my blood test results at the time.

Had I looked, I would have seen that I had a blood test that wasn't exactly negative for Lyme. Lyme disease was first described in the United States in 1977. The Centers for Disease Control and Prevention (CDC), in conjunction with local and state health departments, began nationwide surveillance for the disease beginning in 1980.[1] In 1991, Lyme disease was designated as a nationally notifiable disease, meaning that physicians were required to report cases to their local health departments for purposes of tracking the infection. Therefore, physicians needed to know what "counted" as a positive Lyme disease case that must be reported. Consequently, the CDC drafted surveillance criteria for Lyme disease based on Western blot testing, which tests for antibodies that the body makes to fight off infection. The surveillance criteria required that physicians report cases to the CDC when the Western blot test showed "diagnostic levels" of antibodies; however, the CDC did not set national guidelines for determining diagnostic levels, and it was up to each state to determine the diagnostic levels for itself.[2] A test that met a particular state's diagnostic criteria was considered a CDC-positive test. When I was tested in Massachusetts in 2002, a patient needed to have present five out of ten IgG Western blot bands (markers) in order to be CDC-positive for the state's Lyme disease surveillance criteria. I had four bands positive, not five. Therefore, my test was considered negative for Lyme based on the CDC-surveillance criteria, and they would not report my case as positive to the state. Meanwhile, my body was still producing these four antibodies to the bacteria, an indication that infection might be present. Four out of ten Western blot bands did not mean I didn't have Lyme.[3] This was the beginning of the intersection of my own experiences with the politics and policies of Lyme disease.

The CDC surveillance criteria were developed for tracking and monitoring Lyme disease, and they were never intended to be used for clinical diagnosis.[4] My Western blot lab results, which reported, "Lyme disease negative; A Western blot IgG result is positive ONLY if five (5) of the IgG bands are detected," were based on the surveillance criteria, which meant that my case did not meet the threshold level for reporting.[5] However, these lab results definitely did not mean that I wasn't infected. The CDC surveillance criteria, often interchangeably used by health care providers as diagnostic criteria, led my physicians to the inaccurate conclusion that I did not have Lyme. Typical diagnostic tests for Lyme are highly insensitive, so " . . . a negative test result does not mean you don't have Lyme. There are many reasons why someone who actually has Lyme may have a negative test result. There may not have been time for antibodies to develop; the immune system may be suppressed; or the person may be infected with a strain the test doesn't measure."[6] Days passed, and my condition deteriorated, yet I continued believing I was not infected. Meanwhile, the spiral-shaped bacteria that cause Lyme disease were burrowing deeper into my tissues, squeezing into my joints and synovial fluid, and crossing my blood-brain barrier.

Throughout the fall, I continued visiting Health Services and pressing with questions. A biology major, I searched my textbooks for answers. I was still in pain, and now a puzzling new symptom had appeared: I was reading and rereading the same pages from textbooks, but I could not remember what I had read. There are notes in my medical chart like "exacerbation of arthralgias and myalgias, fatigue" and "? Lyme diagnosis – not supported by labs - after long discussion . . . have decided to retest in 4 weeks if symptoms persist."[7] My relative who was diagnosed with Lyme saw in me the symptoms he had experienced, and he insisted I come back home to New Jersey to see a Lyme literate medical doctor (LLMD). It was not until I visited an LLMD, whose practice specialized in the diagnosis and treatment of tick-borne illnesses, that I began to get answers. The first answer came after running a polymerase chain reaction (PCR) blood test. Whereas the Western blot testing looks for antibodies made in response to the Lyme bacteria, a PCR test looks directly for the presence of the bacteria's actual DNA. When we checked my blood for the DNA of the Lyme bacteria, the results were unequivocally positive. The second thing I learned was that my experience with inaccurate test results was common with Lyme. Some studies indicate that up to 50% of the patients tested for Lyme receive false negative results.[8] Third, I learned that not only did I have Lyme disease, but I also had several other infections that were transmitted by ticks. Without memory of a tick bite, without the hallmark bull's-eye rash, without any known exposure to a tick, this whole illness seemed impossible and foreign. The thought of being bitten by a tick felt violent and violating. I now inhabited a foreign land; I was deep in the woods, living the land of Lyme.

The morning I woke up in pain sent me traveling into a land I knew nothing about, down paths I never intended to travel, paths that out of necessity I learned to navigate. My course changed, not by my choosing, and I learned to inhabit this new land. The topography was deep and dark, like the woods in Grimms' fairy tales. It was filled with dangers, physical and psychological. The space in which I found myself was like the woods after dark, where danger lurked and what seemed uncomplicated and beautiful—like nature or unremarkable lab results—could not be trusted. The rules about entering the land of Lyme were simple: one only had to be bitten.

I was treated with oral antibiotics throughout junior year, but my symptoms did not consistently improve. With my neurological symptoms increasing, my LLMD determined that I needed IV treatment so that we could get antibiotics across the blood-brain barrier. I was still in the woods, but at least now I had a map: a course of treatment that we thought would work well.

The summer after my junior year at BC, I lay on an X-ray table in a hospital's operating room, my left arm out to the side. A doctor numbed the inside of my arm, then found the vein in my upper arm a few inches above my elbow. I watched the X-ray screen like a television as it captured everything in live motion. I watched as a clear tube was inserted into that vein, then up through my arm, then down into my chest. When the tube had reached its resting place near the largest vein in my heart, the doctor secured the tube into my skin with some small black stitches. He had given me a peripherally inserted central catheter, or PICC line. Each day for the next 8 weeks, I would hook myself up to a portable IV pump, which would push cold, potent antibiotics into that tube in my arm, dumping the medicine in the vein. Those weeks I would cross my fingers that the medicine would do its job, that it would cure my illness or at least abate my symptoms, would give me my life back. The day before I returned to BC for senior year, a nurse pulled out the two feet of tubing. An angry-looking scar was left in its wake, just visible under the sleeve of my t-shirt.

The IV antibiotic helped, but I would get better and then relapse. My Lyme disease case was complicated by the presence of three other tick-borne infections: Bartonella (a rod-shaped bacteria that causes fever and lymph node swelling, among other symptoms), Babesia (a red blood cell parasite, much like the one that causes malaria), and Mycoplasma (a small bacteria that causes arthritis and fatigue). I am not alone; it is estimated that about 32% of Lyme patients also have Babesia, 28% have Bartonella, and 15% have Mycoplasma.[9] These were words I had never heard of before my diagnosis, but in navigating this new terrain of Lyme disease, I learned to speak a new language. There are other tick-borne co-infections for which I have, thankfully, never shown signs. The process of finding all of these co-infections took several years, and Lyme patients with co-infections experience more severe illness, more symptoms, and a longer recovery.[10] Fitting with that picture, my road to recovery has been a long one, and unlike some people whose symptoms vanish after a few weeks of basic antibiotics, my experience with Lyme and co-infections has been persistent and chronic. The presence of multiple co-infections partially explained why I felt so ill, and why new symptoms continued to appear over the course of my time at BC and soon afterward.

I have lived with tick-borne illness for the last thirteen years. Like many patients with chronic Lyme disease, I have become an expert in living in this forest. I have experienced hypothyroidism, skin rashes, excruciating migraines, herniated discs and degenerative disc disease in my spine caused by Lyme arthritis, sensitivity to sound and visual patterns, muscle aches and pains, difficulty breathing (a symptom of Babesia known as air hunger), neurological difficulties (like having difficulty finding words or feeling lost in places I know well), cognitive symptoms (like difficulty reading and focusing), psychiatric symptoms (like sleep disturbances and obsessive-compulsive behavior), and that mysteriously moving joint pain.

After years of intensive treatment, and under the guidance of a world-renowned LLMD, my body is now on the road to healing. Lyme disease has been killed off and quelled, but the places in which it lived in my body are like a war zone after a battle. Devastation lies in its wake. I try to rebuild. Although most of my symptoms are alleviated, I sometimes feel aftershocks; some symptoms still linger on.

My body—post-Lyme and its co-infections—is not the same. I face ongoing headaches and anxiety. I face a bone-weary fatigue that settles over me, my constant companion, like the hazy smog over a city. I never experienced these symptoms before Lyme. There are little reminders of my illness everywhere. For example, whenever someplace holds a blood drive, I am not allowed to give blood. The Red Cross will not take my blood donation. I speak with them on the phone and am told that I am "deferred indefinitely," my red blood cells infected with Babesia, permanently overtaken with little ring forms or tetrads of parasites. Grass and the woods terrify me now, triggering traumatic flashbacks to the days when I was sickest, when I wondered how I could have been infected. I can remember the two-thirds of my life that was before Lyme, but it feels so far away. In my physical exam before I was admitted to Boston College, my pediatrician examined my 18-year old body and wrote "Well Adolescent" on my college physical form. That was true for a short time while I was at BC.

At my worst, Lyme disease and my three other tick-borne infections have had me on a gurney in an ER, hooked up to an IV, morphine the only way to relieve the agony of my head and neck. At my worst, Lyme disease has cost me and my family tens of thousands of dollars and left me a shell of myself, my brain and body overtaken. At my worst, Lyme has left me bedridden, sleeping for 18 hours at a clip, bone-weary and barely able to move.

At my best, I feel like I did before that October day in 2002. At my best, I am pain-free. At my best, in quiet mornings or in calm evenings, I swallow vitamins and herbal supplements to try to keep my immune system up, and except for those vitamins I forget I ever was sick.

Most days during the last twelve years have been somewhere between the best and worst. The days are like a game of whack-a-mole, the bacteria and parasites living symbiotically within me, my immune system or medicines and herbs knocking them down one at a time before the others pop up. If I have drenching night sweats, or difficulty breathing (air hunger), the whack-a-mole infection to take down is Babesia. I will share this with my LLMD, who might prescribe thick, paint-like yellow Mepron and little pink azithromycin tablets, or a Chinese herbal product called artemisinin, or some other combination of Western and integrative medicine, and after several weeks or months we will knock that mole back into hiding. But it's not long before another mole pops up, with foot pain and a red, striped rash across my chest, belly, and back that looks like I was clawed by a raptor. These are symptoms of Bartonella, which lives in epithelial skin cells. We can knock it down with Rifampin, an antibiotic whose side effects I hate but whose killing effects are worth it. Living in daily whack-a-mole, I am constantly monitoring symptoms and trying to stay on top of them before they get out of control.

There have been days, months, and years during which I am asymptomatic and feel great. There have been days, months, and years that are worse than I can describe. I have wondered if I was exaggerating the effect of Lyme on my life, but I felt validated when I read a recent study showing that chronic Lyme patients suffer worse quality of life compared with those who face other lifelong diseases, such as congestive heart failure, diabetes, lupus, liver failure, and multiple sclerosis.[11] Although I have reached remission in the past, and although I work toward remission again, I have learned these infections are something I will continually battle.. Lyme and its co-infections have become part of my identity. Being someone who lives with chronic illness has become a sociocultural identifier for me, the same as my gender or race. It is an identity that I never imagined I would hold.

It is also an identity that some do not believe exists. The Infectious Disease Society of America (IDSA), which created guidelines for Lyme treatment in 2000 and revised them in 2006, argues that short courses of antibiotics cure Lyme patients and that a so-called "chronic" Lyme or post-Lyme disease syndrome does not exist. They cite a lack of evidence for persistent infection in Lyme patients who have been treated with antibiotics.[12] If and when symptoms persist after following an IDSA-recommended treatment regimen (usually a short course of doxycycline), the Lyme patient is encouraged to seek other diagnoses or reasons for symptoms. In contrast to the federally-funded IDSA, there exists a nonprofit, international, multidisciplinary medical society named International Lyme and Associated Diseases Society (ILADS) that is dedicated to the diagnosis and appropriate treatment of tick borne diseases.[13] ILADS holds that Lyme is a clinical diagnosis, especially when considering that current screening tests are unreliable.[14] ILADS believes that not only does chronic Lyme disease indeed exist, but also that most cases of chronic Lyme require long courses of antibiotics to relieve symptoms, as there is no test available to prove that the bacteria are eradicated or that the Lyme patient is cured.[15]

When I did not get well after a year of oral antibiotics and eight weeks of IV antibiotics, I was frustrated and exhausted, only to hear from IDSA physicians that this was all in my head or that my Lyme had been treated, so there must be something else wrong with me. Those physicians were wrong in my case. My Lyme case has been persistent and tricky to cure, but with longer courses of antibiotics, I have gotten better. It has been ILADS-affiliated or ILADS-trained physicians that have treated my illnesses and brought me symptomatic relief, although I am not yet fully out of the woods.

Beginning during my time at BC, I found myself caught in the crossfire of infectious disease policy and my own reality, caught between the IDSA and ILADS, stuck between falsely negative test results and positive ones, caught up in an illness that infectious disease doctors said I couldn't possibly have. I have heard Lyme patients say, "You don't get it until you get it." That is, until you or your relatives are caught up by one of these mysterious tick-borne illnesses, you don't understand the magnitude of their impact across every domain of your life, the difficulties that come with inaccurate diagnostic testing, and the frustration that you feel when you know something is wrong but testing shows otherwise. I share the story of my Lyme scar now because an increasingly alarming number of people are facing this illness, with about 300,000 new diagnoses each year.[16] Still others are inexplicably sick but remain in the shadows, due to the unreliability and invalidity of testing, scarcity of LLMDs, and soaring treatment costs.

As I learn to live right on the edge of the woods of Lyme, I know others suffer or are misdiagnosed due to policy and politics, insufficient testing methods, and the guidelines proposed by the IDSA that deny patients like me treatment. The so-called Lyme Wars between the IDSA and ILADS rage on, while patients like me seek a way out of the darkness, out of the land of Lyme.

Time in the woods of Lyme disease is measured not in hours or minutes, days or months, but by those plastic, brightly colored weekly pill organizers. Years into my illness, I would quickly outgrow the standard sized ones they sell at the pharmacy; not every medication, herbal supplement, or vitamin will fit in one of those standard ones. My husband, for a gift, would buy me a bigger pill container set that was easier to open. Each week I take about twenty minutes to fill my pill organizer; each day I gulp down handfuls, morning and night. I get good at taking them two or three at a time, so I can get all fifteen or twenty into me with just a few gulps of water. The idea is that if my immune system stays strong, the bacteria and parasites will be kept quiet, kept at bay.

I am grateful that overall, I do feel better now than I ever imagined I would feel when I was first diagnosed. I have lived a third of my life with Lyme, but I have not always been trapped in its woods. When I have felt well, I have been lucky enough to go on safari in Africa, hike the Grand Canyon, and walk the cobblestone streets of Venice. I was able not only to graduate with a biology degree from Boston College, but also to put myself through graduate school, marry, and pursue a teaching career that I love. When I have felt unwell, I have remembered my doctor's words. He has said that the last chapter of my Lyme story has not yet been written, but we will keep writing until we get the ending that we want.

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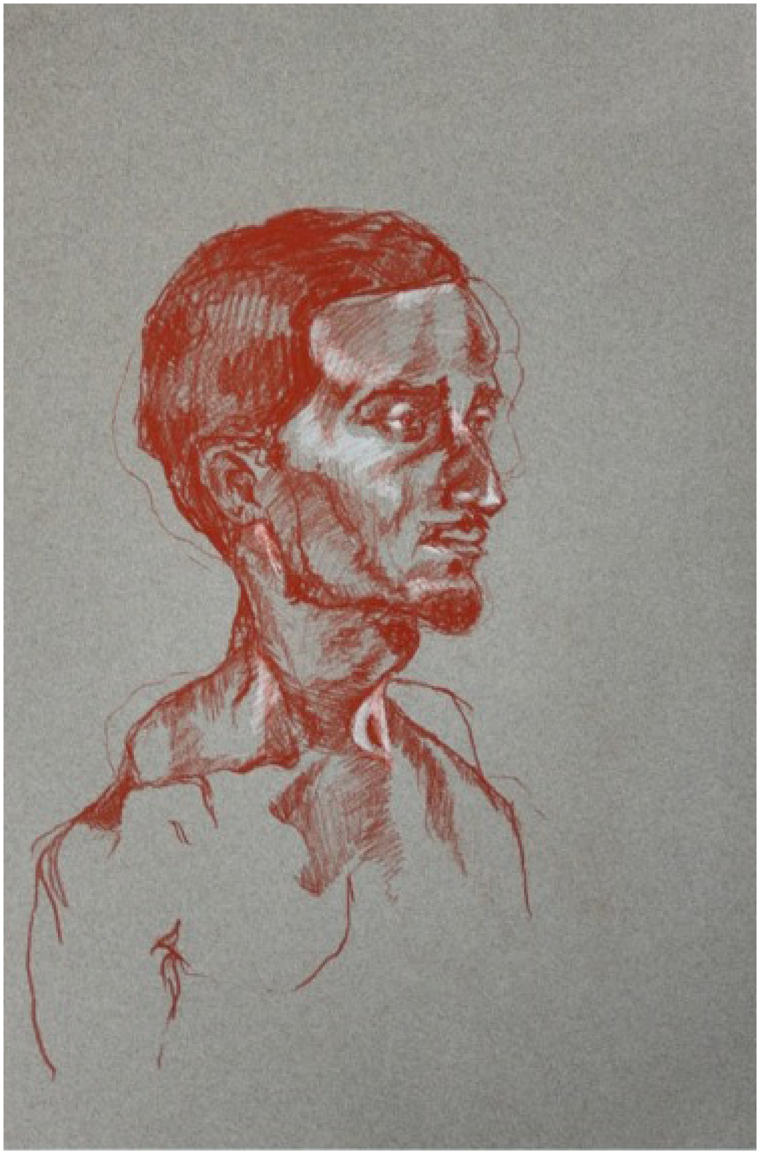

UNTITLED

Cate McAnulty is a senior in the Morrissey College of Arts and Sciences, studying Studio Art with a minor in Medical Humanities, Health, and Culture.

WATCHING MY GRANDMOTHER FADE

Amelie Champagne Lyons is a senior English major and Women & Gender Studies minor in the Morrissey College of Arts and Sciences. Her work was written in memory of her grandmother, Myrtis Champagne.

I already miss the memories I still have. I seek to constrain
them, to prevent, as if it were possible, their loss.
I live in a constant state of nostalgia; I don't want to forget.
I saw it happen, the decay.
I saw my mother watch her mother
fade as her own mind turned against her. Memories slipping

away, out of her control. At the hospital, slipping
she broke her hip. Too late to relearn how to walk. Forget
walks around the nursing home. Instead, constrained
within the binds of a wheelchair she gained weight. We saw her slender body decay
giving form to a new one, one we didn't recognize. Her children saw their mother
displaced, replaced. We were at a loss

of how to respond. When she died no one said, "I'm sorry for your loss."
We had lost who she was years ago. After she was gone we let ourselves forget
the bad years, turning instead to the good memories, let them come slipping
back into our consciousness. We found they hadn't all decayed
over time. Both emotional, my mother
and I fought, cried. We could not constrain

our anger and our guilt. We knew the body was just a constraint;
death freeing. She had become a shell of herself. We had seen her decay,
she hadn't opened her eyes in months. In the end, fork slipping
from her hand, she had forgotten how to eat. Autonomy lost.

So when she died there was a sense of relief. My mother
and I wanted to be able to forget

the times she didn't remember us. But we don't get to choose what we forget.
We remember watching it happen in slow motion, seeing the loss
of the person that was my grandmother. As a mother
who seeks to protect, mine asks, if it happens to her, don't watch her constrained
in the prison of her own mind, as it fails. Instead let her slip
into a crowd in Dubai or Tokyo and don't follow. Death is the time for decay

not life. So I try to preserve my memories through objects, maybe they won't decay
as quickly as my mind. I let myself be paralyzed by loss.
I know it's inevitable; I can't remember every moment. I already forget
what she smelled like; the memories have already slipped
without my noticing. Sometimes my father or mother
says, "Remember when" but as much as I try I can't find it constrained

within my mind. I fear the decay
has already started. I let it get to me. To combat my fear of loss
I seek to trap elusive memories, to no use. They will not be contained, constrained.

STEROIDS FOR SMARTIES

Guy Guenthner is a junior in the Morrissey College of Arts and Sciences majoring in Biology and minoring in Medical Humanities, Health, and Culture. Guy's featured piece is his first to be published in the Medical Humanities Journal, and was originally written for Professor Amy Boesky's “Introduction to Medical Humanities” course. His writing was inspired by the prevalence of Adderall use during final exam periods at Boston College. Guy hopes his work will prompt students and faculty to reflect on and acknowledge a problem our community is currently facing.

A finals week of stressful library hours looms ahead for John Smith. Organic Chem on Monday, Cell Bio on Tuesday, two papers due Thursday, and yet, John isn’t worried. He is confident he can pull a couple all nighters and cram it all in. How can he be so calm you ask? The conversation went something like this.

“Hey man, your roommate has a Addy prescription right? Yea? Awesome, can I get two 25s from you? 10 bucks? Sweet, I’ll stop by later.”

The only hypothetical part of this story is the name. Every finals period, I overhear similar conversations in nearly every class, dining hall, and library. Students talking to that one friend who has an Adderall prescription and is willing to sell them some so they can cram for their big exams. The use of “Addy” as a “study drug” is growing out of control at universities countrywide. Worse, however, is the lack of acknowledgement of abuse of a prescription amphetamine by the students themselves and the rest of society. It’s time for students and universities to stop shrugging their shoulders about Adderall abuse.

Adderall was developed to counteract the symptoms of attention deficit hyperactivity disorder (ADHD). ADHD diagnoses have risen recently as multiple prescription drugs have been developed to counteract its effects. According to the CDC, about 11% of people from ages 4-17 are diagnosed with ADHD, and yet, 1 in 5 American college students report using Adderall without a diagnosis. With some quick math applied, nearly more people are abusing Adderall than taking it for an actual diagnosis.

The blame for Adderall abuse is hard to distinguish. It is natural to point a finger at the student taking Adderall to study, but what about the student selling his or her prescription drug? These student “dealers” have either faked an illness or are tossing aside an actual learning disability to make some side cash. Further, by repeatedly filling prescriptions, students throw away their parents’ well-deserved insurance plan money. These students take advantage of other students’ desire to excel and raise grades at the expense of their health.

The pointed finger could be turned toward the educational system. From the minute a student enters college, the competitiveness of the real world starts to set in. Students are stressed to excel and believe the consequence of failure is judgment from peers, future employers, and even their parents. We cannot, however, place the entire blame on a system only responding to its participants. The educational system is becoming more competitive because students are working harder and striving for more.

In the end, the finger comes back around to the abuser of Adderall. It's an individual's choice to ingest an amphetamine that can block out distractions and increase productivity. A student always has the choice to deny a drug in front of them, but the temptation of results persists. The fact of the matter is the blame cannot rest on anyone's shoulders solely. Adderall is at every university in the country and is consumed by an alarming amount of bright students. So what's next?

The first step is acknowledging the problem. Our culture ostracizes athletes using performance-enhancing drugs to excel in their sports, and yet we turn a blind eye to college kids taking supplements to excel in studies. Non-prescription based Adderall use must be negatively stigmatized by our culture and by students. It's not enough to say, "Well if I don't do it, I don't care if they do."

Students must also be informed of the nature of the drug and its side effects. Many college students, even here at BC, would not consider the illicit use of Adderall as dangerous, yet it is listed as a Schedule II substance by the DEA, right next to cocaine, meth, and morphine on addictive quality.

Prescription drug abuse is a large problem in the U.S. and Adderall abuse should be no different. Hard working students shouldn't have to feel at a disadvantage because they don't take a drug to focus. Drugs are constantly being produced to solve problems, but intelligence does not need fixing. College must and should always be an equal playing field devoted to success through hard work, not drug use.

THE COLOR OF HIV

Russell Simons is a junior Biology major and Medical Humanities, Health, and Culture minor in the Morrissey College of Arts and Sciences. Russell's featured work—"The Color of HIV"—was originally written for Fr. James F. Keenan's course "HIV/AIDS and Ethics." He is interested in the intersections of disease, healthcare, and marginalized populations, and has worked to gain a multifaceted understanding of HIV/AIDS through his volunteer work and research in the Williams Lab at Boston College.

For Louise, who grew up in Wake County, in a rural town of 4,000 where Blacks are clustered on the poorer south side, H.I.V. has quietly joined poverty, drugs and prison stints as part of the tattered fabric of daily life. The oldest of four siblings in a family that struggled to make ends meet on her father's factory wages, Louise became sexually active at 13. Nice homes and good jobs seemed reserved for Whites on the other side of town. The dead-end jobs where most Blacks ended up made school seem irrelevant. Sex, she said, was an easy way to pass time, and a drug dealer's ready supply of cash outweighed whether he had come from—or might soon go to—prison or jail.

''Most of the guys I dealt with had a drug charge at some time," she said. ''I remember this one guy, I saw the gold in his mouth and I thought, 'Ching, ching. He can give me what I want.' But then I was also thinking, 'Is this really what I want?''' She was dumbfounded, she said, when a blood test she took as part of a gynecological exam when she was 19 showed she was H.I.V. positive. She never found out how or where the former prisoner who infected her had picked up the virus, though she assumed it was from sex because she never saw him use intravenous drugs. ''When you think about the things that might happen, you think as long as you don't have a baby you're O.K.," Louise said. ''You think about the guy you're dating, how he might violate probation and go to jail again and you'll be alone. But you never think that he could have this disease. You never think about that." [1]

While Louise is correct when she emphasizes that HIV is something "*you* never think about," she would be better off using the collective *we*. As communities, we avoid thinking about what is difficult, especially when the subject is divisive. When the issues brought up are uncomfortable or taboo. Indeed when the answers to questions no one wishes to ask are not easily discernible or are ultimately unwelcome. For Louise and far too many of us, HIV/AIDS has become a topic that we never think or talk about, even when reason and morality compel us to do so. Those that suffer the most as a result of our communal inaction are not the 'average' citizens, when 'average' is synonymous with white, straight, and socioeconomically stable. Rather it is those who occupy the margins: the poor, the homeless, the members of racial and ethnic minorities, drug users, and any other individuals who, for a variety of reasons, are not welcomed into the inner circle of society. The cases of such marginalized persons are many and diverse. The story of Louise is that of a young, HIV–positive African American woman, whose struggles prompt us to discuss the extent to which her race, financial situation, gender, and sexual experience are related to her HIV status. However, her case also speaks to that of a larger population. This discussion is then best framed as follows: we must work to understand the valences of Louise's story, while connecting her experiences to those of HIV–positive African Americans whose stories too often go untold.

The Color of the Epidemic

The human immunodeficiency virus, like all other viruses, is indiscriminate in transmission. Viral cells do not assess the target for susceptibility before entering into and colonizing the host, yet statistics evaluating the virus's spread would suggest otherwise. HIV breeds amid specific social conditions, and in the United States we observe its proliferation among many of the nation's minority groups. Epidemiologically speaking, it has become an undeniable fact that in the United States the color of the epidemic is and has been shifting, since its identification, from white to black.

In 2010, African Americans accounted for 44% (20,900) of new HIV infections among adults despite representing only 12% of the national population. Men accounted for 70% (14,700) of these cases, and Black men who have sex with men—typically the highest risk group for HIV transmission—numbered 10,600 in new cases (only 600 behind their Non-Hispanic White counterparts). On the whole, African Americans are eight times more likely to contract HIV than are whites. African American males are seven times more likely than white males, and African American women are 20 times more likely than white women, to contract HIV.[2]

What is most worrisome about available data is the inverse relationship between new infections within the two racial groups. Since the late 1980s, the number of newly infected African Americans has exceeded whites, and African Americans now account for roughly 510,100 of Americans with HIV, while whites number 382,600.[3] Neither number is cause for elation, however the ever–steady increases in new and total infections for African Americans point to a disturbing reality of the HIV epidemic: that public health programs, which have shown success among whites, have had a limited effect on the African American population.[4] These data can be explained by the fact that African Americans face considerably more obstacles in the fight against HIV than do whites; that while one group has shown a decrease in new infections because of programs targeted to 'the society's needs', still another has been so unaffected by these programs that in 2012 an estimated 22,581 African Americans (compared to 13,921 whites) were diagnosed with HIV.[5]

However, critics might assert that the high rate of new infections among African Americans can be explained in any of three ways: (1) African Americans participate in high–risk acts more frequently than whites, (2) African Americans do not engage in care as actively or consistently as whites, and (3) different subpopulations must be targeted differently, and that African Americans have not been effectively targeted while whites have.

As for the first of the three points, we know the claim that African Americans engage in more high–risk activity than whites to be inaccurate. African Americans have been shown to engage in less lifetime use of illicit, needle-requiring drugs, and be less likely to use drugs during adolescence than their white counterparts.[6] In addition, despite having a generally younger age of first sexual encounter, higher incidences of contraception use were reported among African Americans adolescents.[7]

While the second point may hold statistical truth,[8] we must also note that African Americans are much less likely to be prescribed anti-retroviral treatment on their first visit to an HIV clinic than are whites,[9] and that this first encounter is extremely important in determining the level of future engagement with the healthcare provider. The clinical experiences of individuals are unique, however any element of racism, stigmatization, or unequal treatment—overt or subliminal—experienced by patients on this first visit decreases the likelihood that they will seek future treatment with the same provider or at all.

The third point quite clearly adds credence to the increased-barriers claim. Public health campaigns ought to be constructed with the entire target population in mind, while also acknowledging—and confronting—the specific obstacles groups might face in receiving care. In the case of HIV, the target populations have expanded over the years from only certain 'vulnerable groups' (i.e. IV drug users, men who have sex with men, sex workers, migrants, etc.) to the larger adult and adolescent communities. All individuals who have sex are at risk of acquiring HIV. The fact that large scale prevention programs, and even targeted attempts by public health officials at working within the African American population, have shown marginal success in decreasing the number of new infections among African Americans speaks to the obstacles towards prevention, transmission, and treatment that are not being met. In order to understand why those who occupy the margins of society are so deeply affected by the HIV epidemic, and why African Americans face considerably more obstacles than whites, we must engage in a critical reflection on the society from which these groups are marginalized and the living conditions of high-risk persons.

Instability and the Transmission of HIV

The efficacy of discussion is limited by the power of language, and continued use of the phrase 'marginalized' does not get at the full picture of what the word is often invoked to describe, nor does it allow readers of pieces on HIV—often those fortunate enough to be pursuing higher education or already established in academia—to get as true an understanding of 'marginalized' living as possible. The problems with 'marginalized' as a descriptor are that it is used to describe a number of disparate groups and that it leaves little room for deeper analysis. We are better suited to use the term 'instable', since it allows for an exploration of the extent to which stability is present in—or absent from— an individual's life, and in which specific areas stability is lacking. 'Instabale', more so than 'marginalized', speaks to the individual experience of an HIV patient, the stigmatization he or she faces, and even the circumstances that perpetuate the spread of HIV. Therefore reflection will be most effective if we adopt a terminology best suited to analysis.

James Keenan, S.J., a Catholic moral theologian and ethicist who has written extensively on the Catholic response to HIV/AIDS, asserts that "HIV breeds specifically where there is social instability, whether that means…those who are affected by civil strife", economic collapse, or uncertain employment, "those who are forced into sexual activity", or are victims of partner infidelity.[10] For Louise, instability is a product of her living environment, sexual activity, and relationships. Her dad's limited income and many dependents place the family in a difficult situation—one that is characteristic of families and people straddling the poverty line. Choices are limited in terms of daily life, and become even more limited when financially burdensome problems arise. With little to aspire to in the way of future employment, Louise assigns nearly no value to education. And what is troubling, other than her self-removal from an educational setting, is that she then looks for entertainment from other sources. It is these other time-occupying activities, particularly the choice to become sexually active without prior sexual education, that are high risk for HIV transmission.

Louise's race undoubtedly plays a dominant role in her life as well. The effects of dark skin color on livelihood in contemporary American society are numerous and well-established elsewhere (and frankly a discussion in this setting would fail to do the topic justice).[11] But at the very least it can be said that having been born into a southern, rural town separated along racial lines, it is likely that Louise experiences racial separation and racism in more areas than just neighborhood division.

In the article commenting on Louise's case, Louise explains that her family refused to believe that a relative of theirs had died from AIDS, instead attributing his passing to sickle cell anemia. Stigmatization was felt so deeply within her own family, Louise says, that when she was diagnosed with HIV, she insisted on seeking care in a neighboring town.[12] Many HIV-infected people share the same apprehensions about revealing their status to loved ones and friends since they fear rejection and isolation. Therefore, we can see that instability is perpetuated not just by social structures and economic status prior to infection, but also by relationships and stigmatization post-infection.

Notice how, although Louise actively chooses to pursue a sexual relationship and disengage from her schoolwork, the instable circumstances which prompt her to do so—her living environment—predate these decisions and even her birth. In other words, she was born into a situation that guided her towards the decisions she made, and her circumstances ultimately work to her detriment. From the onset, her social setting perpetuates instability, leaving the possibility for a stable, formative environment virtually nil. All of us are products of some greater environment, and it not just those who are most severely harmed that evidence this. Yet it is precisely those most negatively impacted that deserve our greatest attention. In recognizing the harm caused to an individual or population by their circumstances, we turn to a discussion of structural violence, which provides a social framework for evaluating the larger impacts instability has on Louise and African Americans.

Structural Violence and the Incarceration Endemic

Structural violence, a term coined by sociologist Johan Galtung in the 1960s, describes the economic, political, legal, religious, cultural, and social structures that stop individuals, groups, and societies from reaching their full potential.[13, 14] Structural violence is deeply connected to the existence of a social machinery of oppression that works, whether deliberately or unconsciously, against instable populations. Often these systems seem so ordinary that they appear almost invisible, however the fact remains that certain institutions, societal practices, and beliefs ultimately serve to further suppress the already marginalized. We see violence enter the lives of all instable persons, whether they are impoverished, homeless, Black, Latino, homosexual, transgendered, or a member of any other minority group.

Louise's case indicates the effects of structural violence on the individual. Particularly for the residents of the poorer side of her town, poverty is a source of violence. Poverty deprives people of opportunity, diminishes the humanity and dignity of a person, and feeds into itself in a seemingly never-ending cycle. Lack of socioeconomic stability and a dearth of respectable employment prevent Louise from reaching her full potential and incite her to explore high-risk behavior. Nationally, African Americans constitute 25.8% of the 42.7 million Americans (14.3% of the total population) who fall below the federal poverty line—that is 9.5 million Americans who, like Louise, face a severe economic burden on top of violence derived from other institutions.[15] It is then not surprising that a 2010 study found the HIV prevalence among heterosexual people living in poverty to be four times higher than the national average.[16]

While the effects of poverty are immense, poverty is not the only source of structural violence. For the greater African American population, one of the major sources of contemporary violence is the criminal justice system. As Robert E. Fullilove, associate dean of the Mailman School of Public Health at Columbia University, explains, "The war on drugs took the group that was at greatest risk for HIV infection and made sure that they would be locked up." Today African Americans males are incarcerated at a rate higher than any other subpopulation in the United States. As of December 2013, Blacks composed 36.4% (549,100) of the total inmate population—a number notably disproportionate to the overall Black populace.[17] Additionally, it is estimated that 1 in 3 Black males will be imprisoned at some point during their lifetime.[18]

With such a high percentage of the population facing imprisonment, structural violence is seen first in the impact of incarceration on those connected to the incarcerated individual; and with the vast majority of incarcerations involving males, Black females like Louise are placed at increased risk. Nina Harawa et al. summarize well the effects of high incarceration on the non-incarcerated African American population, saying incarceration patterns "negatively impact African-American communities by reducing opportunities for economic and educational advancement; diminishing political participation; decreasing the numbers of available sexual and marriage partners for African-American women; disrupting existing sexual relationships and family lives; and changing norms related to sex, monogamy, violence, and drug use."[19]

Incarceration invariably increases the risk of HIV infection for inmates as well, both during and after a sentence. Unprotected sex, rape, and needle sharing (for either tattooing or drug injection purposes) are all potential high-risk actions within a prison setting. Prisoners are placed at further risk by many prison's policies forbidding the distribution of condoms, as well as the lack of prison-provided drug treatment programs—both of which represent a failure on the part of prison officials to respond to high incidences of sexual and drug-related transmission in jail.

Although it might seem backward to identify a system as violent that punishes individuals for their transgressions of codified law, we must recognize the circumstances that incite people to engage in criminal activity in the first place, the general lack of appropriate governmental response to the problems in crime-heavy communities, as well as whether or not the laws are being equally enforced. Since incarceration often compounds with other incidences of structural violence, as crime tends to predominate in low-income environments, we then see how, just as was the case with poverty, incarceration plays into a continuous cycle of instability. Poverty begets crime. Crime begets imprisonment. Imprisonment begets poverty. We perpetuate structural violence in our failure to address the problems that lead individuals to incarceration in the first place, and commit further injustices by returning them to their unchanged pre-incarceration circumstances, knowing full well that they are extremely vulnerable upon reentry to society. (Injustices evidenced in part by recidivism rates: a 2005 study by the Bureau of Justice Statistics study shows that after 5 years, 76.6% of felons had been rearrested.)[20]

The "tattered fabric of daily life" that Louise's case mentions is a summation of the many other forces acting against African Americans that ultimately serve to increase the risk of HIV transmission. Lane et al. expand on Louise's commentary, noting that instances of residential segregation, disproportionate incarceration (as previously mentioned), and the influence of gangs all result in constrained social-sexual networks with a limited number of sexual partners. Because so many males are incarcerated, women have fewer potential partners who are not HIV-infected, leading to high-risk behavior: Thomas Clodfelter, a former felon with HIV who now counsels other ex-convicts, says that "a lot of women…are looking for a man to give them a sense of strength, a sense of authority…men come out of prison, they're all big, got muscles, looking good…and the women, they're all up on them. It's not like people don't know they're putting themselves at risk. They just don't care."[21] And in the treatment and prevention of HIV, limited access to healthcare and STD clinics hinder the ability of the individual to seek further information or receive consultation about infection.[22]

In the end, people are not at risk for HIV simply because of their being marginalized, but because their lives and social settings lack the means and stability needed to live safely - free of societal pressures and practices that we know to be detrimental to the health of a population. Structural violence perpetuates instability and adds fire to the already roaring blaze that is HIV/AIDS.

Female Agency and the Remodeling of Masculinity

'"When you think about the things that might happen, you think as long as you don't have a baby you're O.K."'

Louise's relationships with her drug-dealing partners exemplify incarceration-resultant instability, as well as a much larger problem facing women in a time of HIV: non-agency. Loss of agency is the result of continuous suppression of women, owed to a global androcentric mindset, patriarchal institutions, and traditional female roles. Gillian Paterson, in her piece "Escaping the Gender Trap: Unraveling Patriarchy in a Time of AIDS," asserts that subordinating female gender roles are present in virtually all cultures irrespective of a woman's HIV status, that women are unjustly blamed, stigmatized, and burdened by HIV because of gender role imbalances, and that these imbalances only further worsen when a woman is HIV–positive.[23]

Pre-HIV gender roles are at work in Louise's outlook on her relationship: *when you think about the things that might happen… as long as you don't have a baby you're O.K.* While she appears cognizant of a danger of sexual relationships, Louise never considers that her partner is possible of causing more harm than simply getting her pregnant. As a society, we must actively suppress the notion among sexually active adolescents that a baby is the most harmful outcome of a sexual relationship. Education is an excellent tool for such preventative measures, but teaching about prevention, like imprisoning criminals, is a means only towards allaying the larger problems that already exist.

It would be easy to say "women must also be encouraged to find agency in relationships," however that would forego the much needed discussion about what *men* must be encouraged to do. It is not fair or adequate to say that it is up to women to find agency in a relationship, as that places the onus entirely on the already burdened party. The ongoing movement towards general female equality is absolutely essential, but there must be a simultaneous movement demanding change in male culture. Men must realize that masculinity is defined not by the ability to subjugate others, but rather by an intense maturity and knowledge about ones place and impact. Nowadays many people call for a renunciation of 'traditional masculinity,' which is often associated with the violent and sexually hyperactive tendencies of men, but negative commentary about the role of men does no more good than it does for women. A positive valuation of masculinity must be grounded in a positive valuation of the human—in what it means to be a moral being.

Christian tradition teaches that justice is the guiding virtue for this moral education, as it reminds us that we are part of a collective humanity, and that we must respond to all members with impartiality and egality. But while such an education is often grounded in a religious context, morality extends beyond the confines of religion. Community leaders must impress the universality of moral conduct, leading by example. Moral education should ultimately lead to a more profound understanding of the sexual rights of women, since, as Paterson reminds us, "HIV will not be brought under control until women are better equipped to influence the terms of sexual encounters."[24]

The Response to Racial and Gender Inequality in a Time of HIV

If we accept that there is clear racial disparity in the proliferation of HIV/AIDS, that inequality is due in large part to subjugation of minority groups through violent structures and all consequences thereof, and that structural violence (gender norms included) is perpetuated through improper response, the question we find ourselves asking is: where do we go from here?

First, we must acknowledge that public health officials confronting racial health disparities understand the social determinants of health, but lack the means to challenge these constructs. Public health officials have adopted a human rights framework and language in response to the HIV/AIDS pandemic, drawing upon the essences of Catholic moral and social teaching in a secularized fashion. However this framework does not always succeed in impelling others to act, especially those who can make the difference.

Second, those who are capable of fixing these broken systems are political figures that see little advantage in addressing structural violence and criminal justice disparities because the problems in question are so deeply rooted that nothing short of system reformation will be effective. While one would hope that politicians could be more easily convinced to act on morality alone, the current state of the political establishment does not lend itself to the cooperation necessary for institutional overhaul and appropriation of funds necessary to combat structurally violent systems. Therefore the impetus for change must come from the larger American public. We see the potentially constructive temperament of many regarding racial injustice in the response to the Black Lives Matter movement, so there is hope that racial disparities will be elevated to the status of 'politically worthwhile'. The difficulty of changing societal practices will inevitably lie in our actual response once political consensus is reached, and we will then find ourselves asking what we should do in specific. Whatever the response, it must be cognizant of the dignity and rights of all Americans, not just those who wield wealth and political power.

Third, the stories of individuals like Louise can be powerful educational tools. It takes courage to be open about ones HIV experience, so we must encourage loved ones, friends, and neighbors to be honest about their experiences both for their own betterment and that of others struggling with an HIV–positive diagnosis. Louise tells us she views her own story "as testimony, so people will start to be honest."[25] Perhaps it is these individual cases that best supplement public health's human rights framework, simultaneously shifting the HIV/AIDS paradigm from 'we never talk about it' to 'we must talk about it.' It is saddening, though, to think that after 30 years of suffering from HIV/AIDS, the American public still remains largely impartial to the epidemic.

Frederick Douglass reminds us, "Where justice is denied, where poverty is enforced, where ignorance prevails, and where any one class is made to feel that society is in an organized conspiracy to oppress, rob, and degrade them, neither persons nor property will be safe."[26] Are we not ashamed that the words of an abolitionist from nearly 150 years ago still ring emphatically true today? Let us not be remembered by future generations for inaction in a time of great need, but rather for the conscience and compassion to address our society's most profound shortfalls.

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HANDS

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BLACKBIRD

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I was born with Cerebral Palsy, more specifically spastic left hemiplegia. Because I was lucky enough to have been born with a relatively mild case, essentially all it amounts to is a lack of control, flexibility, and strength on the left side of my body. I usually have to explain to people that no, it's not genetic or contagious and no, I don't exactly know how I got it. I was sold a few different excuses growing up, including that my mother had slipped and fallen while she was pregnant, or my father's personal favorite, that the forceps used to aid in my natural delivery had somehow been the cause. Of course, neither of these tales makes particular sense given that it was an *in utero* trauma owing to a lack of oxygen, and so it wasn't long into my adult life before my big brother gave me the full story.

For as long as I can remember, my father was an abusive alcoholic prone to fits of mindless violence. During one particular bender, my pregnant mother interfered and my brother, only a boy of seven then, watched as the brute choked her unconscious. While this episode is no smoking gun, I find it a far more satisfactory explanation than an accidental fall or a forceps mishap. I can still imagine the veins in my father's leathery hands bulging to burst as he gripped tighter and tighter around her throat, squeezing the life out of the green eyes I was destined to inherit. I cannot definitively say that this story is the genesis of my disability but something in it resonates with my soul and makes a certain sense to me. Brutal as it may be, it is easy to imagine in that moment the lights in my fetal mind going dark one by one as the oxygen ran out. The way my brain cells must have begun to spoil and die like milk left to rot in a powerless refrigerator after a strong storm. The dime sized infarct establishing itself in my brain's right hemisphere and changing the course of my life forever.

I went a year after birth before being diagnosed with CP and when I finally was, the forecast was grim. Doctors told my mother and father that they should forget about me playing sports or running - their son would be lucky to walk. My mother, defiant as she was radical, had other plans in mind and swore to change her baby boy's fate. I was fortunate to grow up in the Boston area and blessed to have access to the some of the best hospitals, doctors, and treatments in the world. My mother enrolled me in a near constant physical and occupational therapy regimen often up to six days a week. She sought out each and every experimental treatment possible, from electrodes to Botox and even Reiki. No stone was to be left unturned and absolutely nothing left on the table, no matter how small or seemingly ridiculous.

Over time, I received every kind of therapy under the sun from aquatic therapy and hippotherapy to ice skating and sailing with Easter Seals. The Botox injections, though excruciating, did wonders to loosen my constantly tense left side and the occupational therapy helped to put that flexibility and relaxation to use in the form of improved and expanded functions. Heading into fourth grade, I had surgery at Boston Children's Hospital during which major work was done to my left leg and translated into a few bed ridden weeks at the hospital. Among the most significant components of the procedure was the cutting and lengthening of the Achilles and the breaking and repositioning of my tibia to combat the inward dragging of my left foot. I sat with my mother, clinging tightly to her hand, many weeks later when the cast came off. After the obscene noise of the cast-cutter and the accompanying bone-rattling vibrations from its blade had ceased, the plaster shell fell away and I stared at my leg covered in red, throbbing scars. Dried blood caked the chalky fabric of the white cast lining, while the pinnacle of the carnage was a massive, foot long scar tracing its way down the front of my hairless leg. My mother gripped my hand tighter than ever, choking back her tears as the orthopedist quipped that "girls dig scars," and I nodded with a grim smile.

The next few years were relatively normal as my education progressed and my treatments dialed down. I was plateauing, reaching a quality of life whereby further treatment could only add marginal improvements. Things were quiet until my mother was diagnosed with late stage gastric cancer in the fall of 2007, when I was just thirteen. Soon, I was swept up in the whirlwind of her own treatments. It was a fascinating and horrifying reversal, having to care for my mother as she had so often done for me. I watched uneasily the fanatical determination with which she continued to struggle against the odds, not for herself but for the sake of my brother and me.

She strived to retain some modicum of her grace even as my tasks began to include sprinting to retrieve the "puke bucket" when the nausea washed over her or lifting the portable chemotherapy dispenser she constantly wore on her hip when she found herself too weak. The issues I had with my own body were soon dwarfed and replaced with a deep respect for my mother. I watched, heartbroken, as the beautiful woman who raised me shriveled to a ghastly eighty pounds. Every trace of the tall, pretty girl who had modeled in her youth was erased and replaced by that disease. The long blonde locks atop her head that I so cherished fell out in clumps, until one day she had enough and begged me to help her shave it all off. And so, on a cool spring afternoon together we climbed into the tub in our bathroom and shaved each other's heads. With trembling hand I brought the horrid buzzer to bear on her soft scalp only to find that it coasted over her head with barely any resistance at all, tearing up huge patches of gold and showering us in the sad remnants of her rapidly dwindling vitality. The tiny flecks of her shorn hair cascaded from her mantle like the last rays of a setting sun. They stung and scraped my youthful skin but the physical damage was trivial compared to the collapse currently taking place in my mind. With the deed finally done, we clutched each other sporting matching buzz cuts covered in each other's hair and tears, utterly broken.

My mother's hair never grew back and was, for the rest of her short life, replaced by a crown of stringy, plainly artificial flaxen thorns. By the time she died in February of 2009, just one day shy of my parents' wedding anniversary on Valentine's Day, she was unrecognizable. The pallid, emaciated corpse laying in the casket before me with green eyes entombed behind immovable slabs for lids whose soothing voice was silenced forever behind those pouted wax lips was not my mother. My mother and greatest advocate had left this world long before her body hit the cold metal table of the morgue or the disturbingly plush interior of that pink casket. She would be glad for that because she was spared witnessing the chaos of my life in the weeks, months, and years following her death.

Not even a week after the funeral, our father tried to kick my brother and me out of our house. It felt like evil personified when he sneered as us that, he would "make sure (we) were homeless if it was the last thing (he) did." Because of some clever legal maneuvering that my mother had undertaken in the final days of her life, we were able to stay. Eventually, he was forced into his own ancestral home in Roslindale and my brother (now my legal guardian) and I, only twenty and fourteen, were left on our own. Years of legal battles for the fate of my guardianship and our tenure in the house would ensue, not to mention the soul crushing work of figuring out how to live without our mother. The cross I bore had somehow gone from having a "disability" to being an orphan without any time for adjustment.

And yet, in that stage of my life, there had already been a shift occurring in the way I perceived my disability. As a child, I had always associated it with practical inconveniences like the pain from procedures and braces, my complete lack of athletic ability and subsequently being passed over for every pickup game ever, and everyday struggles, like barely being able to tie my shoes or zip my coat. The older I got, the more distance was put between me and those earthly complications. It took me years, but I mastered the daily challenges long before my mother died and the braces and procedures had all but ceased heading into high school. I was growing into my body and now had the intellect to use it to its fullest, which offset my lack of athleticism. I had undergone about as much physical healing as my body would allow and had adapted to use it in ways that gave me the greatest quality of life possible. I rarely had the need to use my left arm and hand as anything more than a grasper and I still limped, though most would tell me they thought it was simply an athletic injury. The cost-benefit ratio of further treatments and regimens began to wear thin for me, especially with how complicated the rest of my life had become. I still maintained yearly visits to my specialist to keep my favorite pediatrician happy, but the focus of my disability had decidedly shifted toward more existential, spiritual issues.

Then, sophomore year rolled around and I began to drive. I always had a passive interest in cars owing to my father and my brother's admitted status as gearheads. My brother only owned fast cars and even raced them at New England Dragway, sometimes running the quarter mile in as little as eleven seconds. That being said, I never really *got* it. I never played with matchbox cars as a child nor understood the passion and fanaticism with which young men regarded cars and racing or the indelible mark the automobile had made on American culture. Then I turned sixteen and held a wheel in my hands as I drove for the first time and I finally understood.

To call this experience revelatory would be a cruel understatement. Driving to me was a borderline spiritual experience.

By the time I was able to purchase my own car in the spring of my junior year, a jet black 1997 Eagle Talon TSi AWD, I was completely and utterly indoctrinated. I connected with that car on a deeper level than with anything I had since my mother's death. All my life, I had been saddled with a broken cage of a body and now suddenly something set my soul free and bid me to fly. I had been forced by circumstance to be a sharp boy and yet was somehow powerless to use any of my intellect or will to force my own limbs into complying with my wishes. I had control over so much except the thing which was closest to me, my mind a prisoner in its own body. But that car changed everything. With that car, I let go of my body the moment I climbed into its interior. Settling in the grey leather driver's seat, I melded my mind with the steel creature's chassis. My mind controlled her body and the two of us, one being.

All my life, I knew the frustrations of having to plan my actions out three steps ahead of my peers so as not to trip or exhibit some display of clumsiness. And I knew all of the frustrations of being able to push my body into athleticism, even to the degree of being a varsity athlete, but never enjoying a moment of it. The Talon showed up and washed all of this weariness from my soul. When I piloted the Talon, my mind was in absolute control and it was no longer my crippled body that received the signals of my desires. Instead it was the Talon and whatever I asked for, if she were able, she provided. It didn't take me long to discover what a very capable vessel she was and what a fine team we made.

For the first time in my life, through this second body, I was capable of feats my peers could only imagine. At that point in our lives, my friends were all still strapped with borrowed or hand-me-down economy cars and I had a bona fide sports car, aged though it was. I became capable of so much and my compatriots so little. I had worn many braces and endured artificial attempts to improve my function over the course of my life but this car, this silicone sweetheart, is what finally made me feel whole.

Granted, it changed nothing about the lopsided husk of a body I inhabited with my asymmetrical and underdeveloped left side. And I still stared with sunken eyes into the mirror every day disgusted by a body I saw as a horror to behold. But on nights when I would throw my worn, brown leather jacket around my shoulders, itself a suit of armor that disguised my shorter left arm in its pocket, and go bombing around the mountain roads of the Blue Hills, I felt a kind of freedom the likes of which I had never even come close to tasting. The Talon gave me a sense of power, agility, and speed that my poor broken body never could. She gave me freedom, independence, and the blissful elegance of simply existing in a world with a fully functioning form. The car was incapable of doing anything without my direction and my body incapable of doing anything of the sort hers was. Every time I climbed into that seat and inserted the key into the ignition, the simple act of turning the motor over was a joining ceremony and a symbol of commitment. I poured my soul, my essence, everything I had ever been into that mechanical vessel and together we became two halves of a whole. She stood as a Golem, dispatched from God to deliver me from my suffering and that it was in our connection, in our magical bond that she took on some sort of life.

The Talon delivered me from more than just the trials of my disability. She became my home and my trusted companion.

When my mother passed away, there was a bottomless void in my life. The connection I had with her was irreplaceable in its depth and breadth. My brother could not simply absorb the relationship my mother had with me because he and I had a different relationship, deep and passionate in its own way. I never expected anyone to remind me of my mother, much less an inanimate object, but with the Talon I began to experience things that echoed inexplicably of her.

When I awoke each morning, the first thing of real meaning or substance I saw was her. I saw her just as I had seen my mother, and she carried me to school exhausted just as my mother had every single morning. And over the course of our drive down Morrissey Boulevard to BC High, as I idly talked aloud, cursed at commuters, and sang along to songs, I realized I was doing the same things I would have as if my mother were in the car with me. In the evenings when, grumbling, I would fling my backpack into the passenger seat and complain the whole way home, the Talon was there to listen.

In our drives through the Hills at night, sometimes a song would come on that energized the both of us and I would lead the Talon through the curves of those roads laughing and smiling. We were dancing, just as my mother and I had done in our tiny kitchen when I was but a child. On the way to my first date nervous as ever it was the hold of the Talon's seat and my grip around the leather wheel that, like a firm embrace, gave me the strength to press on. It was her sharp and impressive features that gave me some sense of confidence. Most importantly, I loved the fact that behind a steering wheel, with my feet planted on the floorboard, it was nearly impossible to discern my CP. I experienced the best parts of my youth inside or alongside that car and in many ways she became a pillar of my life just as my mother might have been. In the winters, when the cold was too brutal to bear and in the summers when heat too overpowering, it was within the Talon's interior that I took shelter. When the snow was piled high or the rain fell in buckets or I stupidly came into a corner too fast, the car somehow provided. She was my caregiver.

Out of all the therapy I received in life, I consider this "automotive therapy" one of the most important and most formative. It came out of nowhere and years later I still have difficulty describing or quantifying it, yet no corrective brace had ever made me feel half of what the Talon did every day we were together and no medical therapy could heal my heart and soul the way she did. Nothing had so changed the way I viewed myself or my potential, and absolutely nothing gave me the confidence and freedom that she did. I owe everything about the health of my body and the quality of my life to the doctors and hospitals that treated me over the years, but I owe everything regarding the health of my heart and soul to the Talon. It was in her that the promise made to me in the lyrics to one of my mother's favorite songs was fulfilled:

"Blackbird singing in the dead of night
Take these broken wings and learn to fly
All your life
You were only waiting for this moment to arise.

Blackbird singing in the dead of night
Take these sunken eyes and learn to see
All your life
You were only waiting for this moment to be free."

SAVE THE CHILDREN… —VACCINATE!

Theresa Rager is a junior Biology major and Medical Humanities, Health, and Culture minor in the Morrissey College of Arts and Science. Theresa's second piece in this issue of the journal—"Save the Children…Vaccinate!"—was written for Professor Amy Boesky's "Intro to Medical Humanities" course.

Less than a month into 2015 there was an infectious outbreak that sent many kids home from Disneyland with what initially appeared to be the common cold but quickly turned into a full-body rash—measles. By July 24, 2015, the CDC reported 183 cases of measles across 24 states and Washington, DC. But the outbreak has left many Americans asking, how and why did this happen?

A quick Google search can tell you that a measles vaccine is readily available. In fact, measles is vaccinated against along with mumps and rubella in the immunity concoction known as MMR. MMR was licensed in 1968 and became officially recommended for all children in 1977. The introduction of this vaccine led to a dramatic decrease in measles infection rates and has proven to produce immunity in 90-100% of inoculated children.

So, how does an outbreak like this occur? It starts with herd immunity. Herd immunity is the protection a population receives from an infectious disease when a certain percentage of the population is appropriately vaccinated. For measles, herd immunity can be achieved when 88-92% of the population receives the MMR vaccine. However, when this threshold is not met, the population becomes at risk. It's a simple probability problem. An infected person has a greater chance of coming in contact with an unvaccinated person if the herd immunity threshold is not met. The newly infected person has the potential to infect many others, and from there it is an exponential equation summing up to an outbreak. Now the question becomes, why is our population not meeting the herd immunity threshold?

There will always be members of the population that cannot be vaccinated—the designated 8-12% that public health statisticians allow for in their herd immunity threshold calculations. Many of these people are immunocompromised. Whether they have received transplants and must take immunosuppressants or have an autoimmune disease, vaccination is a health risk these patients cannot afford to take. In the case of measles, many older Americans have a lifetime immunity from childhood infection, but this elderly cohort is dying without being replaced by a younger, vaccinated cohort.

Since Dr. Andrew Wakefield's 1998 publication in *The Lancet*, many parents have chosen not to vaccinate their children, particularly with MMR, for fear of a link between vaccines and autism. Wakefield published a study of twelve children who had been vaccinated with MMR and were diagnosed with autism. Immediately after its publication, the validity of the study was questioned for ethical and logistical reasons. Many subsequent studies have been published that disprove Wakefield's publication, causing *The Lancet* and ten of the thirteen authors to retract their claims. Nevertheless, the fear persists in American parents' minds.

The NIH recognizes that the prevalence of autism has increased in conjunction with the increase of infant vaccination rates but also cites two reasons for this apparent correlation. First, new diagnostic mechanisms for autism have led to hypervigilance in diagnosing. It is important to remember that autism is a spectrum disorder, meaning patients can express a wide range of symptoms. With this influx of diagnoses, children with more mild symptoms receive the diagnosis, leading to the statistics noting an increased prevalence of autism. Secondly, the NIH recognizes a temporal association between the age of autism diagnosis and vaccination. The first dose of MMR is given between 12-18 months of age, which is the same age that most children are diagnosed with autism. Yet, it is highly unlikely that such a disorder could develop to a diagnosable degree in such a short time frame. Ultimately, the most compelling piece of evidence is actually the lack of evidence. There are no epidemiological studies showing an association between vaccines and autism. Autism pathogenesis is strongly genetic and neurodevelopmental. A vaccine at 12-18 months of age cannot explain a disorder that has roots in embryonic development.

While it is unfortunate that many Americans, mostly children, contracted measles this year, most of them will also survive; they will suffer from the symptoms but eventually recover. Nevertheless, let us think critically about what has occurred here. The unfounded fear of a link between autism and vaccines has caused a drop in our herd immunity for measles that has put the population at risk. What would happen if our herd immunity for more deadly diseases dropped? Dare I mention polio? Hepatitis? Meningitis? We have received a warning sign from this measles outbreak. Parents, save us all from the infectious diseases the research community has worked so hard to put at bay. Vaccinate your children.

GEOGRAPHICAL AND FINANCIAL DISPARITIES IN THE AMERICAN MEDICAL RESOURCE ALLOCATION

Bridie Lawlor is a junior in the Morrissey College of Arts and Sciences double majoring in Philosophy and Communications with a minor in Medical Humanities, Health, and Culture. Her featured piece was originally written for the class "Contemporary Issues in Public Health."

In 2009, Steve Jobs received a liver transplant in a hospital in Tennessee, a location geographically far from his primary residence in California. After this transplant procedure, many people accused Steve Jobs of cheating the system with his fame, wealth, or personal connections. These accusations were wrong, as Steve Jobs' liver transplant was completely legal—although he did have an advantage.[1] Steve Job's advantage was his financial wealth, which is the source of the gap within the American medical resource allocation system. Because of his financial position, Steve Jobs was able to place his name on multiple transplant lists (ML) in the United States. The only requirement to putting a name on multiple transplant lists, is that the patient could arrive at the transplant center almost immediately after an organ becomes available. A person can do this if they are in a position that will allow for an extended stay in a hotel nearby or the ability to race a private jet across the country. According to Shlapentokh's and Beasley's novel *Restricting Freedoms*,

> *The reason that some people might be able to get transplants more quickly is that they're standing in more lines. Nothing prevents someone from being evaluated and listed at multiple transplant centers. As long as a patient has the wherewithal to fly around the country—and be available at the drop of a hat if a liver becomes available (this is where the private jet comes in handy)—a patient can, in theory, be evaluated by all the transplant centers in the country.*[2]

It's this loophole in the medical resource allocation system that forms financial and geographical disparities and contributes to a larger controversial issue in public health. How does financial status or geographical location affect one's chance of receiving medical resources?

How Does Medical Resource Allocation Work at the Population Level?

As stated earlier, potential transplant patients with extreme financial wealth have an advantage by placing their name on multiple transplant waiting lists, thus increasing their odds of receiving an organ donation. However, for those who aren't in this position and who are specifically at a low socioeconomic status, their position may place them extremely against the odds to receive a donation. Gill et. al. found household income to be a key part of the socioeconomic determinants of health in their analysis of racial and income disparities in regards to kidney donations. Studies show poor health outcomes in low-income groups due to a higher potential of engaging in high-risk behaviors that contribute to health issues such as diabetes, obesity, and psychiatric illnesses.[3] When potential donors are found with adverse health statuses, they are often unable to donate organs. "As a result, prospective donors from low-income populations may frequently be found medically unsuitable to donate a kidney." In addition, costs such as post-donation medical claims and health complications related to the donation are not covered by health insurance, lowering the chance that people in low-income areas will donate an organ.[4] What makes the disparity worse is the chance of an organ becoming available in a low-income area and having it received by a ML patient who lives nowhere near the region, taking it away from the person who can only hope for an organ at a single transplant center near their home due to financial limitations. Vagefi et. al. analyzed the socioeconomic factors that contributed to whether approximately 60,000 candidates on the United Network for Organ Sharing Standard Transplant Analysis and Research File from 2005 to 2011 had names on ML or a single transplant list (SL). The results showed the ML candidates were more often male, white, college-educated, blood type 0, and privately-insured. Besides blood type, the other results showed geographic and socioeconomic privileges in those people whom use ML for transplants. The article also stated, "However, as ML remains used by a few, and the profile of ML candidates suggests that these few are socioeconomically-privileged, then the question is whether ML should continue to exist, a question that has been debated extensively."[5]

What Are Arguments for ML in the Medical Resource Allocation System?

The arguments for the medical resource allocation system to function as it does currently include: it rewards the citizens in our country who have contributed to our society and favors those who will mostly likely be able to pay for the heavy financial costs of post-transplant procedures. Persad, Wertheimer, and Emanuel analyze four categories of ethical values for allocation principles: "treating people equally, favoring the worst-off, maximizing total benefits, and rewarding social usefulness."[6] Treating people equally includes a lottery system and operating on a first–come first-served basis. Favoring the worst off includes allocating resources to the sickest and youngest first. Maximizing total benefits includes saving more lives or maximizing the life years saved. Promoting and rewarding social usefulness is the ethical group that resonates most with the United States' current medical resource allocation system and includes instrumental value and reciprocity. This allocation tactic helps to "promote other important values (future oriented) and rewards those who implemented important values (past orientated)."[7] For example, Steve Jobs would fall into both categories as someone who promoted important values and greatly contributed to society through the development of the Apple products as well as someone could help promote other important values into society by receiving a transplant. By eliminating the ML option and financial advantages in the medical resource system, the United States' medical system would not be allowed to reward the people who have greatly contributed to our country's society and would, presumably, not prevent the deaths of those who could one day be our greatest heroes. For example, what if one of our country's greatest doctors needed a transplant? What if this doctor were to be the doctor to cure breast cancer in the future, but only if he or she received a transplant? In addition to rewarding social usefulness, keeping ML within the medical resource allocation system could be seen as more efficient. According to United Network for Organ Sharing (UNOS), the cost of post-liver transplant admission for 180 days was $93,000 and the cost of immunosuppressants were about $23,000 in 2011. If ML were eliminated from the medical resource allocation system to eliminate financial and geographical disparities, many recipients would not be able to financially sustain the post-transplant costs and would presumably die sooner than someone who could afford the post-treatment finances. This point raises the issue of quantifying the value and cost of life. With ML included in the policy, the American medical resource allocation system favors the wealthy. Within the system of our ethical values of allocation, the current policy appears to give organs to the great contributors to society and/or the wealthy, because they can afford the costs of traveling to various transplant centers as well as the post-procedure treatment. Theoretically, these recipients can use the organ more efficiently than someone who is of low-income status and will not be able to afford the treatment, and therefore will "waste" the organ.

What Are Arguments against the Medical Resource Allocation System?

Mahle encapsulates the financial disparities that the ML transplant list entails. He writes that the transportation costs to visit multiple transplant centers—let alone the costs to stay or arrive in the event of an available organ—are unattainable to many patients waiting for organs. He writes, "It is likely that a small proportion of families will explore the possibility of multiple listing. One hopes that our community continues to analyze this practice to ensure that those [children] most in need of transplant, rather than with the most resources, have the highest priority for scarce donor organs."[8] Furthermore, the availability of organs in low-income areas is lesser because the population in that area statistically engages in high-risk behaviors more frequently, leading to illnesses that prevent effectiveness of a transplant from ill host bodies.[9] Since the organ availability list is presumably shorter in low-income areas, the disparity is made greater when high-income patients place their name on multiple transplant lists and take the available organs away from those who are geographically and financially confined to that one transplant area.

Who Are the Stakeholders Involved in Medical Resource Allocation?

The stakeholders involved in the American medical resource allocation system include: UNOS, the organ transplant doctors, the advisors to the potential recipients, the potential recipients, the organ donors, and the transplant centers. From this extensive list of stakeholders, it is obvious that there are a variety of different interests within this system. With competing interests, a solution to appeal to the interests of everyone involved in medical resource allocation is difficult to find, but a solution that favors the majority rather than the wealthy is one that I seek to find.

What are some recommendations for this Public Health Issue?

White et. al. researched the outcome of New York's "ban on entry to multiple transplant lists for cadaver kidney transplant, and the impact of the ban on equity in access to transplantation."[10] The authors concluded that the ban was effective in reducing the amount of multiple listing for patients in New York, however, the "results suggest that banning multiple listing is not likely to result in large improvements in equity to transplantation." This result is most likely due to the geographical disparities associated with organ availability. To reduce this geographical disparity, there needs to be a focus on reducing the high-risk behaviors in low-income areas that inhibit organ donation. In addition, there must be adequate financial coverage to potential donors who are uninsured or cannot afford post-donation treatment. These changes, in addition to limiting the number of transplant lists a patient can add his or her name, are an ideal solution. I recommend patients allowing patients to add their name to three lists, therefore rewarding them for "social usefulness" while also reducing the financial and geographical disparities associated with ML within the medical resource allocation system.

ENDNOTES

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THE CUT

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As the sun's light began to fade, Pia found herself in the master bathroom on the second story of her four-bedroom, recently renovated suburban home. Nothing littered the spotless countertop and she didn't want to make a mess; the bathroom had just been cleaned. Facing her reflection in the mirror, Pia's eyes flitted as they scanned her hair. It was dark, thick and ran straight down the middle of her back, faultless. She silently thanked her mother. This would be the third and last time, she thought. All for the sake of long, dark, thick hair. All in the name of beauty.

Now was the time. Shell-shaped and awkward, the sink wasn't big enough. She'd use the tub instead. Walking over to the freestanding bathtub, she alternately turned the hot and cold knobs, wondering how far above ninety-eight degrees would feel too hot. As the water rose, she poured Johnson's Baby Wash into the tub, staring blankly as bubbles formed and skimmed the water's surface. From beneath the vanity sink she pulled out a pink double-bladed, brand new disposable razor and placed it, along with a white washcloth, on the edge of the bathtub. With the tub half full, she turned both knobs right. The hottest of the water rose slowly towards the ceiling, where it hung precariously, toying with the effects of gravity. She reached in to test the water. Perfect, she thought. She undressed herself, leaving her clothes in a neatly folded pile next to the towels on the bench near to the tub. A soft coo from the other room reminded her it was time.

Pia made her way into the adjoining bedroom. From the crib in the corner, her baby girl stared up expectantly. Bits of dark hair spiked up and pointed in various directions, giving the baby a playful look. With round cheeks, small eyes, and few teeth, she resembled most babies. Pia noticed how the diapered baby's muscles twitched as they worked to support the weight of her torso. It had only been a few weeks since she'd learned to sit up steadily on her own. Carefully, Pia bent over, reached out, and drew the baby close to her chest. Natural oils met and meshed as their hot skins touched, responded, and reminded them of their bond. Laying the baby down on the bed near the crib, the child fussed as Pia removed the dirty diaper. She skillfully wiped her off, rolled up the diaper and disposed of it in the deodorized pail.

Pia thought back to the other two times. Each occasion, the result had left her unsatisfied. The third time is supposed to be the last time and things would turn out differently. Back in the bathroom, she briefly straddled the tub's side as she stepped into the foamy water, baby in arms. Standing in the wake, she watched the baby's mouth match the sounds that met the air as Pia bent her right leg, followed by her left. She found herself kneeling, sitting on her ankles with the baby cradled in the hook formed by her left arm. She reached with her right hand for the washcloth, wet it in the soapy water and began to bathe her.

Beginning at the feet, she feathered the soap between the baby's miniature toes, up her stocky calves, behind her creased knees, and across her round thighs. The washcloth made its way up the baby's soft stomach, in and out of her bellybutton, then around to her back, softly massaging the muscles beneath the smooth skin. When reaching the nape of the neck, Pia reapplied soap and began forming soft circles as she gently scrubbed the baby's scalp. Avoiding her open eyes, Pia worked to soften the pores that held the existing brown strands. Only an inch long, the tufts were short. It was getting dark and thick, but there was room for improvement. The baby shivered and sought the warmth of her mother's body. Pia thought about a day when she'd recount this moment, when her baby would thank her for the effort.

Having formed a frothy wig atop the baby's head, Pia traded the washcloth for the razor. The first time she had begun on the left side, the second time on the right. Now, she'd begin front and center. Placing the razor's edge in line with the child's small and supple nose, Pia grasped the handle with her index finger and thumb before commencing. Locking her wrist, she moved her entire arm from the front of the scalp towards the back, listening as skin met metal. A single valley of rose-tinted scalp revealed itself in between two masses of foam. She exhaled and cooed, calming the restless baby. Satisfaction. Gaining confidence, her movements grew swifter as she moved towards the left edge. Pia reviewed the comical split wig and laughed. The half-sheared baby fidgeted as water droplets caught soap bubbles and stray hair, following the soft form of her face. Pia moved quickly, wiping away any residue before it reached the baby's squinting eyes. She was halfway towards reaching her definition of accomplishment.

Her left arm began to ache underneath the baby's weight as she turned her attention towards the remaining white froth. After rinsing the razor in the now lukewarm water, she continued. Starting at the center once more, she slid the razor towards the posterior part of the head, making sure to catch every hair. Gradually, one wig transformed into the other as the bubbles disappeared and smooth skin displaced any existing fuzz, leaving behind uniformity. As she followed the curve of the right ear, the razor made its final move. The etching stopped and Pia placed the razor back on the tub's edge. She sat the baby in front of her, wrapping her motherly legs behind the baby, making sure she didn't fall backwards. Pia turned the child's head to the left, then to the right as she rinsed off any remaining soap and hair just as gently as she wiped away her daughter's tears. The water now cold, the baby whined.

Only the fading sunlight illuminated the room. The two sat facing each other. One proud. One upset. The baby's skin now unvaryingly smooth and spotless. This was the third and the last time, Pia reminded herself.

NOT TO BE FORGOTTEN

Sarah Ramsey is a sophomore in the Carroll School of Management studying Marketing and Entrepreneurship with a minor in Medical Humanities, Health, and Culture. Outside of her academic work, Sarah is a council member of the Appalachia Volunteer Program and writes a food blog, "Sweet Olympia."

She is grey.
Her wrinkles pull her face in an infinite ache,
stretching the years until they meld into folds.
The rims of the blinds are covered with dust,
she looks outside the single window,
greeted with the view of concrete, pavement, and dry skies.
Her eyes are sharp.
Still piercing through the tears, longing for home,
away from the potted plants, sterile smell, nurses' chatter.
away from the timed intervals, structured days, tasteless food.
Her blue veins trickle down pale slender arms,
plastic chains hold her down,
inserted into her very being,
unknown substances are pumped in,
she endures.
Her granddaughter speaks to her AS IF she were a child,
the nurses greet her everyday to ask how she has been,
AS IF she went on a grand adventure the night before.
She smells the scent of death,
She lies solitary, looking out of the single window.
He is young.
Just enrolled into the force.
Fit and strong.
Destined for greatness he aced every test he took.
Memorized books upon books filled with inconceivable knowledge.
He does not listen.
She wants to be home
where sunlight is not limited
to a three by four window.
She wants to go in peace,
not living
where the sound of beeping monitors outbids the birds.
She wants a voice
not being
the old woman in Room 202.
She is alone
lying next to millions of others.