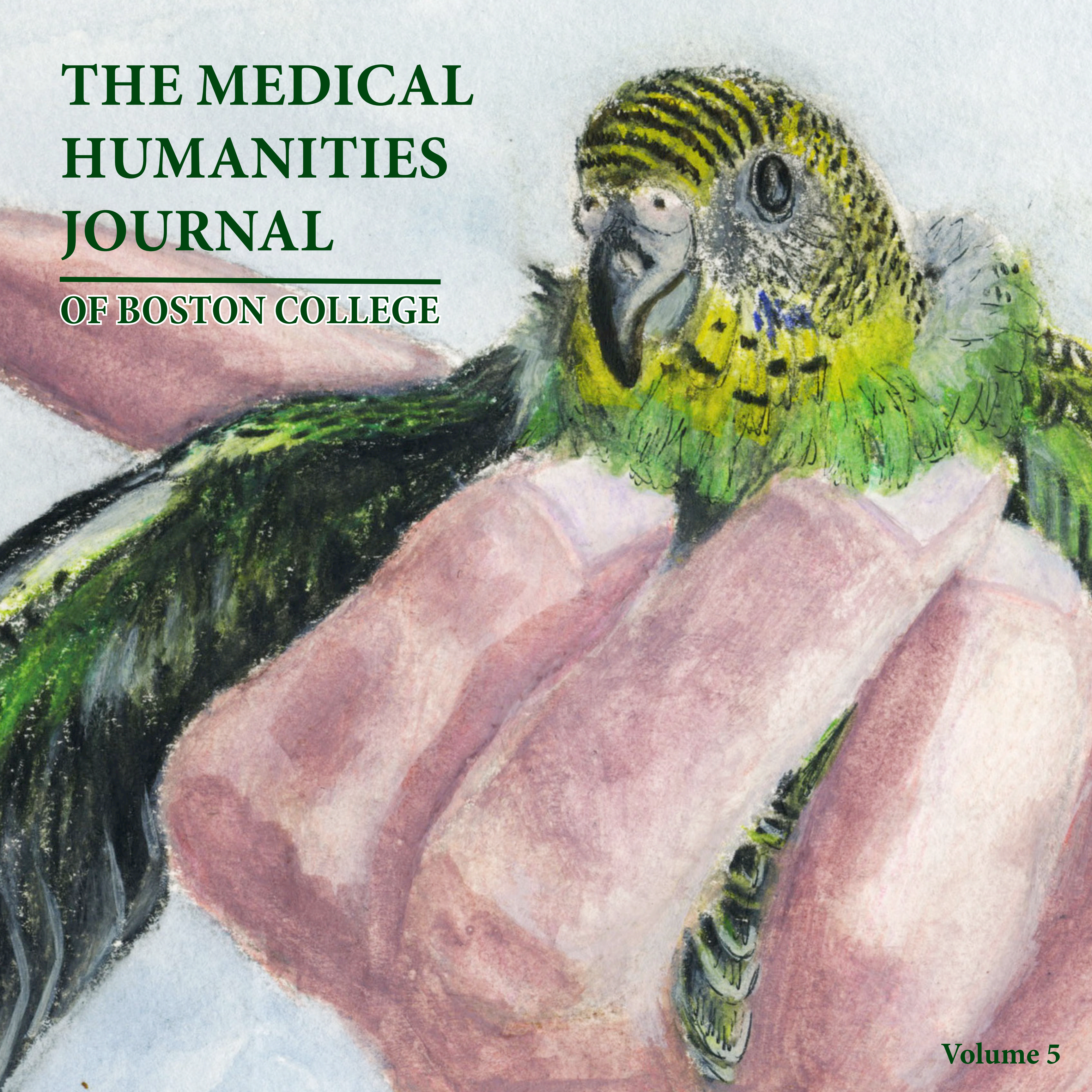
THE MEDICAL HUMANITIES JOURNAL

OF BOSTON COLLEGE



Volume 5

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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EDITORS' NOTE

We all enter university eager to become specialists in our own fields of interest, be it chemistry, economics, nursing, or art history. We are often driven by our passions, which prompt us to take separate paths towards the attainment of our goals. In light of our individualized engagements, we tend to forget what keeps us interconnected; one of our shared experiences is that of health and illness.

The Medical Humanities Journal of Boston College seeks to bring all of our experiences to light in an effort to communicate the breadth of the medical humanities. Through pieces like Cailin MacQuarrie's op-ed on the expansion of the Victim Compensation Fund for 9/11 victims, Ivelisse Mandato's reflection on the stigma against physical illness, and Matthew Davis's comparison of the healthcare systems in Ireland and Scotland, we hope that our journal helps readers see that despite our differences, we are connected through our losses, our desire to be loved and supported, our internal struggles, and our celebrations of life.

While health is a topic that is pertinent to all of us, it is highly individualized. Health is on a continuum, characterized by personal progresses and setbacks. We seek to expand the definition of health to include physical, mental, emotional, spiritual, and social wellbeing. Healing for some might represent a cure. Healing for others might mean eternal peace. Different outcomes generate different responses in individuals and in their loved ones.

Spring of 2019 was distressing, complex, and difficult for our student body. Being faced with the passing of our peer Patrick Gregorek has prompted grief, puzzlement, and heartache across campus. Some of us knew him personally as a close friend, a roommate, a group member, and a classmate. All of us know him as a peer at Boston College.

Coping can be an especially difficult process to undergo alone. For this issue, we have collectively decided to dedicate our publication to Patrick, and to encourage members of our community to address the topics of death, dying, loss, and grief. We hope that these pages serve as an outlet for our emotions, and work to make this experience less isolating. Our journal has always aimed to foster an open space for interdisciplinary conversations. Loss is often devastating. The more we talk and the more we reflect, we begin to make sense of events in our lives that are difficult to come to terms with. Through the touching words of Patrick's friends and through words about loss from BC professors, the themes of love, support, and togetherness unfailingly emerge. This publication has reinforced our belief in the healing powers of expression.

We extend our deepest gratitude to the talented authors and artists who contributed to our journal. Thank you to members of our board for pouring their hearts into compiling a moving publication. Thank you to our readers for participating in these conversations, and for helping us sustain our overarching goals. MHJBC is committed to giving others a voice, and aims to remove stigma that exists around certain topics. All in all, we hope that this journal does justice to our efforts of delivering feelings of comfort, strength, care, and love.

Aleksa Qilleri and Heena Nissaraly
Co Editors-in-Chief

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In Memory of Patrick Gregorek:

LOVE BLURS BORDERS

Kathryn Giordano

“¡Tiralo a mí!” Throw it to me. My fingers clumsily clutch the at the seams of the baseball as I attempt to wind my hand back like the pros I’ve seen in the MLB. My hand glides forward. The mandatory baby blue scrubs adhere to the sides of my arm, providing just enough restriction for the ball to land at the feet of my playmate. Her gap-toothed grin is reserved and her eyes tinted with an unfocused gloss. I can feel the corners of my mouth fall as the baseball leaves the tips of my fingers and her eyes struggle to focus on the object flying towards her.

“KG!” The trip leader’s voice rings in my ears and I turn my head. Her mouth is moving but her words become lost in the chatter of patient families discussing current maladies and excitement over the possibility of receiving a hygiene pack. Realizing I’ve probably spent more time at this clinic playing with younger patients than packing medications or taking vitals, I jog over to the coordinator.

“Did you hear what I said?” I shake my head. “It’s your turn to sit in on consultation. The doctor’s getting lunch now, but she’ll be back in five. She speaks mostly Spanish and some English, so just ask if there’s something you miss. I can always help translate.” I nod my head and walk into the consultation room.

It’s a small classroom, concealed with silver metal roofing and walled with thin, dorm-like concrete. My scrubs cling to my body, uncomfortably latching onto my legs and arms with every movement. I plop down in an elementary school-sized desk and kick my legs out. This was nothing like the crinkly white sanitizing paper I sat on before leaving. In the US, I waited in air conditioning and admired the travel doctor’s “Sahara Desert” images. She had small bejeweled elephants next to the photos, adding a sense of mystique and adventure that glorified travel in developing countries. How did I become so wrapped up in that illusion?

The doctor returned from lunch, speaking a message into her iPhone in Spanish that was too fast to make out. “Sorry,” she said in broken English. “It’s difficult to find signal outside Panama City. I had a few bars and wanted to check on my daughter.” I grin. “No worries, my mom likes to do the same,” I said.

“KG, you guys ready?” The doctor and I turn our heads to the small opening at the front of the classroom. The coordinator stands in the center of the door, hands at her sides. A little girl peaks around the wall beside her, stretching her arm up in an attempt to reach the coordinator’s. The pads of their fingertips touch.

The coordinator enters as the young girl trails behind with another woman in tow. The older woman braces her hands on the sides of the plastic chair before us and lowers herself slowly. The little girl, with eyes wide, attempts to do the same, but instead tucks her right knee and hoists herself up. Watching her feet as she turns her body, she plops down in her chair and allows a small smile to peak out from underneath her hung head. The doctor begins to converse with the older woman. I pick up words from their phrases: “ojos, fiebre, ver.” Eyes. Fever. To see. The small girl’s head pulls up on the last word. Her eyes interlock with mine, fighting for a bond she so desperately did not want to let go. But within a moment, her right eye gave way. It drifts to the side, frantically searching for anything to hold onto. Why couldn’t she find it?

***

“I can’t find a good spot.” The doctor prodded my arm with a thin needle. “This one will make it feel tender and if you’ve had swelling here in the past…” The paper crinkled as my weight shifted on the benchtop. For a kid who’s pre-med, receiving vaccinations should come easily. If anything, I should have embraced them, but the clinching of my toes and the hardened grimace on my face said otherwise. “This minimizes the contraction of serious diseases like yellow fever, malaria…” The doctor’s voice trailed off. “I don’t care! I don’t want the shot,” I whined.

“Kathryn, suck it up and take the needle.” My mom sat in the corner, failing to lift her gaze from her iPhone, which beeped with new emails and Amazon Prime offers every five minutes. “You’re not going to Panama without the proper vaccinations. You don’t want to get something serious. You’ll get something rare and with your luck lately, you’ll come back… I don’t know… blind for all we know. Now take the damn shot!”

***

The rapid Spanish subsides and the doctor lifts herself from the school desk. She wraps her fingers around the sides of her iPhone, using her opposite finger to tap the touchscreen. A bright, blinding light comes on. She walks towards the little girl and uses two fingers to pull up her chin. The doctor moves the light across her eyes, back and forth. The little’s girl’s head swings with the movement of the light. From my angle, I watch as her left eye follows, glancing periodically at the doctor’s face. No expression. She turns the light off, guides the little girl’s chin down and walks back to the desk beside me. The little girl fidgets, forcibly straightening one leg. Her arms stretch to the sides of the chair, attempting to hang them over, but only her fingers reach the end. Without showing teeth, she smiles at me.

The Spanish picks up again. This time, it goes so fast all I retain is “no vee,” “no sé,” and “no puedo ayudarle.” The older woman’s eyes swell with small tears as her contemplative stare shifts towards the little girl. The child is kicking her feet now, just as unaware as I am to the current situation. The older woman interlocks her fingers around the girl’s arm, guiding her hand into the air, resembling the signal parents in the US use to tell their kids it’s time to leave. The woman stares at the ground, murmurs a quick “gracias” and walks out.

I look at the doctor. She stares straight for a moment, fixating on a mural reading “Comunidad sobre todo” on the school wall before us. Community before all. She turns slowly. “She’s blind in her right eye. I do not know what illness caused it and I do not know how to fix it. She needs surgery and her mother cannot afford it. There is nothing I can do.” The shocking words spin in my mind and I pause, attempting to find any possible solution. I had no difficulty interpreting the interaction before, but now, I was stalled. There was nothing. Slowly, I adopted the same gaze she held before. “Comunidad sobre todo” peeks out the corner of my vision. I think back to my visit with the travel doctor before leaving on the trip. It was a routine check-up with supplemental vaccinations required by the US to leave and return home. My visit was smooth, my doctor was thorough and when it was all over, she plopped pamphlets titled “Common Allergic Reactions to Vaccinations” and “What Does this Vaccination Do?” into my hands and ushered me out the door.

At that moment, I felt distant. I made sense of the situation, but I did not understand. I will never understand. I’ve never had a life-altering diagnosis nor been in a situation where financing treatment was the first priority. I thought of the phrases I translated from the doctor and mother’s dialogue in that consultation session: she cannot see, I don’t know, and I cannot help you. Never have I heard those words from a practicing physician: so motivated by desire yet so constrained by their environment. I still regret it to this day, but without realizing, my mind fell prey to the classic issue plaguing the medical field. The rich lead healthy lives while the quality of life for the poor dwindles.

My thoughts, thankfully, broke off with the sound of the baseball bouncing across the concrete floor, followed by the patter of feet. Our previous patient rushes in, picks up the ball and looks at me. Her right eye no longer struggles to connect with mine, but contently sits at the side. Slowly a smile forms, revealing a wide, gapped-tooth smile. The skin around the edges of her eyes sinches as she pushes her chin out, showing the space between her teeth with a proud innocence. She removes one hand from the ball, tucks all fingers but one and points at me. Her remaining fingers uncoil and she beckons for me to join. I look at the doctor who smiles and nods in her direction. With scrubs still suctioned to my thighs, I rise and begin to walk towards the girl. She giggles and runs out the door, arms moving from side to side as she carries the baseball in front of her. The light shines on my face and the little girl turns around, throwing the ball with so little force that it lands feet away from me. I run forward, grab it, and toss the ball back, missing her entirely. She doubles over and laughs, clutching her sides as she chases after my mediocre toss.

Her smile was so big and full of life. I couldn't help but smile back. Her diagnosis was untreatable, not due to its complexity but to social and economic factors. Most people would shut down, finding every excuse to pity their situation. Yet here she was, exuberant and behaving as though life itself was trickling along like normal. As people in today's society, opportunity is not equally distributed, but love, laughter, and optimism are. They have no borders, revealing the values we've shared all along.

Lost in the White Dust: Forgetting 9/11 Too Soon

Cailin MacQuarrie

The September 11th Victim Compensation Fund (VCF) has been providing vital funding to victims of the 9/11 terrorist attacks so that they may receive desperately needed healthcare for nearly 20 years, so why is it that all of a sudden funding is becoming an issue? The original Fund was initiated in 2001, and when in 2011 President Obama signed into effect the James Zadroga Health and Compensation Act, the VCF was also relaunched for a period of 5 years. In 2015, the then President recertified the VCF for another 5-year period.

So then, where's the problem? It's 2019, and the Fund is still in effect for nearly 2 more years before we need to worry about re-inciting the Fund, right? The fact is, the Fund isn't a bottomless fountain of money, and it reaches its limit at $7.3 billion. With roughly $5 billion already doled out (to 21,000 claimants), that leaves a disturbingly inadequate amount of money to cover an estimated 19,000 claimants that haven't yet been addressed, as well as whomever files a claim within the next 2 years.

An obvious problem is already present: there isn't enough money to take care of every claimant seeking the security provided by the Fund. However, there is another, even more grave problem which is only just beginning to rear its ugly head. When the Towers collapsed nearly 20 years ago, an innumerable amount of people, first responders and civilians alike, inhaled the infamous white dust which was an amalgam of toxic particles including lead and asbestos. While many health effects were immediately evident, the World Trade Center cough among them, an even more ominous wave of obstacles is upon us. According to John Feal, a first responder and 9/11 advocate, "more people will die from illnesses related to 9/11 than from the terrorist attack at the World Trade Center", a harsh reality that we are only now beginning to face. Those toxic particles have had ample time to incubate, transforming a historical atrocity into an emerging, modern day public health dilemma.

The combination of the already dwindling source of funding and the rapidly increasing rates of 9/11-related cancer only mean one thing: innocent people are going to continue to suffer and more lives are going to be lost as a result of the events that took place on a single day two decades ago. Those who are ignorant and uninformed will falsely state that because the Fund hasn't run out yet, it isn't a pressing issue. Anyone who states this is gravely incorrect. In fact, the need to secure more funding has never been more urgent than it is right now. The clearly unsatisfactory $2.8 billion left to be divvied up has resulted in cuts in compensation to 9/11 victims by as much as 70% in an effort to stretch the remaining balance of the fund as thin as possible. Rupa Bhattacharyya, the administrator for VCF, stated that as of October 2018, 8,000 more claims had been made with the fund. At a monetary dead end, Bhattacharyya has exhausted every option and is left with no choice but to cut the compensation given to the victims of this catastrophe.

I implore you, why should anything less than 100% compensation be acceptable, especially to those first-responders who gave their 100% on that day? Why should those who were lucky enough to narrowly cheat death have to face this reincarnated horror, and why should they have to face it without support? Just as the white plume of dust and debris billowed out across lower Manhattan, expanding and tainting everything it touched, so has 9/11-related disease. We were in a better position with the white dust, though, for it was visible and palpable, and we could collect it and study it. Disease, however, is invisible and intangible, and it's had 20 years to grow and spread and get stronger. The truth is, we have no idea what health effects we're truly dealing with, and we won't know until people come seeking help. The question is, will those with the power to right this wrong allocate more money to the Victim Compensation Fund so that we can help these human beings when they do?


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Damon Tweedy Critical Review

Cailin MacQuarrie

During Dr. Damon Tweedy's Park Street Lecture, which centered on his novel Black Man in a White Coat: A Doctor's Reflections on Race and Medicine, he widened the scope of the discussion to something much broader than just the issue of race and medicine: the systematic issue of ongoing racism in our society. Tweedy skillfully argued that the racially-centered issues he describes in his book, and the problematic racially-motivated instances in our society as a whole, are merely indicators of a much more deeply entrenched problem of racism in our society, one that we continue to combat half a century after the end of the Jim Crow Era.

Tweedy began the evening's conversation by not focusing on his own personal experiences with race and medicine, but by examining the larger issue at hand. Specifically, Tweedy discussed the semi-recent surfacing of Governor Ralph Northam's racist 1984 Eastern Virginia Medical School yearbook photos. The reasons that these photos are problematic were immediately evident and numerous, yet there were still those who raised the notion that, "He's a good person having a bad day." Tweedy introduced the point that when racist events surrounding an individual emerge, the debate always ensues of whether or not the person is a "bad person" because of the other seemingly "good things" the person has done. The question of whether all of the "good things" the person has done can be overshadowed by a single event arises. Tweedy correctly states that while it's imperative that we condemn these incidences for what they are, hateful, racist acts, we also can't be so focused on the individual in these situations. Rather, we must turn our attention to the larger problem which is that a number of people obviously saw these photos, didn't see anything wrong with them, and approved them to be published. This example perfectly encapsulates Tweedy's argument that we can't just view individual instances of racism as isolated events, but that we must look at racism as a whole and the group that it stems from.

Throughout his lecture, Tweedy emphasized the power of our words, urging the audience of students, faculty, and socially conscious citizens to continue the narrative he incited with his novel and lecture, imploring us to have real conversations with real people. Undoubtedly, Tweedy came to Boston College to spark conversation, stating "For me to come here and talk and for that to be the end of it is no good." From this single conversation that was had during the Park Street Lecture, he wanted innumerable different conversations to emerge and for all of us to be more aware. He called on us to recognize how much weight our words, written or spoken, carry, citing the specific example of the inherent bias that's present in medical charting. "Your words have tremendous power", he stated, referencing how often he's come across unnecessary and racially-focused bits of information in patients' medical charts, which can skew the way the patient is perceived, potentially impact the care given, maintain "durable stereotypes", and sustain the false narrative that "being black is a risk factor for getting sick". Tweedy was correctly vehement in how critical it is that this changes. He generously shared with us some of his more awkward experiences as a doctor, in which he was made to feel like the "other" and served as "reminders of being different". One instance in particular that he described was when he was working the night shift and his patient told him that she was worried about him working the night shift and having to get up in the morning to go to basketball practice. Tweedy jokingly stated that the woman thought he was "a basketball player moonlighting as a doctor" and that he was "Clark Kent except with a white coat and a basketball jersey underneath." While his delivery was comical, it didn't take away from the fact that assumptions such as the one that Dr. Damon Tweedy is a basketball player and not a physician are problematic and indicative of a systematic issue.

Dr. Tweedy concluded his lecture with a quote from Dr. Martin Luther King Jr.: "If I cannot do great things, I can do small things in a great way." This applies to everybody in Dr. Tweedy's audience, and everybody at Boston College, in that we're all responsible to at least do the small but great thing of continuing the conversation he began. As university students we may feel that we're at the bottom of the totem pole, that we don't have a voice, that we don't have the power to spark change, but Dr. Tweedy assured us that the opposite is true. The fact is that we're in an incredibly unique and privileged position as college students in that we're celebrated for sharing what we think and feel and there are ample opportunities for us to do so. We applaud Dr. Damon Tweedy for bringing to light that all it takes for us to incite change is to recognize the power of our words, and then use them to start a new narrative.

"Placebo and Nocebo" Effct - Explaining the Divergent Impacts of HIV/AIDS Initiatives

Derek Xu

As of 2017 36.9 million people were living with Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS) worldwide, and today the disease remains one of the most notorious global health challenges. Developments in therapeutics and diagnostic testing have allowed for HIV/AIDS to be managed without significant consequence. As of 2017, only 75% of people living with the disease were aware of their HIV status and only 59% of those living with HIV (21.7 million people) had access to antiretroviral therapy (ART). The resilience of this disease in the face of global health initiatives can be explained by two distinct but interconnected conundrums: the negligence of HIV/AIDS's pervasive impact on all sectors of life (personal, career, and societal), and the unintended consequences of punitive societal condemnation. Neither of these challenges directly relate to the biological efficacy of medicinal treatments, but pose challenges to providing patients with the treatments that they require.

Many of the policies and plans today implemented by public health programs revolve not around the physiological efficacy of treatments, but instead around the relationship between the HIV/AIDS afflicted population and the healthcare system as a whole. Many of the policies approach the epidemic in a way similar to how a garden is "pruned and weeded;" following the logic that improving the health of the HIV/AIDS positive population will limit the spread of the disease. The goal is to provide prophylactic measures and symptomatic treatments which, when managed well, could slowly improve the overall health of the community. While many of these approaches have demonstrated success, some end up facilitating more harm than good.

This harm is often psychological rather than physiological, allowing fear and to invade and pervade throughout the HIV/AIDS population. Severe poverty, punitive condemnation by both society and the legislature, and mental health issues within the HIV/AIDS community are fueled by the failure of global outreach programs. The concept of the "Placebo Effect" and its lesser-known but implicitly more notorious counterpart, the "Nocebo Effect", characterize how certain global healthcare approaches are being carried out and provides a lens into how future initiatives should be orientated.

The concept of the "Placebo vs Nocebo Effect" is unique in its suggestion that something which is "physically inert" could have a significant impact on the health of individuals living with HIV/AIDS without directly interacting with the biological mechanisms of disease. The "Nocebo Effect" posits that a patient's negative expectations can lead to an increase in and intensification of the negative aspects of their treatment, both perceived and physiological. Such a phenomenon can be attributed to the concept of "somatization," the tendency to experience and communicate psychological distress in the form of somatic symptoms. With regards to HIV/AIDS, a patient's seemingly morbid prognosis and resulting decrease in quality of life can be partially attributed to the extremely negative and harmful stereotypes associated with the disease, particularly its presence in a plethora of other controversial issues. The severity of the HIV/AIDS epidemic as a whole stems from the unproductive and erroneous world view on the issue and resulting erroneous public health policies, not the prevalence and transmission of the disease itself.

Many of the concerns of issues living with HIV/AIDS, such as fear of stigmatization and loss of "health integrity," are psychological and societal in nature, encouraging a global health emphasis on issues beyond the biology of the disease. It is important, however, that the global health community avoid unfairly de-emphasizing the physiological concerns surrounding HIV/AIDS maintenance. This could lead to a misrepresentation of HIV/AIDS in which it appears that treatment "success" is simply due to improving the appearance of the epidemic, while doing nothing to actually alleviate the symptoms of patients. Initiatives into both outreach and self- reflection need to refine these two juxtaposed issues with regards to future research/treatment, political, and public perceptions.

In December 2004, the leading Ugandan newspaper published a headline proclaiming that "Flawed Uganda AIDS Research Misleads World." This report recapitulated the revelations posed by Associated Press reporter John Solomon, who claimed that a Kampala-based study, which evaluated the prevention of mother-to-child HIV transmission, "may have underreported thousands of severe reactions, including deaths" due to in part by the study drug, nevirapine. The collective Ugandan and American researchers involved in the study, identified as HIVNET 12, decried the "unfair" stories with anger. In their eyes, the press release threatened to undermine one of the most promising HIV-prevention strategies available to protect newborns in low-income countries.

For example, the recent rise of "postcolonial technoscience theory" seeks to destabilize, or at least challenge, the assumption that Western knowledge is objective, authoritative and universally applicable. Both proponents and opponents of the theory invoked the concept of "ethics" during the HIVNET 12 and AZT African studies scandal. Critics of the studies argued that they were exploitative and treated African patients as "guinea pigs" in the name of science. Defenders of the studies, on the other hand, contended that local scientists approved of the methods, and that the intentions were to improve the care of patients in medically resource-strapped countries. They argued that the imposition of North American and European standards on poor countries constituted "ethical imperialism". This argument, however, can be considered a red herring as critics never questioned the intent of the studies. Instead, their purpose was to explore an issue of morality and disregard for human life. It would be difficult for anyone to justify the utilitarian notion of "sacrificing few to save many." In many cases, the disparities between "first-world" vs "developing" countries in respect to resource access and human research standards encumber efforts to the address the AIDS/HIV epidemic with moral setbacks.

When human rights and the value of human life are ignored in the name progress, the consequences are exploitative studies like that of HIVNET 12 and AZT, in which participants suffer due to experimental design. These scenarios can both be critically analyzed under the Doctrine of Double Effect, a Christian method of exploring the morality of an action that brings about good while also causing serious harm. This doctrine assigns relative value to the different actions at play and stitches together the best narrative out of all of them. The doctrine considers four conditions: 1) The nature-of-the-act condition, in which the action must be either morally good or indifferent, 2) The means-end condition, where the bad effect must not be the means by which one achieves the good effect, 3) The right-intention condition, in that the intention must be purely good, and 4) The proportionality condition, in which the bad effect must not be disproportionate to the good effect. Edmund Tramont, the NIH's AIDS Research Chief, rewrote the HIVNET12 report in a way that affirmed the study's scientific findings while downplaying concerns about the safety and quality of the research, attempting to force the narrative of this research to fit within the four conditions for an acceptable "double effect".

These trials of less effective treatments in poor countries are controversial and troublesome. Conducting research that is useful to "developing" countries often entails testing treatments that, while still helpful, are nonetheless substandard. While the relative low cost of these treatments may ensure more widespread accessibility, they are often less effective or have an increased chance of side effects when compared with treatments provided in wealthier countries like the United States. This brings up a moral dilemma: Is research that is conducted in countries with fewer resources justified in falling short of the standards set in "first world" countries? Given the limited access to resources in these countries, sometimes the only alternative to this lower standard is to not conduct the research at all. This would essentially bar doctors in poor countries from conducting locally relevant research which might save or improve their patients' lives. These debates explore the criteria upon which scientific inquiry is vetted as well as the intractable international inequalities that pervade the scientific landscape.

To sum up and to quote Johanna Crane, "the debate is not merely about 'right' and 'wrong,' but about how science travels, and about how to forge useful and humane scientific knowledge across terrains of difference and inequality." For a supposed leader like HIVNET 012 researcher Francis Mmiro to assert that "what you may call a serious side effect in the Crane 859 US is not a serious side effect in Kampala" is a seriously problematic statement in that it encourages those benefit from such findings and those who seek to conduct further research to use superficial determinations of severity. In order to avoid such ethical missteps, all those involved in scientific and medical research must reflect on the consequences of their actions and work in a way that avoids perpetuating low standards and human mistreatment. For every step of the process there should be reflection and reevaluation to ensure that something beneficial, such as a public healthcare initiative, is oriented solely towards the good while avoiding the bad.

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January 13th, 1990

Jenna Santos

January 13, 1990. It was an icy Saturday night when my dad was a passenger in his cousin Arthur's car. My dad was spending time in Arthur's new apartment after a long syllabus week. You could say he was enjoying the calm before the storm. His could foresee how his life would be bombarded with the struggles of a wintery commute to Chestnut Hill, the complexities of Father McGowan's business statistics course, and the challenge of making time for his girlfriend, Anna, an education student at Salem State. But what was about to happen could have never crossed his mind, for the storm my dad was about to weather was much greater than he could have ever predicted. January 13th would mark the transition from Mike before the accident to Mike after the accident.

Life has the ability to ebb and flow, and it is a part of the human condition to anticipate the fickle and fragile nature of moments that forge a lifetime. As humans, we have a hardcoded reliance that allows us to endure the difficult and unexpected. Like the homeostatic mechanisms that regulate our bodily functions, mentally we know that even when things get tough, they will eventually get better. While this is usually true, it is not always the case: accidents, depression, terminal illness, are just a few of the many things that can throw a wrench in the plans. I think my dad understood the anticipation and the uncertainty of life in a very basic sense.

January 13th, 1990. The call to reach my mom at Loon Mountain. "Judy, Mike was in a very bad accident, Mike's mother is calling for Anna. It is very important that you get down there as soon as possible. Don't tell her what happened, it's too devastating to tell her bluntly, he might not make it by the time you get back."

When the body reaches the lower quartile of the homeostatic range, it is common to break into reservoirs of ions and proteins or use the build-up of some gradient that sums the activation energy to move on to the next stage in a biological mechanism. During survival mode, our body does anything and everything to maintain life. As a response to lower quartileconditions, the body produces a stimulus that activates biological processes that aim for a return to the interquartile range; the normal range. My biochemistry professor, Dr. Folker explains biological processes as a glorified game dominated by probability. Our cells do not have a greater likeness or affinity to one process or another, we cannot personify our cells, but rather, given a set of conditions within a microenvironment, it is likely the cells will respond when conditions are more favorable. Even when the conditions are favorable and the probability of a return to normalcy is likely, there is always that minuet chance that things will not return within their normal range. Murphy's law expresses that if something can go wrong, it will go wrong. Sometimes things just happen that way.

February 8, 1990. "Your fever isn't going away. The doctors don't understand why. You also had a seizure one day during the first week. Your head was badly injured and your body is trying to tell us that. Mom thought it [the seizure] was because of her because she was in to see you when it happened."

When the mind cannot find a logical pathway to make sense of the inexplicable, the mind tends to place blame on itself, or a higher power. Fate is the idea that there is an invisible acting force that has some part in the agency of individual lives. Lia Lee's parents believed that she contracted "the spirit catches you and you fall down" from the slamming of a door. My Vavo thought she induced my dad's seizure because she was in the hospital room. Sometimes when moments in time pile up to the point of incomprehensibility, the mind tends to search for a loophole, an explanation, a meaning behind it all. Sometimes there isn't an explanation. As humans, we have a natural inclination to understand our condition; but sometimes we simply can't.

February 18, 1990. "We are all so happy you are slowly improving. We can't understand why God would let this happen to such a special person. Finally, you are coming back to us, hang in there my darling brother. This is truly a miracle."

In the well-known parable from the Old Testament, the story of Job, Job is a man who loses everything that is dear to him. The story of Job toils with the idea of retributive justice: the concept that good things happen to good people and vice versa. It is so easy to adopt the concept of retributive justice because it seems logical. Until coming to Boston College, I would have agreed with the connection between suffering and retributive justice. What I have come to realize is that to be human means to be limited, ignorant, and finite; we are standing before the mystery, whatever it may be. The question my family asked was, why is God letting Mike suffer? Why did God let Mike fly out of the passenger door? But instead, the question should have been, what is the true meaning of suffering? Before Boston College, I believed that suffering is a direct result of God's will and that God imparts suffering on the wicked. After reading the Bible for myself, I have come to learn a new face to faith and suffering: suffering is the damming condition all finite creatures must face, but faith is the acceptance that suffering is mysterious and blind. I wish my family could have recognized this during the months following my dad's accident. I wish they could recognize this today.

February 28, 1990. "Uncle JoJo would drive me to Lowell at 5 in the morning so I could be with dad before any of his family got there. They were all so angry all the time, fighting with the nurses and doctors, not pushing dad in the right ways. It was frustrating to watch, and I was a fragile shell of a human. One morning I was so out of it, I forgot to wash the shampoo out of my hair and I walked out to the car and Uncle JoJo told me I had white suds everywhere ...I asked Uncle JoJo to go in and talk sports to dad while he was in a coma because I know dad loved sports. Uncle JoJo would tell him all the stats, then I would go in and play his favorite music. Who knows if he could hear any of it."

Andrew Solomon said, "To be creatures who love, we must be creatures who can despair at what we lose." I think about my parents when I read this quote. My mom often talks about "growing up quick". One day her youth completely vanished before she had time to tug on the few remaining strings. My dad's accident, unforeseen and sudden, led my mom to make lots of decisions that were no longer solely about her. When I think of strength and sacrifice, I think of my mom. I could never imagine going through what she endured at 18 years old. I cannot fathom the intensity of my mom's pain when she found out her best friend would never be the same.

My dad is a fully functioning adult with college degrees and unsteady employment. His recovery was truly a miracle. Despite what veneer is exposed to families experiencing the fallout of an accident, or any major life-altering event, there is no sugar coating the before and after version of each person. My mom loved Mike before the accident, and she loves Mike after the accident. They are partly the same Mike, but no one in my family will deny that he's never returned back to who he once was. With the amount of brain damage he sustained, how could he? What they all may fail to notice is their own lack of return to how they once were. Love is powerful; its unconditionality ignites a glimmer of hope that love will always prevail in the darkest of times.

March 25, 1990. "Our long awaited day has finally arrived. You're coming home today. Your memory is improving, so is your speech. The past months have been long and unbearable at times. You are a fighter, Mike. Welcome home!"

March 25, 2017: My 18th birthday. "Jen, do you want a PB&J for lunch?" I respond calmly, "No thanks Dad, I'm allergic to peanuts." I've been allergic to peanuts for 18 years.

So where does this leave me? Looking back on a story that only became mine 9 years after it began is a difficult feat. How can I do justice to a narrative, with so many perspectives, so much pain, but yet so much hope and triumph? How do I live a life of my own, when the one I lead is deeply influenced by the events that came before me?

The dynamic answer that continues to change is complex: this narrative is only partly mine, it leaves me at Boston College, on the precipice of the past and the future. Boston College is a place where I am forging my own path, but also walking the same lanes my dad walked when his life was forever changed. I believe F. Scott Fitzgerald could offer some form of hiatus to a narrative currently in action, one unfinished, "Gatsby believed in the green light, the orgastic future that year by year recedes before us. It eluded us then, but that's no matter...So we beat on, boats against the current, borne back ceaselessly into the past."

A Fearful Response: Healthcare Workers and Ebola

Mitchell Lavoie

In 2014, the extremely fatal Ebola virus ravaged through the countries of Sierra Leone, Guinea, and Liberia, killing over 11,000 people and infecting even more. This outbreak led to a significant response mounted by the Centers for Disease Control and Prevention (CDC) of the United States. Many healthcare workers from the United States answered the call to serve and were initially applauded for their heroic actions abroad. They even managed to land a spot in Time Magazine's prestigious Person of the Year issue, honoring all of the Ebola fighters as "the ones who answered the call" ("TIME Person of the Year"). However, this warm U.S. response was not consistent for healthcare workers Dr. Craig Spencer and nurse Kaci Hickox, Ebola workers who spent time in Guinea and Sierra Leone respectively. Instead, they were greeted at America's borders with hostility and utter fear. The media narrative only fueled this fear, further vilifying them. Their image was not one that resembled the other healthcare workers in TIME as the U.S. met their return with hasty public health policy and negative public opinion. These two healthcare workers were presented as the "superspreader" as discussed in Priscilla Wald's Contagious, representing a major characteristic in the outbreak narrative which helped drive the fear. The fear has even deeper roots, though, resulting from previous outbreak narratives of Ebola and hemorrhagic fever, such as Richard Preston's 1994 novel The Hot Zone which, in an effort to find meaning out of an epidemic, only caused mass hysteria and fear (Rosenberg, Quammen). As a result, the initial positive U.S. response towards the Ebola workers in 2014 was replaced by stigma and poor treatment for many of these same individuals .

Healthcare Workers following 2003 SARS outbreak in the U.S. and abroad: Policy and Treatment

To first understand the poor treatment of U.S. healthcare workers after the 2014 Ebola outbreak, specifically that of Dr. Spencer and nurse Kaci Hickox, it is necessary to grasp how the poor treatment they endured, such as the stigma for their work abroad and the stringent policy put in place upon their arrival to the U.S., was not as significant in the SARS outbreak in 2003. Severe acute respiratory syndrome (SARS) is a respiratory illness that is caused by coronavirus and infected people in more than two dozen countries (SARS CDC). In the United States, Canada, and Hong Kong, constant surveillance and quarantine or home isolation for those who contracted SARS was common policy and enacted worldwide (Cetron et al.). Furthermore, in the U.S. the CDC only recommended passive surveillance for those exposed to SARS or whom came from an area of SARS transmission, such as healthcare workers, stating that they should monitor themselves for 10 days and seek out medical care if they become symptomatic (Cetron et al). This was not the case for other nations such as Canada and China, where even if an individual was exposed to SARS, they needed to be isolated in their home. The U.S. followed the CDC recommendation however, and opted for this passive surveillance, as it would not impede on an individual's "due process" or civil liberties (Cetron et al). What is more is that in the United States, travel advisories and health alerts were created for flights traveling to and from places where SARS transmission was present, recommending 10-day personal surveillance for healthcare workers and others after they returned. This response from the United States was much more mild compared to what was set in motion in China, Canada, and Singapore. In these countries, a much more stringent policy at the borders was put in place, where pre and post travel screenings were mandated, isolating all ill travelers who entered the country. While the screenings may seem warranted, it was the mandatory quarantine of healthy travelers coming from areas of high SARS transmission that had damaging effects (Cetron et al). It is through the comparison to these policies that makes evident that healthcare workers returning to the United States were treated far better than those in other countries, with a nation that rightfully respected the civil liberties of individuals by not throwing healthy individuals into quarantine.

SARS, however, was an outbreak somewhat different than the Ebola outbreak in West Africa in 2014. SARS traveled rapidly and many healthcare workers became patients because of the work they did (Singer et al). This characteristic is not consistent with the Ebola outbreak in 2014. Much of this can be attributed to the more stringent usage of personal protective equipment in West Africa for Ebola versus relatively less intense equipment in nations like Canada and China, with gloves and an N95 respirator masks for SARS (Cetron et al). Due to the large volume of SARS patients in hospitals, many healthcare officials became infected. Even in the wake of their infection or the potential to be infected, about 80% of healthcare workers noted that they did not feel stigmatized because of their work in a hospital (YaMei et al) (Nickell et al). This was different than that for Ebola, where both healthcare workers Dr. Spencer and Kaci Hickox received overwhelming stigma in the form of negative public opinion. This begs the question of why stigma was not as prevalent in a terrifying outbreak such as SARS as compared to the 2014 Ebola outbreak.

Why Ebola in 2014 was different: the effect of the outbreak narrative

The outbreak narrative, as Wald describes it, "begins with an emerging infection, follows it through the global networks of contact, and ends with its containment." This is only a piece of the outbreak narrative formula, but it is one that is very evident in the outbreak narratives that have helped foster the fear that characterized the 2014 Ebola outbreak in West Africa (Quammen). Furthermore, it is typical for the outbreak narrative to cast Africa as "an epidemiological ground zero, otherworldly, a primordial state out of which anything might arise" (Wald 32). Africa is often where an infection emerges and can then travel through the global networks of contact. As Wald also notes, "an infection may be endemic to an impoverished area, but it emerges when it appears-or threatens to appear-in a metropolitan center of the North," clearly demonstrating that the fear that comes out of Ebola and its transmission takes full form when it comes out of Africa and slowly travels elsewhere (34). This traveling is represented as the dots and lines on epidemiological maps that are indicative of an outbreak narrative, bringing "fear and reassurance" to many (Wald 37). The fear that emerges from these maps comes from these representations of the spreading infection through modes of transportation, and out of Africa to places like the United States (Wald 37).

Richard Preston's 1994 The Hot Zone gripped the attention of many, painting a horrifying picture of Ebola and hemorrhagic fever while capturing Wald's outbreak narrative formula, especially the out of Africa component. At the start of the novel, character Charles Monet contracts a hemorrhagic fever and boards a plane in an effort to seek medical attention elsewhere. His infection was a "hot virus from the rainforest" which "lives within a twenty-four-hour plane flight from every city on Earth" (Preston 11). In his outbreak narrative, theinfection did in fact emerge from Africa and was traveling through the global networks of contact. In addition, Preston notes that "all of earth's cities are connected by a web of airline routes. The web is a network. Once a virus hits the net, it can shoot anywhere in a day - Paris, Tokyo, New York, Los Angeles, wherever planes can fly. Charles Monet and the life form inside him had entered the net" (12). The potential path of the viruspaints Monet as a "super spreader" of disease that could infect thousands of people, encouraging a fear of infection (Wald). The fear emanating from the threat of these "networks" spreading Ebola globally incited mass fearHowever, the fear that emanated around Ebola from The Hot Zone had other sources as well.

The fear of transmission of Ebola came more specifically from the lack of knowledge of how it actually was transmitted. In an interview with The New York Times in the wake of the 2014 epidemic, Preston associates part of the fear of Ebola from his book with the limited knowledge of the disease and its transmission back in 1994. "Initially, there were a lot of fears that Ebola could mutate to become the airborne Andromeda strain that would wipe us all out," stated Preston, also noting that "With what we know now about the genetic code of the virus, Ebola does not travel through the air in airborne form and is very unlikely to mutate that way" (Alter). The fear of airborne transmissionwas enough to cause mass panic, even if the claims were proven wrong years later. That initial fear persisted, even horror novel writer Stephen King called it "one of the most horrifying things I've ever read" (Alter). Preston also notes that what is "terrifying about Ebola" is that "Ebola is invisible. It's a monster without a face. With the science that we have now, we can perceive Ebola as being not one thing but as a swarm, and the swarm is moving through the human population and expanding its numbers. It's the nonhuman other that all human beings are contending with in many different ways" (Alter). This non-human aspectof Ebola and its monster-like ravaging abilities are a significant factor of the fear that emanated from it.

Preston's vivid descriptions of Ebola's effects on the human body brought this monster to life, yet it was his parallel of the origins of Ebola with HIV that made Ebola a more imminent threat to many Americans. In his book, Preston describesMonet's plane ride on his way to Nairobi in vivid detail. According to Preston "you see that his lips are smeared with something slippery and red, mixed with black specks, as if he has been chewing coffee grounds. His eyes are the color of rubies, and his face is an expressionless mass of bruises… the muscles of his face froop. The connective tissue in his face is dissolving, and his face appears to hang from the underlying bone, as if the face is detaching itself from the skull" (17-18). Monet liquified and lost all personality from a damaged brain due to the virus, andthis dehumanization establishes the horror of the infection (Wald 35). Charles Rosenberg in his book Explaining Epidemics focuses on the framing of disease. He mentions that "disease does not exist as a social phenomenon until we agree that it does - until it is named," and in this case, characterized (306). Preston's description of the horrifying features is enough to incite fear, only to heighten the sense when he compares it with HIV's breadth of transmission as well as its Africanorigins. Preston brought the roots of HIV to the foot of Mount Elgon where Monet is thought to have contracted the virus in Kenya. Preston notes that HIV "does not travel easily from person to person" however, which makes the easy transmission of a virus like Ebola, and its "volatile and rapid" nature much more frightening (Wald 35). The dehumanizing nature of the disease, along with its African origins, similar to that of HIV, created the path for fear to emanate out of Africa, just like the disease itself. It was Wald, however, that characterized this phenomenon, "Preston's depiction of its effects reads like a description of the ravages of HIV on fast forward," potentially as widespread and equally as fearful (Wald 35).

The Narratives of Fear: Dr. Craig Spencer

The progression of the outbreak narrative as described by Wald corresponds closely to the specific narratives that emerged around the U.S. healthcare workers. In the typical outbreak narrative, there are the global networks of contact that a disease can infiltrate, which is represented quite well by the specific narrative of Dr. Craig

Spencer. Dr. Spencer was a U.S. healthcare worker stationed in Guinea to help fight Ebola in 2014. In October of 2014, he returned to New York City where he attempted to assimilate back into everyday life. He stated that "I slept long hours and had a hard time connecting with old friends" after returning from Guinea (Spencer). On October 23, 2014 Dr. Spencer became New York's first Ebola patient, reporting a high fever and testing positive for the disease. Overnight, a heroic fighter of disease was cast as a pariah.

People fear the unknown, and Ebola, a once foreign disease now on U.S. soil, suddenly became close to home for many Americans. In the days leading up to his quarantine, Dr. Spencer took the subway, went out to eat, and even went bowling in New York City in an effort to maintain normalcy. However, after his quarantine, these actions were widely criticized, as people all across New York City, and even the country, feared that Ebola could be transmitted as easily as the common cold. According to Rosenberg, "An epidemic is almost by definition frightening; numbers of unfortunates are seized with grave illness, one after another exhibiting similarly alarming and alarmingly similar symptoms" (293). As a healthcare worker returning from a place of epidemic and subsequently contracting the disease, the fear of epidemic was much more potent. Due to this fear, Spencer's seemingly insignificant actions in New York City prior to his hospitalization were condemned and he was deemed a "fraud," among other things (Spencer). Even Donald Trump criticized Dr. Spencer, tweeting "The Ebola doctor who just flew to N.Y. from West Africa and went on the subway, bowling and dining is a very SELFISH man-should have known," which only gave into hysteria that ensued (Jula et al). The potential for him to become a "super spreader" and infect all of New York City, similar to the narrative legacies of "Typhoid Mary" and "Patient Zero," regarding the AIDS epidemic, certainly contributed to this public fear, with the public condemnations only adding fuel to the fire (Wald, 70).

After Dr. Spencer fell sick public fear led to negative opinion regarding Spencer's actions preceding his hospitalization, directly leading to the stigma against him. Specifically, the lack of scientific knowledge among politicians and the public alike aided in the manifestation of fear. Spencer chided those who encouraged this stigma, stating that "after my diagnosis, the media and politicians could have educated the public about Ebola. Instead, they spent hours retracing my steps through New York and debating whether Ebola can be transmitted through a bowling ball" (Spencer). The fear that Ebola could have been transmitted so easily was a major player in the fear of the disease. What is more is that in the typical outbreak narrative, as defined by Wald, as well as in Spencer's specific case, the carrier and potential spreader have a social responsibility, a "measure of citizenship," to be cognizant of their space in society, as the "bodily interconnectedness" in the city of New York could easily transmit a disease through shared spaces, such as a bowling alley (Wald 70). Spencer's violation of this social contract cast him as a villain and outcast for not upholding his responsibility as a citizen and subsequently threatening the health of many (Wald 70). His work in Guinea was nowhere to be mentioned, but his Sunday afternoon at the bowling alley was all over the news. This fear further exacerbated negative public opinion through outlandish media headlines such as "Ebola: the ISIS of Biological Agents?", and "Nurses in safety gear got Ebola, why wouldn't you?" (Spencer). This only contributed more to Spencer being treated as a pariah as well as the general public fear towards other Ebola aid workers. Scientifically however, it was nearly impossible for Spencer to have transmitted the disease when he was afebrile (Spencer, Ebola CDC). Yet this knowledge stayed out of the news which left fear to be the only tangible thought seen by the public.

In this moment of uncertainty and fear, public officials instituted policy to further isolate the heroic fighters of disease, using Dr. Spencer's narrative to influence public health measures. At the time of Dr. Spencer's quarantine, Governors from New York and New Jersey gave into public fear and took advantage of it to enforce their executive power and implemented strict 21-day quarantine laws even if said worker wore their personal protective equipment (PPE) when in contact with Ebola patients in West Africa (Csebestyen). These policies were not based in scientific fact, ignoring the CDC's recommendation of personal monitoring or monitoring by public health officials, stating nothing of a mandated quarantine recommendation ("Public Health Professionals Gateway"). This then begs the question of why such stringent public policy was instituted. It is important to note the proximity of Dr. Spencer's quarantine, late October 2014, with the impending midterm elections in early November. Spencer eluded to politicians utilizing public fear to institute strict quarantine laws, stating that "We all lose when we allow irrational fear, fueled in part by prime-time ratings and political expediency, to supersede pragmatic public health preparedness" (Spencer). Furthermore, after the midterm elections on November 4, 2014, Spencer noted that to politicians "the ebola epidemic ended," bringing light to the lack of public attention after the elections (Spencer). Rosenberg also clearly characterizes these actions through his work in framing disease, stating that "perception implies explanation. Certainly this is the case during epidemics, when fear and anxiety create an imperative need for understanding and thus reassurance" (294). Politicians played off of the opportunity to reassure the public that they were safe. Therefore, the institution of such policy was a tangible way in which fear aided in the elections of politicians at the expense of healthcare workers.

The Narratives of Fear: Nurse Kaci Hickox

Dr. Spencer's narrative however is not the only one that clearly demonstrates such a negative response towards Ebola healthcare workers. Nurse Kaci Hickox is one such worker who experienced negative response upon reentry to the U.S., although she was plagued with a different kind of fear and response than Dr. Spencer. Hickox is a nurse from Maine who worked in Sierra Leone fighting Ebola in 2014 under the auspices of Doctors Without Borders, around the same time that Dr. Spencer was stationed in Guinea. The medical team lead for a 35-bed Ebola case management center, she worked 12 to 14 hour shifts while wearing the cumbersome PPE that theoretically isolates the aid worker from the fatal infection ("TIME Person of The Year"). She returned to Newark International Airport on October 24, 2014, and was met by a frenzy of officials asking her questions regarding her stay in West Africa. Eventually, after six hours of being in an airport, she ran a high temperature with a forehead scan thermometer, which often yields falsely high readings for people under stress (Miles). She was subsequently ordered into a quarantine tent in a New Jersey hospital by Governor Chris Christie, where she tested asymptomatic and negative for the disease but remained for three days (Miles). In New Jersey, Kaci Hickox was seen as a potential superspreader and through the utilization of public fear, the governor relegated her to dehumanizing and unwarranted quarantine in an apparent political showing of strength and supposed commitment to the protection of his state, "reassuring" the public but also working towards his midterm election agenda (Miles 2).

Governor Chris Christie, however, was not the only official to utilize public fear of Hickox's potential infection to stigmatize and quarantine her. In fact, when Hickox was released to Maine under secret convoy, governor Paul LePage ordered her to be quarantined in her home for 21 days, threatening any defiance with a court order. To further exacerbate the situation, Maine's CDC released their newly revised Ebola policy, which stated that for "A traveler who did come into direct contact with or treat Ebola- positive individuals and who is not currently exhibiting symptoms of disease… we will work collaboratively with the affected individual to establish quarantine of the individual in his or her home for 21 days after the last possible exposure to Ebola" (Miles). The policy also mentioned the protection of public safety through an "abundance of caution," of which they will use when a "healthcare worker who came into contact with Ebola-positive individuals returns soon from New Jersey" (Miles 1). This policy was tailor made to Ms. Hickox, as seen in the blatant referral to her return from New Jersey. Priscilla Wald points that there is a "conflict arising from the state's obligation to safeguard both civil liberties and public health and well being" (70). The civil liberties of Hickox, she claimed, were violated and the mandatory quarantine policies in Maine, New Jersey, and New York are a flagrant utilization of public fear to implement hasty public policy that is not based in scientific fact or evidence but for political expediency at the expense of an individual's "personal civil rights" (Miles) ("Matt Lauer and US Nurse Kaci Hickox").

What is different about Hickox's situation, as opposed to Spencer's, was that she did not in fact have Ebola. Her subsequent quarantine was enabled through a lack of coordination and a sense of public fear that surrounded the Ebola epidemic. The Maine court system that rejected Governor LePage's court order recognized this public fear and the lack of scientific evidence for taking an "abundance of caution," stating that "the court is fully aware of the misconception, misinformation, bad science, and bad information being spread from shore to shore in our country with respect to Ebola. The court is fully aware that people are acting out of fear and this fear is not entirely rational" (Miles 2). While this fear is present, it is due to misconceptions of Ebola itself and how it is transmitted, such as that it can be transmitted if someone is asymptomatic of the disease. Rosenberg again clearly articulates the motives of these political leaders, stating "Disease is… an occasion for and potential legitimation of public policy, an aspect of social role and individual identity" (305). An opportunity was seen to institute policy that would reassure constituents all in the name of politics (Miles, Rosenberg 294). The institution of such policy, however, simultaneously removed her "individual identity" in the quarantine. The transmission misconception played directly into Hickox's quarantine, casting her as a hazard and human vector, like the age old tales of Typhoid Mary and Patient Zero, as mentioned by Wald, and like Charles Monet in Preston's book (Wald 70).

Public fear led to even more criticism and poor treatment of Hickox as well as other healthcare workers. In an interview with Kaci Hickox in 2014, Today show host Matt Lauer interrupted the villainized Hickox and pointed out that days before her arrival, Dr. Craig Spencer had been walking around New York with Ebola. He proceeded to ask her "do you understand what that did to the psyche of public officials in what is a metropolis of 9 million people?" ("Matt Lauer and US Nurse Kaci Hickox"). This irrational fear from Dr. Spencer's initial quarantine and diagnosis was enough to justify the quarantine of Hickox (Miles). The workers were consequently seen as public dissidents not caring about, as Wald called it, their "social responsibility" or measure of "citizenship" to quarantine themselves. Furthermore, in this interview Hickox stated that "if you are going to put a policy like that in place [21 day quarantine] that impedes on my civil rights, then you need to have the administrative details worked out before you detain me in an airport" ("Matt Lauer and US Nurse Kaci Hickox"). Hickox's disenfranchisement further demonstrates the negative response and stigma toward an individual who worked so hard to save many lives abroad. Wald's outbreak narrative construction is again poignant, stating that "conflict arising from the state's obligation to safeguard both civil liberties and public health and well being" (70). In this case, the state infringed on her civil liberties in an effort to institute public policy that would alienate her and cast her as a health hazard for "political expediency" (Miles).

Change in Policy Since 2014

Kaci Hickox did not stand for this abhorrent treatment however and in 2017 filed a lawsuit against Governor Chris Christie for his violation of her civil liberties (Santora). She initially sought compensation in the amount

of $250,000 but dropped the suit under the agreement to create a 'Bill of Rights' for "individuals subject to possible quarantine or isolation in New Jersey" and this "sets a model for other states to replicate" (Harrison). This policy sparked by Hickox achieves many things. First, Quarantine or isolation will be imposed only when "medically and epidemiologically necessary to prevent the spread of Ebola," however they must be carried out in the "least restrictive means to prevent the spread of Ebola," and after less restrictive measures have been explored (Harrison). Finally, there must be a comprehensive order documenting information such as the legal authority under which the order is issued, the medical basis, and a statement explaining the right to hold an attorney and appeal (Harrison). While this is only one policy change since the disastrous display in 2014, it is a step in the right direction, one that "upholds the values of liberty and due process" (Santora).

Conclusion and Implications

The debilitating quarantine policy implemented by politicians during the Ebola outbreak in 2014 was a novel response to epidemic among healthcare workers in the United States. In the 2003 SARS outbreak, there was a clear line in the sand that the United States would not cross, the violation of civil liberties. It would not institute the mandatory quarantine of healthy travelers from areas of high SARS transmission, something that other nations like China did (Cetron et al). The U.S. instead followed CDC recommendation and aided on the side of not potentially violating any civil liberties or "due process" of aid workers (Cetron et al). The novelty of the U.S. response in 2014 then came not from precedent, but from public fear and the utilization of this fear by politicians.

Dr. Craig Spencer and Kaci Hickox's heroic actions were met with intense and turbulent public fear that they would be Wald's "superspreader" that brought Ebola back to the United States. While in Africa, their heroic actions saved many, but at home, they were health hazards that belonged no where near the American public. Not all outbreak narratives are the same however, and Hickox was plagued with pronounced neglect of civil liberties while Spencer was shamed for his actions. As a result of their hard work and efforts, governors from New York, New Jersey, and Maine instituted strict 21-day home quarantine laws that went against CDC recommendation of simple self monitoring, the practice that Dr. Spencer underwent when he reported himself to the board of health (Spencer). Fear drove a response that resulted in stigma and negative public opinion which culminated in public health policies that could, as Hickox mentions, "have a chilling effect" on future generations of workers in their willingness to fight disease ("Matt Lauer and US Nurse Kaci Hickox"). These mandatory quarantine laws essentially cast returning aid workers as pariahs and hazards to greater public health. Spencer argues that this negative response will have debilitating effects on the decision of future aid workers to help fight Ebola and other epidemics (Spencer).

Public health policy was therefore informed by the politics of fear and as Spencer mentions "if the U.S. public policy response undermined efforts to send more volunteers to West Africa, and thus allowed the outbreak to continue longer than it might have, we would all be culpable" (Spencer). This could undermine the ability to fight disease effectively and the response of the United States could have put many lives at stake (Spencer). The outbreak narratives of Dr. Spencer and Kaci Hickox, and the detrimental effects that resulted, demonstrate a need for pragmatic public health policy to inhibit a similar situation from happening again. The fear of being quarantined however is not as strong as the call to serve as can be seen with Hickox's belief in systemic quarantine policy change. Ms. Hickox did not take the money in an effort to effect real change that would protect the civil liberties of other heroic and asymptomatic healthcare workers on their return from fighting Ebola.

While the fear and the U.S. response reduced the humanity of Dr. Spencer and Kaci Hickox to vectors of disease, paralleling the concepts of Wald's outbreak narrative as well as Preston's presentation of Ebola itself as a dehumanizing monster, resulting in a disastrous and harsh quarantine policy, they both stated that they would go back to West Africa to help fight Ebola (Spencer, "Matt Lauer and US Nurse Kaci Hickox"). Through the understanding of the source of fear surrounding Ebola using the outbreak narrative and Preston's novel, as well as the comparison to the SARS outbreak, one can grasp the novelty of U.S. response in 2014 in its neglect for aid workers through the politics of fear. However, Hickox's commitment to the betterment of quarantine policy and rights of healthcare workers is apparent through her institution and work towards a "bill of rights" for those quarantined. Furthermore, even though it was discovered that politicians utilized this fear for their own gain, individuals like Hickox and Dr. Spencer will not be stopped, and will continue their efforts in West Africa and beyond. The call to serve and the commitment to the oppressed may outshine the narratives and politics of fear.

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Healthcare Systems: A Comparative Analysis of Healthcare in Ireland, Northern Ireland, and Scotland

Matthew Davis

All citizens of the countries of Ireland, Northern Ireland, and Scotland are entitled to receive public health care. However, with different systems set in place in each country, the treatments and processes involving this care fluctuate. Even citizens in the same country are often victims of issues with their respective healthcare systems. Irishmen and women who live on Inis Oirr, the smallest of the three Aran Islands – part of the greater Republic of Ireland – must suffer through great difficulties in times of medical needs. A representative from the island, while claiming that their health services are "on par" with that of the mainland, also admitted that elders and pregnant women need to travel to the mainland – with all expenses paid out of their own pocket – just to have access to this mainland healthcare. Similarly, a study involving the Scottish Social Attitudes Survey also feel that emergency coverage is significantly weaker in rural areas, once more putting at-risk groups such as the elderly in an unsafe situation. Despite these policies containing vast differences between each country and severe disparities between groups and locations within the countries, healthcare is still seen as essential within the major nations of the British Isles. This paper will go further into detail concerning the specific healthcare systems of Ireland, Northern Ireland, and Scotland, and will explore how these differences affect the citizens of each respective country.

Overview of healthcare and its importance

There are many different types of healthcare systems that countries choose to utilize. While each country creates their own variation, forming the vast differentiation of policies, there are four basic models which all healthcare is based on the Beveridge, Bismarck, National Health Insurance, and Out-of-Pocket Model. The Beveridge model, which is observed in states such as Great Britain and Spain, provides medical services to their citizens through governmental taxes. In theory, most hospitals are owned by the government. The Bismarck model, seen in Germany, France, and Japan, for example, utilizes an insurance system with privatized hospitals. The National Health Insurance model, primarily found in Canada and South Korea, uses private-sector providers with government funding. The Out-of-Pocket model is seen in less developed countries. In this system, if one can afford medical care, they will purchase it. If they cannot afford the proper medical attention, they will be forced into staying sick or dying.

Despite there being only four basic models, when it comes to healthcare policy nearly every country has distinct variations. Jacob S. Hacker, an expert of healthcare policy from Yale University, explains that the form of these policies "depends on the market structures, policy ideas, interest group strategies, and public views." In other words, each nation has its own history, political ideologies, and economic abilities. These differences in the political institutions of each nation "influences…the types of interests and ideas…and the kinds of policies that countries adopt." This is how a country like the United States can have a healthcare system with aspects from all four models; or how two nations utilizing the same model can have vastly different policies.

Ireland - The Present

The Republic of Ireland has historically had a healthcare system based off of the Beveridge model, similar to that of Great Britain and the United Kingdom. As the Beveridge model suggests, the majority of medical and emergency facilities are owned and ran by the government, although there also is a large private sector in Ireland as well. The Irish National Health Service (Irish NHS) was launched on January 1, 2005, after the Health Act of 2004. In this act, the Health Service Executive (HSE) was formed to utilize "the resources available to it in the most beneficial, effective, and efficient manner to improve, promote, and protect the health and welfare of the public." While 100% of Irish citizens are covered under the HSE, coverage is only completely free for approximately 37% of the population. Funding for this system comes from a tax-bracket-like-system known as the "Universal Social Charge." In this system, 2% of all employee's wages are deducted "for the first 10,000 euros a year, 4% on the next 6,000 euros, and 7% above that." Despite these taxes taken out with the intention of paying for medical coverage, many people still have to pay minor fees if they choose to not have private health insurance – 50 euros for a doctor's visit, 100 euros for an emergency room visit, etc. According to Brian Barrett, Head of the Economic, Rural, and Community Development Section of the Galway County Council, Ireland spends approximately 13 to 14 billion euros a year on the HSE and is a major reason public service is the largest employer in the country – totaling up to over 100,000 employees.

The Past

In 2011, the Irish healthcare system attempted to undergo extreme and radical alterations, with the ultimate goal of turning it away from the UK's form of Beveridge, and into more of a "Bismarckian" system. This new system, the Universal Health Insurance (UHI), was led into formation by the center-right Fine Gael party – the party of senator Neale Richmond – with assistance from the center-left Labour Party. The goal of UHI was to switch Ireland from a two-tier system – where the Health Act of 2004 ultimately gave more or better treatment and care to wealthier individuals who could afford more – into a one-tiered system "built around the patient, rewarding performance from doctors and hospitals." Based on the Dutch healthcare system, UHI was advocated for in the government from 2011 to 2016. It pushed for equal access to healthcare based on medical needs rather than income, a standard insurance package for social and health services, universal general practitioner care, and more. Fine Gael, the party responsible for UHI, has the main goal of "ensuring that everyone has timely access to the health service and that the service is significantly better," as shared through documentation from Senator Richmond. Despite this optimistic goal and it being the preferred option for over 5 years in the government, the idea was scrapped due to its cost of implementation being too drastic.

The Future

Since the primary care system found in the HSE is a largely mistrusted system among the citizens of the Republic of Ireland, the government is still trying new ways to create a one-tiered system, where they also can fix many of the problems that cause this lack of trust. The newest method is called "Sláintecare." Sláintecare, similar to UHI, is a plan for a "universal, single-tier public health service where care is provided on the basis of health rather than ability to pay." This ten year plan is the first time in Ireland all of the major parties have come to a political consensus on a health reform plan. Not only will Sláintecare accomplish all of the positives that the Fine Gael set out in the UHI, but it will also provide services such as maximum waiting times guaranteed, earlier and better access to mental health services and a new and improved HSE board. A recent snag in this process has revealed, however, that this ten year process could take longer, mainly due to concerns over cost. The Taoiseach, Leo Varadkar, explains how difficult it is to start new and expensive healthcare programs:

> While we accept the Sláintecare report, at the moment health spending is already running about 8.6 per cent ahead of last year, so we're already spending a lot of additional money on healthcare, and when you are increasing spending by 8.6 per cent per year already, it is difficult to find even more money on top of that to implement other programmes.

While Varadkar and the rest of the Irish government are in support of Sláintecare, the need of additional money – especially with the looming economic concern regarding Brexit – is going to significantly slow down the process of reform, prolonging cheaper, and more attainable healthcare for the people of Ireland. This elongated process brings with it a reason for skepticism and the large sense of distrust that the Irish citizens feel towards their primary care system.

The Positive and Negative Effects for the Irish People

The most obvious and significant positive effect of the current Irish healthcare system run under the HSE for the citizens is the fact that 100% of the population is covered by public healthcare. The only slight exception to this "universal healthcare system" is that students from outside of the EU who come to Ireland to study are not eligible. Instead of having access to the public systems, they must purchase their own private insurance – such as GeoBlue. There are also a multitude of private or other specialized public services that individuals can sign up for, such as the Drugs Payment Scheme, which lowers the costs of prescription drugs one has to pay each month, the Long-Term Illness Scheme, which helps pay for care if one has any long-term diseases or conditions, and the Maternity and Infant Care Scheme, which helps with the costs of having a child or children.

Despite these positives that Irishmen and women can enjoy, their healthcare system also brings along many negatives that they must overcome. Most notably, Ireland ranked worst out of all European countries for accessibility for their patients. In other words, on average, Irish hospitals have the most amount of people waiting for treatment, for the longest amount of time. According to official documentation from Senator Richmond, while most citizens "receive a hospital appointment or operation in six months or less…far too many people wait too long." Two groups, the Irish Nurses and Midwives Organisation, and the Irish Medical Organisation, blame this accommodation issue on staffing, however, as previously stated, that is hard to fathom as the health system employs over 100,000 workers. The Irish government is attempting to combat this issue through its new programs, such as Sláintecare. Yet as of right now the accommodation limitations very strongly set back citizens in need of care, surgeries, or general medical attention. The Irish healthcare system also does not offer its citizens access to "no-fault malpractice insurance, a right to a second appointment, or online booking of appointments or e-prescriptions." These issues, along with many others such as a limited range of specialized services available, and prevention of misbehavior towards alcohol and physical activity all amount to the Irish citizens looking towards more expensive routes for their needs, or as is the case for many, suffering through them instead.

Northern Ireland

Compared to the Republic of Ireland, Northern Ireland has much more of a Beveridge model healthcare system, as it is part of the United Kingdom. Just like the Beveridge model states, the majority of healthcare in Northern Ireland is from the public sector. The Northern Irish healthcare system is often referred to as the National Health Services, as it is in the rest of the United Kingdom and Ireland as well. More accurately, though, its proper name is Health and Social Care (HSC) – as it is one of only two countries in the United Kingdom that also provides social care. It is fully funded by the Northern Ireland Executive, through the Department of Health, in Stormont, Belfast. However, since Northern Ireland is a part of the United Kingdom, taxes from any citizen of the UK can be charged for it. The Public Health Agency is responsible for regulating all health and social care laws and policies. It was created in 2009 in an attempt to reform the health systems in the area. The key functions of this agency are improving health and social wellbeing, protecting the health of the people of Northern Ireland, creating and commissioning policy, and research. It is also their purpose, and the purpose of the HSC in general, to try and reduce, and ultimately eliminate health inequalities.

The Positive and Negative Effects for the Northern Irish People

The attempt to monitor and combat against these inequalities, as well as bringing in other social care is a significant positive to the citizens of Northern Ireland. The Institute of Public Health in Ireland defines health inequalities as "preventable and unjust differences in health status experienced by certain population groups." Since the United Kingdom is a Beveridge system – with all of its people qualifying for free public healthcare – social status, gender, and other characteristics of the like do not play as much of a role in the treatment of medical issues or conditions. However, Northern Ireland has had a significant social inequality issue as well, mainly due to many poor economic and environmental working and living conditions. These conditions have worsened over the past couple of decades due to the troubles and fighting between nationalists and loyalists, and will have difficulties recovering naturally due to the economic implications that Brexit could bring on the area of Northern Ireland. These inequalities often lead to dangerous health behaviors such as "smoking, obesity, lack of physical activity, poor nutrition, [and] abuse of drugs and alcohol." Therefore, the HSC created programs such as "Investing for Health," in 2002, the "Health and Social Care Inequalities Monitoring System," the "Family Nurse Partnership" for teenage mothers, and "Roots of Empathy" to reduce levels of stress and aggression in school children. The HSC also created educative strategies to encourage positive physical behavior, such as safe alcohol consumption, reducing the amount of smoking, increasing the levels of breastfeeding and encouraging physical activity, and many more. Even though health inequalities still are prevalent in Northern Ireland, the citizens have many opportunities through the HSC to get help and proper social care.

Despite this attempt at lessening social inequalities, there are many negatives that Northern Irish individuals need to overcome when it comes to their healthcare. First, similar to their neighbors of the south, Northern Ireland struggles greatly with accessibility for their patients. Northern Ireland has, by far, the highest average percentage of patients out of all of the countries in the United Kingdom, despite spending the second most on health services. Even with receiving reviews stating the need for a major healthcare transformation, specifically when it comes to accommodation, it has remained essentially stagnant, with only minor changes being made. One cause for this difficulty in alteration is that, as explained, the HSC is funded and run through the Northern Ireland Executive, which currently has been shut down for over two years. All backing and policy are now coming from Westminster, under the United Kingdom's ruling, and decisions for the well-being of the Northern Irish citizens are often no longer put as a main priority.

Another issue that the Northern Irish healthcare system does not adequately cover is mental health, despite being one of the only countries in the United Kingdom to cover social health. Mental health, specifically post-traumatic stress disorder, or PTSD, is very common in Northern Ireland. Loyalist Jim Watt explained that both loyalists and nationalists are struggling with severe mental health issues due to their involvement in the fighting between one another. Close to 30% of Northern Irish citizens have admitted to having long-term mental illnesses, and 25% more people with mental health issues than England and Scotland. The HSC, even though there is a great need for it, does minimal to help those who have suffered greatly and have mental diseases because of it.

Scotland

Scotland's healthcare system is very similar to Northern Ireland, since it is also a member of the United Kingdom. It is likewise run under an NHS system, however as it is for all UK countries, it is its own separate NHS. It became devolved in 1999 and since then was operated under its own management and administration. It is funded through Westminster through a block grant, and spends approximately $12 billion a year on healthcare. Similar to Northern Ireland, Scotland is the only other country to also cover social care in its policies. While the vast majority of citizens utilize the public healthcare system, around 8.5% use some other form of private insurance, mainly for the use of dental or fertility care. Scotland also has a new organization, the Healthcare Improvement Scotland, or HIS, which is responsible for reviewing and examining the healthcare facilities of the country.

The Positive and Negative Effects for the Scottish People

According to the Scottish Social Attitudes Survey, the vast majority of Scots feel that their healthcare is generally good and acts with them in mind. Sixty-one percent of people surveyed in 2013 felt satisfied with the Scottish NHS, and eighty-five percent said their general care was good or excellent. Scotland is also the only country in the United Kingdom that provides free and personal nursing care to any citizen over the age of 65 that needs it. This care can help with services such as personal hygiene, maintaining proper food and diet, any personal assistance, and more, and the payment will be covered through the public healthcare system.

Despite a very high approval rating from its users, the Scottish healthcare system still brings many negative effects onto its people. As stated earlier, many Scottish citizens feel that there is an inequality in healthcare coverage between those in cities versus those in more rural areas. The same survey that shows high approval also shows that 79% polled believe the level of access to healthcare should be equal throughout the entire country, no matter the location. The majority of the people living in these rural areas are disproportionately elderly – 65 years old and up. They often need more or specialized care that they cannot always travel for. Even in Ireland where access to care is limited in places like the Aran Islands, they still manage to offer a "highly effective offshore medical corps of doctors and nurses."

It is often difficult for the Scottish government to put new organizations or programs into action, however, due to their funding system. Every year Scotland is granted a lump sum from Westminster to spend on all of their public and social services, healthcare included. If Westminster decides to cut that funding, Scotland has no choice but to cut certain programs, and healthcare is often the one to take the hit. While Scotland does have a say, as they have representatives in Parliament as well as organizations such as the British-Irish Council which help to exchange information, discuss issues, and come up with the best endeavors on how to solve problems and reach agreements, it is ultimately up to the United Kingdom's decision. This is just one issue that comes with a country not having self-rule.

Conclusion

Healthcare, no matter the type or level, is important and beneficial to the citizens of a country. Whether it be for limiting the price of surgery, simplifying the process of getting pharmaceuticals, or shortening the waiting period, proper health and medical care are becoming seen as a right more than a privilege – especially in the three countries of Ireland, Northern Ireland, and Scotland. However, proper coverage does not stop at the border of a country. Specifically, in the British Isles, citizens travel from one nation to another for specialized procedures and treatment. Senator Richmond of the Irish political party Fine Gael and expert of European Affairs explains that "healthcare in Ireland is largely operated on an all island basis, and you would regularly see patients travel to the UK and indeed from the UK to Ireland for [specialized] care." While there are many difficulties with the healthcare systems of the countries, Irishmen of both North and South and Scotsmen should ultimately feel grateful for their right to public healthcare.

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And, Finally, I cried.

Ivelisse Mandato

The bus lurched forward and my stomach churned. No – this couldn’t be happening. I took my medication. I know I took it. I think I took it… Did I take it? As we continued to roll through the early morning traffic, I came to a conclusion – I didn’t take it. My eyes began to dart around the bus, wondering if anyone could see my panic. This couldn’t be happening. I ripped the window open and the frigid, winter air flooded in. “The other people on the bus will understand,” I hoped. With my head halfway out the window, fighting for fresh air, I thought “You can’t do this. You CANNOT do this. You are already the girl with cancer.” My knuckles whitened as my hands gripped the seat. Eyes tightly shut, I begged myself to hold on just a little bit longer. Thirty minutes. Twenty minutes. My hands grew clammy and the nausea moved its way up to my throat, at first slowly creeping, but now all at once. Fifteen minutes. Ten minutes. Tears pricked my eyes as I realized I wouldn’t make it. I was so close.

The bus pulled up to a red light and I flew out of my seat. My feet slammed heavily onto the floor as I raced to the front of the bus and searched for the words I learned in Spanish class. The words that I hoped would overcome the language barrier. The woman driving looked at me with widened eyes, first startled, then concerned. My face burned. I couldn’t meet her gaze as I choked out, “Basura? Por favor! Lo siento.” She frantically searched the front of the bus before thrusting a plastic bag into my arms. I spent the walk back to my seat staring at the bag. It was fuzzy – a white blob. I blinked back the tears. “You can’t vomit AND cry on this bus. You just can’t.” As the bus moved forward, I shoved my face into the bag. Bile was the only thing that came up. I hadn’t eaten breakfast yet, there was nothing else to throw up. I spent the rest of the bus ride dry heaving into the bag. Too afraid to meet the eyes of the other girls, I stared at the cloudy, yellow liquid until the end of the ride. Breathing in and out, I felt the embarrassment seep in. I was acutely aware of the discomfort I was bringing everyone else by forcing them to listen to my retching. I didn’t need to look up - I could already see their faces. It was the same face that I saw when I walked past them in the hallway. Eyes darted from me to the wall. Back to me. Back to the wall. Should they say something to me? Should they ignore me? The emotion on their faces always the same. Pity – always apparent. The pity that I never wanted. The pity that I hated. I shot up as the bus stopped and the doors began to open. Brushing the shoulders of the other girls, I stared at the ground as I briskly walked from the bus to the building. I watched as the black plastic flooring became gray concrete, which quickly turned into tile. I was inside. Clutching the plastic bag, I made a beeline to the bathroom, I locked myself into a stall, and – finally – I cried.

GLASSES

Matthew Davis

Quinn was always a troublemaker at camp. Some counselors say that she didn't get enough attention at home, so she would act out more frequently here. So when another one of Quinn's crying fits came along one Friday afternoon, only an hour or so before everyone was ready to leave, people were just brushing her off.

I was sitting at the front desk, doing my administrative work when I heard a commotion coming from the back room. It was a first-year counselor – I never got her name, but she was always nice to me and good with the kids – holding Quinn's hand. They were walking to the nurse's office, which is right next to the front desk. The counselor said they were outside on the playground when Quinn started to feel dizzy, talking about her grandfather who died over 6 years ago. The little girl just stood there, hysterically crying, on the verge of hyperventilating. She pulled away her hand the counselor was holding to wipe her nose, rubbing the lenses of her pink unicorn sunglasses with her left hand.

At the sign of crying, everyone's heads turned and worry filled their eyes. But then they noticed the tears came from the eyes of little Quinn, the same eyes who cried 4 out of the 5 days that week. "What is it NOW, Quinn?", they would say. "Stop crying, Quinn," "Just. Calm. Down, Quinn." Usually the attention of adults even noticing her crying was enough to quiet the girl. But with the day being nearly over, even this was too much to attempt to quiet Quinn who often, literally, cried wolf.

Yet I knew this was more than just one of her usual attention-seeking stunts. I saw this before. I knew what she needed. And it was not being told to calm down.

I got out from behind the desk, squatted down to her eye level, and encouraged her to keep breathing. "Inhale deeply. Exhale slowly." I told her that I was there with her, there for her, telling her that whatever she saw, heard, or thought of, was okay. It will all be okay.

In the face of that little 7-year-old, I saw the face of a boy. Slightly chubby. Thin glasses. Older than I'd like to admit. I shook that thought out of my head and continued my conversation with Quinn.

I told her how much I liked her pink "shades," as she called them. She started to smile slightly, out of the left corner of her mouth. Within minutes, the nice counselor was taking a now calm, albeit red-faced Quinn back outside to the other kids.

I went back to my desk, adjusted my own glasses, and finished my work.

Changing Tides

Sydney Shugrue

2005

Every summer since I was born, my family and I have spent a few weeks during the summer at my grandparents' house in Avalon, New Jersey. It never truly feels like summer until we arrive down the shore and I feel the salty breeze rustle my hair. This summer is no different, and the moment we arrive I rush up the stairs and into the bedroom, quickly throwing on my bathing suit. I run back outside where my mother spends 10 minutes covering every inch of my body with sunscreen. After she has completed her thorough job, my cousins and I hop on our bikes and speed down the street to the sandy path that will lead us to the promised land: the beach.

After we drop our bikes, we carefully select the perfect spot on the beach: not too far back, but not too close to the ocean that our things will get wet during high tide. We then take off towards the water, making a game out of who will dive into the freezing ocean first. After we are all completely soaked and have adjusted to the cold water, my grandpa decides to join us in the ocean. He slowly wades in, attempting to jump over the waves pretending they are monsters that will eat his feet. We all burst into laughter and run back to the shore to join him in his game. Once we have successfully avoided all the monsters, we float out a bit deeper, my grandpa keeping a constant eye on us. While my cousins and brother body surf the waves, I stand with my grandpa. I watch him as the warm sun reflects off the blue ocean, illuminating his face. He looks so young, energy and life glistening in his eyes. When he sees me looking at him, he grabs a piece of seaweed from the ocean and pretends to eat it.

"It is full of protein and super delicious! Here, you should try a piece!" my grandpa says, laughing and handing me another piece of seaweed.

I laugh the way most children do, a laugh that comes from deep down, a laugh so hard it makes my stomach hurt. Regardless, I continue to laugh, smiling up at my grandfather.

2010

Another year, another summer down at the shore. Since we are older now, we aren't spending as many weeks at my grandparents' house, but I am happy with any amount of time I can get in my favorite place on earth. We pull up into the driveway, the rocks crunching underneath our tires. My grandma opens the door and stands on the landing, smiling down at us as we hop out of the car. As I always do, I rush up the stairs and into the house, stopping to take in the smell of fresh linen and lavender. Instead of heading straight to the beach, I make my way upstairs to say hello to my grandpa. He sits in his old grey reclining chair, watching golf on the television. He doesn't hear me come up the stairs, and he only notices me after I have called for him a third time. I bend down and give him a hug and a kiss on the cheek. He is thinner than the last time I saw him and his face is more wrinkled. I ask him if he is going to come to the beach with us, and he says yes.

After an hour, I have fully unpacked all my summer clothes and have put on my new bathing suit. This time I have put on my own sunscreen, using quite a bit less than my mother would like; that way I can get a good tan. I run upstairs to see if my grandpa is ready to go.

"Hey grandpa, are you ready?"

"Ready for what?" He asks, looking puzzled.

"Ready to go to the beach, remember? You said you were going to come with,"

"Oh, okay," he replies, less enthusiastically.

He then goes to stand up, bracing his arms on the sides of the chair to push himself up. The first time he tries to stand, his arms give out and he plops back down into his chair. The second time, he is able to get up, but it takes a bit more effort. After he has changed, we make our way to the beach, I on my bike, and my grandpa being driven to the entrance by my grandma. We finally arrive on the warm sand, seashells poking up here and there. My grandpa sets up his chair while I throw my things on the ground and prepare to take off towards the ocean. I wait for my grandpa to join, but when I look back, he has sat down in his chair and pulled out a newspaper.

2015

This year we only get to spend one week down at the shore because my grandparents have decided to start renting the beach house. It makes sense they would want to make some money off of the house, but it still makes me sad that I only get to spend one week in Avalon. We arrive at the house and neither of my grandparents come out to greet us. Instead, they only know we have arrived when we walk up the stairs and into the living room. Both my grandparents are seated in their respective chairs, golf playing softly in the background. My grandpa has thinned out yet again and looks as though he is 85, not 75. I give him a quick kiss on the cheek, and he shakily lifts his arms to give me a soft hug. He goes to stand out of his chair to hug my mother, his daughter, putting his hands on the chair's arms and trying to push himself up. He falls back into his chair, and when he tries a second time, he is still unable to get up.

"Here grandpa, let me help you, these chairs can be difficult to get out of," I say, looping my arm underneath his and slowly pulling him up.

He mumbles a thank you and shuffles over to give my mom a hug and kiss on the cheek. I know there is no way he can get to the beach anymore, let alone walk on the unstable sand, so I go downstairs, put my bathing suit on, and head to the beach alone.

Dinner time rolls around and we all gather at the table to eat. My cousin Ryan, being a pain as usual, decides it would be funny to drink from his glass by tipping it sideways into his mouth. My cousins and I think it is hilarious, and my aunt rolls her eyes. My grandpa, however, is not amused. Out of nowhere, he slams his fist onto the table and says,

"Stop that right now. This is my house and I will not have you behaving that way."

This is the first time I have ever really heard my grandfather yell. When I look at him, his face is red and his hands are quivering. My aunt responds by shouting back at him, and the evening descends into harsh words and more yelling. I excuse myself from the table and make my way to my mom's room, where I find her sitting on the edge of her bed, with tears in her eyes.

"He never used to be like that" she says, wiping away a tear. I pull her into a hug, and we both try to ignore the commotion upstairs.

2018

We are going to the shore again this year, perhaps the last time we will be here for a while. It is harder to make time to go to Avalon during the summer between all our jobs and school. This year we arrive before my grandparents do, so we get the house to ourselves for a little while. I find myself being happy that we have some time in the house before my grandparents get here, because once they arrive it will be a lot more stressful.

Eventually, my grandparents arrive at the house and my brother and I help carry their luggage into the house. We all make our way upstairs, my grandpa being the last one to come up. On the last step, he loses his footing and falls, making a hard thud on the hardwood floor. My brother runs over and helps lift my grandpa to his feet. He quietly thanks my brother, and then shuffles over to his chair as if nothing happened. My mother and grandmother leave the room, probably going to talk about how my grandpa needs more help than my grandma can provide. My brother retreats downstairs, probably to go play video games. I want to follow him, because I no longer know what to talk to my grandpa about. Most of the stories he tells are figments of his imagination, remnants of a life he wishes he had. We sit in silence for a few minutes until my grandpa finally says,

"So, when am I going to get to see my grandkids again?"

"Which grandkids?" I ask.

"Your children," he says, looking puzzled.

"Grandpa, I am Sydney, your granddaughter. My mom
 is your daughter, Liz, remember?"

"Oh, right," he says, and turns his gaze back towards to window.

I look at him, sitting in his chair, the warm outside light highlighting his frail body. His face is wrinkled and he looks tired and worn down by life. His hands rest in his lap, and I can see them shaking. After a little while, he turns his face and looks at me. His eyes are empty and lack the light that used to shine within. He turns his attention back to the golf, and I close my eyes, trying to remember how his smile could once light up an entire room.

At Home

Carol Dickinson

She died peacefully at home. These are words we use so often when talking about death. They offer comfort, something positive to lean into when the pain is immediate and the loss incomprehensible. To know that our loved one was at home, surrounded by the familiar smell their own room, in their favorite pajamas, and in the company of those they held closest provides a small, yet anchoring, sense of peace as we face the challenge of saying a final good-bye.

When a brain tumor began bleeding uncontrollably, there was only one thing remaining to do: to go home. My mom's journey with cancer was beginning to seem hopeful. While we knew that there was no cure for advanced melanoma, a new treatment promised more time. She was walking and reading again, and plans for the holidays and family vacations replaced conversations about infusions and physical therapy. It seemed like we were just learning how to live again, despite terminal illness. But the journey came to a halt a mere four months after her diagnosis. A headache sent her to the hospital, where scans revealed the problematic bleeding. Over the next 24 hours, her responsiveness diminished rapidly. By the time I got off the plane and to the hospital, she could no longer talk or open her eyes. Arm raises turned to hand squeezes, then small muscle twitches, then nothing.

The decision was obvious. We knew what she wanted. There would be no ventilators or feeding tubes. No futile efforts of emergency surgery or full-brain radiation. After the obligatory meeting with the on-call physician and social worker in the Oncology ICU, the paper-work was finalized and hospice care was arranged. When my dad leaned over and whispered in her ear, "Sweetie, I'm taking you home," she lifted her arm for a final time to hug him around the neck. Our decision was affirmed and we knew it was time. Led by a medical transport van, we all headed home.

Nobody ever tells you what exactly is required to die peacefully at home. There was no warning that a hospital bed may not fit through the interior doorways of our house, or that the hospice nurse would only visit once a day. I had no idea how difficult it would be to administer medicine to someone who was unable to swallow or that a two-hour medication schedule meant I would not sleep for days.

When we arrived home, the transport service situated my mother while I met with the hospice nurse assigned to oversee my mom's care. In 20 minutes, I received a crash-course in nursing. She explained the uses of and dosages of 13 different medications that I was to administer as needed and made me acutely aware that any confusion or mistake could lead to a lethal dose. My only objective was to minimize any pain. But how would I know if she was in pain? There were no words, no movements, no hints. When I asked, the nurse ominously raised an eyebrow and said, "You'll know."

I wanted to run. I had walked through the necessary motions and held it together all day, but this was too much. I frantically tried to absorb every word the nurse said, but the sudden understanding that my family would never look the same again devoured my processing capabilities. She threw out a cloud of cold, clinical symptoms. Terminal fever. Terminal agitation. Dyspnea. Skin mottling. My throat tightened in a mix of anger and panic. To her, the woman in the next room was one of many patients. Another person of no consequence that she was to watch die over the next few days. But that was my mother. I wanted the nurse out of our home immediately but was also completely terrified for the moment she would leave.

She finally stopped and took a breath. Looking up from her clipboard for the first time, she said to me, “Remember, you are giving her a gift.”

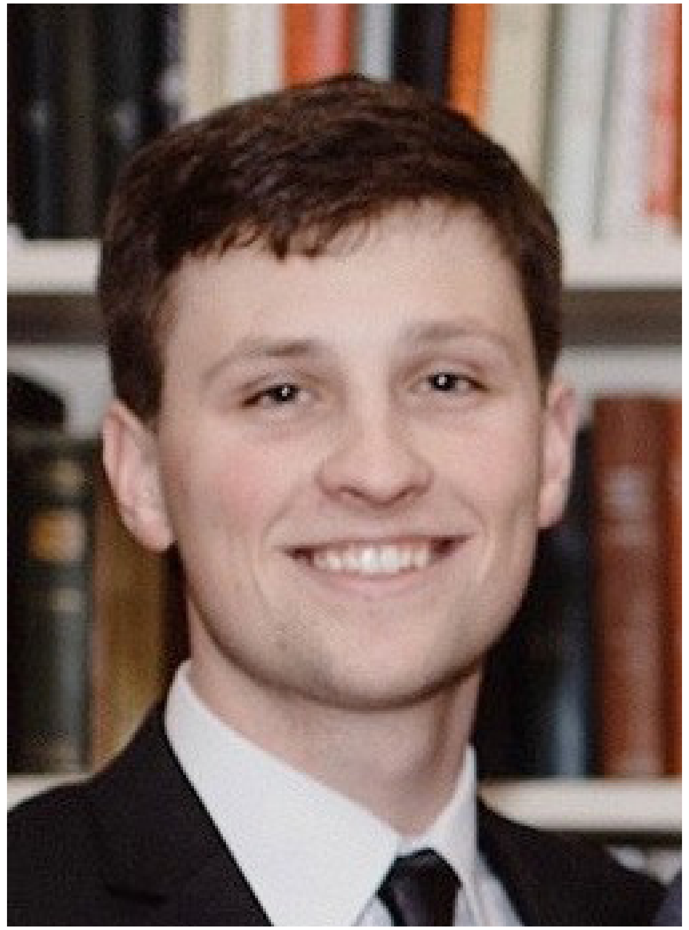
Sometimes I question if the next four days actually ever happened. When you are waiting for someone you love to die, the passage of time becomes an unfamiliar thing. There is nothing more to hope for and nothing more to be done. All you can do is wait in the strange in-between. Between the desire to hold on and the readiness to let go. Between dread and anticipation. Between life and death.

I occupied myself with the tasks associated with my mom’s care. I wanted to do a good job even though I knew that it would be of little consequence. I had a constant awareness that the worst and best that could happen were, strangely, the exact same thing and precisely what we were waiting for. I grew numb to the high numbers on the thermometer that once caused alarm. Changing compresses that turned warm minutes after being placed her forehead gave me a sense of purpose. I passed minutes by counting respirations, panicking anytime they exceed 26 of fell below 12. I never was able to control the fear that engulfed my whole body every time I approached the door to my mom’s room. Every day, when a nurse visited I unsuccessfully fought the urge to ask the same question: How much time is left? I don’t know if I asked out of fear or a need for assurance that this wouldn’t last forever. Either way, there was never an answer.

The final moment, the one I had anticipated with dread and fear, was probably the easiest of the entire four-day period. It was just the two of us, and I knew, well before the second hand on the clock confirmed it, that it had been her last breath. There was no gasp or vision of spiritual ascension, but somehow, I knew. There was peace, for both of us. The days to follow would be tiresome and painful, just as the days before, but in that moment, all pain was gone.

I now understand that gift that the hospice nurse mentioned. Dying at home is not easy. It requires immense love and sacrifice. Love to overcome fear and dread. To open the door each time despite not knowing what awaits on the other side, and to provide care when it is entirely hopeless. And sacrifice to surrender to the painful unknowns. To forgo happy final memories for ones of helplessness and confusion, and to bear witness to the entire progression of your own loss. But in the end, there is peace at home. And that peace is a gift, one we both give and receive.

In Loving Memory of Patrick Gregorek



Remembering Him Through Words

By Alexander Gardiner

As you know, Boston College has lost a dear member of our community. Last Sunday, March 24, God called Patrick Gregorek home. Pat was my friend and roommate. This has been the hardest week of my life but knowing Pat for 3 of his nearly 22 years has truly been a blessing. He was incredibly considerate and purposeful with the most gentle and loving soul. Whenever I would return from practice, he would unfailing ask me how VIP is going, wondering about our songs and choreo, begging me reveal our secret Showdown theme. Well, Pat, this year's theme is about love and family, supporting each other through the good times and the hard. It's about remembering our loved ones and knowing that even if they aren't with us anymore, they never leave us. And so tonight, I dance for you, Pat; VIP dedicates our set to you. I bet the seats are pretty good from Heaven, and I hope you enjoy the show.

By Alexandra Moran

I met Pat the second day of our freshman year. I was immediately drawn to Pat and we became fast friends in our shared theology class, sitting next to each other and sticking together during class field trips. Pat would always ask the most thoughtful questions and I found his continual pondering of small and large things alike to be so fascinating. He had the best sense of humor and we'd often just make eye contact and start smiling. I have so many beautiful, joyful moments with Pat, of lunches and conversations, singing with him every Wednesday and Sunday with LAG, and just hanging out laughing. He was so loved by so many people. His smile and kindness and curiosity touched so many. His presence in my life and especially in the LAG community will be so deeply missed. I'm struggling with this feeling of incompleteness, with sitting in rehearsal and in mass and knowing that it's not right or complete because Pat isn't there. But despite the grief and sadness, somehow I know that Pat is eternally with us. Pat will forever remain in my heart as one of the most beautiful friendships of my life.

CORDUROY, BLUE

MATTHEW DAVIS

In Memory of Patrick J. Gregorek

He always had a way.

Had a way to make you think.

He was so inquisitive
Always searching for answers
Seeking explanations
Not settling for anything less than truth.

He was so attentive
Listening to every note ring throughout the air
Reading every lyric as they fly across the room
Proving with his eyes that he cares.

He was so strong
Fighting a war without enlisting any soldiers
not wanting to spill anyone else's blood.

Had a way to stand out.

He was loud and proud.
Not caring if he may have been wrong
Standing tall in his navy blazer
Looking for no one else's approval.

He was funny in the most serious way.
Searching for a laugh both for and from him
Grinning from ear to ear
Spreading his smile like a disease.

He was so bright
Shining the path forward so others could see
in the darkness that he walked through.

He always had a way.

He still does.

He will find his answers and finally understand the truth.

He will sing along to every lyric hitting the perfect note.

He will put down his weapon and put on his jacket and
laugh and smile until we do again.

He is our light.

By Professor Amy Boesky, PhD

How does literature help us engage with loss? “About suffering, they were never wrong, the old masters,” W.H. Auden writes in a poem called “Musee des Beaux Arts,” noting the way artists capture both the obduracy of grief and its eruption in the ordinary, the day-to-day. Literature gives grief both outlet and shape. The traditional elegy, with its movement from lament to consolation, helped give expression to the “stages of grief” long before Elizabeth Kubler-Ross wrote her well-known book on that subject. To my mind, there is something about the shape and structure of elegy that is tremendously important to those of us who grieve the loss of a loved one. While “eulogy” lauds the attributes of the individual who has died, “elegy” has its deepest roots in song and ritual, in recognizing both the permanence of loss and what the poet Mary Jo Bang (You Were You Are Elegy) calls “the ineffable sense of continuance.” Scholars of medical humanities and narrative medicine recognize that these organizing frames help us both to remember and to heal. To give shape to loss in art or literature is a way of beginning to order what is profoundly disordering, a re-membering that is intrinsically important as we resume our shared work of life.

By Professor Sara Moorman, PhD

Three weeks after my baby brother’s college graduation, my grandma called my mom.

“I just wanted to let you know that I don’t feel well this morning, and I’m going to the hospital.”

Everything was wrong. Kidneys, lungs, cancer everywhere. Her doctor offered treatment.

“Thank you, doctor, but no.” And she was discharged to wait.

I had a trip planned to Scotland the next week.

“Go. I’ll be fine. GO!”

While I was gone, she stopped walking. Eating. Responding. But she breathed evenly.

Landed at Logan, called my mom. My mom entered the bedroom and said, “She’s back.”

By morning, my grandma had left.

Mary Rosenson Moorman, 1918-2012

By Professor Anne Elezabeth Pluto, PhD

Poetry has always been a force in my life. An echo, a special way to count time, a memory recorder. Before I started first grade my father bought me my first poetry book. He was a man who loved words and could joke in the several languages he spoke. He was man of abundant imagination and perspective. He died at the age of 91 from painful cancer – that had miraculously disappeared for 17 years; my mother – his deep love – died 8 years later at the age of 92. My response to the events of their illnesses and deaths was to write a series of poems which later became a book : Benign Protection (Cervena Barva Press – 2016). The writing process gave space for memory and grief. I would surround myself with talismans – small things that belonged to them, as if to call their ghosts back to me, to feel what I had lost, to let them know they were loved and missed.

I have been to Samarqand

For my father

Two years ago
May now as you made yourself
ready for death I wanted to
remain, relieve her of her duty
and be a good daughter.
You sent me home
to die with her
alone.

I have been to Samarqand
that final time
a journey by water
the dream geography more full
than life, the mosque, the church
the covered women singing
the Stations of the Cross
the goblin boat to take me back
by morning
I travel by train, north and walk
to the park, it's hot and burning
to see the icons at the Met
to look into the eyes of each
and every opalescent Virgin
in the house of the father
she guides the souls in comfort to Samarra.
Her eyes
follow me, at home

I present you a gift
war traveler
who prayed
at every house of the father
St. Sophia's in Kiev,
the Friday Mosque of Tashkent,
the Bucharian Synagogue on Sepyornaya Street
the tomb of the Prophet Daniel where his stolen
bones grow the stops along the bloody way
in Iran, Iraq, in Syria
then Lebanon, in Egypt
and Palestine,
in Bethlehem at the Church of the Nativity
where the Ottoman Turks
had made the doorways four feet high
to keep the wild horsemen out
to Jerusalem
where they meet God as three
a trinity of one almighty
city to destroy the houses of the father

a caravansary on the journey
backwards to Samarra
you put messages in the wall
went into the Holy Sepulcher
and stumbled along the Viva Dolorosa
saw the dome of the rock
where Mohammed rode
a winged stallion to Heaven
across the Mediterranean
in Monte Casino you protected
the mountain
then the monastery
and in Rome
lifted your face to the ceiling
of the Sistine Chapel.

Now hear
the word of God
as the pain goes through
you like hot lead
as your bones move
lengthwise into sleep upon the bed.
I have brought your last book
in prescience and redemption
in secret and in silence
open it, alone, look
study the compassionate
face of Mary
the distant face of Christ
the icons
we cannot escape
imprinted on us since
baptism, I hear you
pray and I pray too
for your life that spanned
the century
let the light hold fast
enter Hagia Sophia
the final house of the father
go then, backwards to Samarra
leave your shoes at the door
see Christ who never was
removed before your destiny
is achieved, explore.

A rise, and go
Vladimir
for the kingdom of Heaven
is upon you.

Since Patrick's passing and the compilation of this journal, we have experienced the loss of another two Boston College students.

Our thoughts, words, and love extend to Alexander Urtula and Saoirse Kennedy Hill.