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MISSION STATEMENT

The Medical Humanities Journal of Boston College seeks to:

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

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EDITORS' NOTE

Over the last three years of our lives, a reverence has grown for the place of writing in medicine. Like many of the students who contribute to this journal, our journey began with an introductory course in medical humanities. What was initially an esoteric pairing of seemingly disparate worlds has since grown into a fundamental harmony of thoughts, providing a framework to consider the interplay between health and human experience. For both of us, there is no medicine without a commitment to the whole individual; there is no medicine without an appreciation for the narratives, vulnerability, and relationships that define our existences.

In many ways, the physician works at the intersection of life's emotive and physiological forces, necessitating a consideration of much more than the disease presented to them. The works in this issue of *The Medical Humanities Journal of Boston College* prove that the role of the physician is multidimensional. Colleen Brady's "What Matters in the End" and Erin Annunziato's "This is What You're Here For" both substantiate the importance of a dynamic patient-provider relationship.

We learn that our evaluations of others have much to do with perception. "Caution: At Your Own Risk," Samantha Ng's beautiful photography series, calls us to focalize life where we would otherwise visualize suffering. Nathalie Lavoie's "Popular Myths" emphasizes the danger of racial and gender stereotypes in medical practice. And Sarah Ramsey's "It is Easy to Forget" shifts the conversation on perception to remind us that disease does not define or diminish a life lived.

"Freedom to Decide" brings forth the contemporary conversation on patient autonomy in end-of-life care, while


"Shackled" and "Uganda's 'Killer Nurse' Destroys Country's Fight Against HIV/AIDS" highlight the continued marginalization of vulnerable populations and make clear that patients' rights are all too often neglected.

In this issue, our first as executive editors, we are fortunate enough to hear from four physicians, each who extends the connection between clinical practice and the humanities—between medicine and writing: Drs. Rita Charon, Danielle Ofri, Perri Klass, and Caleb Gardner. Charon reveals her methodology for uncovering the mysteries of her patients through her writing outlets. Ofri offers writing as a way of seeing that there is always more to consider; there is more to the patient, to the diagnosis, and to the ever-teetering balance between health and illness. Klass elucidates the storytelling process and the ways in which medical training has affected her writing. Gardner shares his personal experience as a medical student, discussing how he often relied on both the sciences and the humanities when one alone did not provide solace or meaning. Each of these contributors reminds us that narrative is a vital part of medicine and not merely an afterthought; for the physician acts as an interpreter to the patient's illness experience as much as a source of clinical expertise.

As always, we are honored and grateful that these authors have shared their work with us. We would like to especially thank the editorial board, our advisors, and our readers as we continue to explore the medical humanities in all their richness and power.

With enduring gratitude,

Russell Simons and Theresa Rager
EDITOR-IN-CHIEF AND MANAGING EDITOR



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M R. ALZHEIMER'S

MATTHEW QUINLAN

I was in eighth grade when my mom first told me there was something wrong with my dad. We didn't know what it was. My mom attributed it to stress, but there was something worse going on. At first, I started looking for signs, anything that could tell me what was going on. But what I didn't know was that I didn't need to look for it. It would find me.

Later that year, my dad was diagnosed with Alzheimer's. Alzheimer's is terminal. Alzheimer's would murder my dad. Not quickly like his dad had been killed, but slowly. Slowly, it would poison his brain. Slowly, it would steal him away from me. Every part of him would disintegrate into dust before we even buried his body.

Alzheimer's is a sadistic psychopath. A serial killer who tortures the minds of the elderly, and occasionally dips into the minds of the youth, to fulfill his sick thirst for blood. For Alzheimer's, it isn't enough to kill his victims. They needed to suffer. Alzheimer's would torture them. Alzheimer's would torment their soul. They needed to be destroyed. Every one of their relationships needed to be smashed, every memory needed to burn, and every will needed to be crushed.

Alzheimer's makes sure that his targets and those around him beg for death. He torments his victims until he becomes like a saint when they finally pass. Alzheimer's kills.

Within months of my dad's diagnosis, Alzheimer's began his work. I laid on the couch next to my dad on a lazy Sunday morning. The TV blared. Meet the Press was on. The day was January 28th, 2009. It would mark the beginning of the end.

A review of Barack Obama's inauguration came on. The analysts were deliberating when my dad broke our silence.

"Did I ever tell you about the time I went to Barack Obama's inauguration? He called me up to stand next to him. I was on the stage when the first African American president was called into the Presidency of the United States."

Exactly a week before, I sat next to my dad and watched the inauguration on the TV.

At first, I thought it was a joke. But the severity and seriousness suggested otherwise. He wasn't kidding. This memory was real to him.

The diagnosis the doctor had made was real. The minor forgetfulness and disorientation was real. My dad was dying.

Tears welled in my eyes, but I buried my face into my dad's shoulder. He wouldn't understand why I was crying. The doctor said about half of Alzheimer's patients never understand they have it. My dad would never know he had Alzheimer's.

For nearly all of high school, it wasn't discussed. No one asked. No one looked. Mental illness is not the type of thing people talk about. The elephant in the room that no one would talk about.

The process of neurodegeneration was taking place. Days would go by and my dad would forget what he wanted to say. Then, he would forget where he was. Then, he would forget who I was. The good days were far and few in between. So much so, that I never wished for a good day. On those days, I felt as tangled as my dad. I felt like Alzheimer's was injecting my brain with his poison. I felt as if all my neural pathways were being tangled and overrun with amyloid beta plaques. On those days, nothing made sense. On those days, I wished they would just end. My brain couldn't make a switch like that. Alzheimer's was holding my dad hostage. He was boasting.

Alzheimer's would dangle my dad right in front of me, daring me to take the bait. I'd clutch on to my dad, but he would rip him away from me again. Alzheimer's did not offer mercy. Instead, he derived pleasure in utter misery. He derived pleasure in seeing one's family and friends as weak as the victims themselves. He derived pleasure in playing with the human soul like an eight year old boy would smash together his playthings and throw them on the ground. When Alzheimer's offered hope, it was because without hope he could not lead you into more despair.

Some days I'd come home, and Alzheimer's was playing a trick on my dad. He'd strap my dad down in his chair and show pictures until they became real in his mind. One day, he refused to leave the house because Alzheimer's had convinced him he was being hunted. Alzheimer's told him he had inherited 500 million dollars. My dad wanted to give it away to charity, but he couldn't leave the house. "The people" would kill him.

On other days, I wouldn't even leave the house and my dad wouldn't recognize me. Alzheimer's would whisper into his ears and cover my dad's eyes until my face and voice no longer made sense to him. My dad would yell, "Get away from me. Where's my son?"

Misplaced guilt would overwhelm me. I was exactly what my dad was looking for but I was unable to give it to him. Why couldn't I help him? I'd try desperately to calm him down. I'd have to leave the room so he'd forget that I was the demon who stole his son.

My dad's life would end with me screaming his name as drool dribbled out of his mouth. His blue eyes vacant and rolling to the back of his head.

Alzheimer's work was done. Within minutes, my dad would forget to breathe.

The man that killed my dad hasn't been caught. A few times before, the investigators thought they'd identified him. He lingers deep in the dark alleys of the mind, always just out of reach. He cowardly hides behind what's most precious to us, to ensure any uncalculated steps lead to self-destruction.

With an aging population, Alzheimer's will continue to take more and more victims. While no time should be wasted in life, plans shouldn't be thrown out altogether. It's easy to disregard Alzheimer's a criminal affecting only those at the end of their lives, but he's a threat for anyone who wants to live. Alzheimer's is not a natural way to die; it's a cold-blooded murder of the mind and body. Dementia is a serious issue that needs no exaggeration, only the truth.

TRAUMA OF MILITARY NURSES

CHARLOTTE CHANG

Introduction

On the wall of the Vietnam Veterans Memorial in Washington D.C., eight of the 58,000 names of those who sacrificed their lives in Vietnam are female, all of whom had fallen as part of the Army Nurse Corps. The stories of nurses are part of the few and easily forgotten amongst the hundreds of thousands that exist from The Vietnam War. War time experiences and post-war experiences of American military nurses in war zones have traditionally been a neglected subject of Post Traumatic Stress Disorder (PTSD) research. In part, the small ratio of females to males serving in the military has resulted in an extremely small sample size for research, and also has made research funding difficult for a demographic of soldiers that seems comparatively insignificant. Females were unable to serve in combat zones until the Korean War, where 500 nurses served as Army and Navy nurses in combat areas. By the Vietnam War, a significant population of over 7,000 female nurses served in combat zones, finally warranting studies of PTSD occurring among nursing and medical personnel veterans. Arguably, military nurses are prone to suffer from PTSD due to their unique experience and role both as nursing professionals and roles in a majority female military corp. However, diagnosis of PTSD is often dependent on the understanding and definition of PTSD relative to its time period. Thus, this paper is divided into three main sections. The first begins with an overview of DSM's evolution in the understanding of PTSD in relation to military nursing, depicting how initial diagnoses and notions of PTSD resulted in minimal

diagnoses of PTSD in nurses in the immediate years following Vietnam. The second part introduces various qualitative post-war studies regarding Vietnam nurse experiences, which were supplemented by first hand memories from nurse veterans to demonstrate the potential, risk, and relevance of PTSD in this particular population. The final section utilizes previous discussions of Vietnam era nurses as a foundation for comparison to 21st century understanding of PTSD and prospective diagnosis in modern military nurses in Afghanistan.

Relationship Between Military Nurses and PTSD

Studies on the relationship between Vietnam nurses and PTSD began in the 1980s, and have spanned research studies and theses over the past three decades. These studies indicate that the evolution in understanding of PTSD has affected the prevalence of PTSD diagnosis to military nurse veterans. Different studies conducted during different historical time periods have shown varying degrees of correlation of PTSD in veteran nurses from Vietnam. A study conducted in the early 1980s by the Department of Military Psychiatry and Walter Reed Army Institute of Research determined that PTSD diagnosis rates for Vietnam veteran nurses was 3.3%, while estimating that the rate of PTSD in civilian Vietnam veterans was somewhere between 18-53%.¹ In this study, PTSD was assessed through past and current difficulties in dealing with Vietnam memories, sleep disturbances, expressing feelings and emotions to others, emotional numbness, concentration,

and dealing with feelings of guilt. This criteria prevented nurses from fulfilling all the standards of PTSD populations. The Department of Military Psychiatry attributed the low PTSD diagnosis rates in veteran nurses in comparison to veterans of other branches to the higher prevalence of social support for nurse veterans during times of warfare. Another interpretation made by military psychologists was that Vietnam nurses experienced less direct danger and exposure to violence, resulting in lower levels of stress reactions leading to PTSD among nurses. Various primary interviews with nurses, however, both confirmed and contradicted these study findings. A significant number of nurses recounted high levels of positive social support while in Vietnam both at their base and in their healthcare teams. While direct exposure to violence was less common to nurses, indirect exposure to violent and destructive aftermath of combat was common. Indirect exposure was an important factor in the development of shell shock in war zones, a characteristic that was often noted among medics in World War II. Despite this existing evidence from WWII, it is interesting to note that the Department of Psychiatry thought that even the 3.3% diagnosis rate was an overestimation of the real proportion of nurses affected with PTSD, noting a lack of resources and the small sample size as confounding variables; had there been a sufficient sample size, they believed that the real proportion would be close to 0.85%.²

This study leads readers to focus on how the diagnosis of PTSD was based upon 1980 DSM-III Post Traumatic Stress Disorder criteria. Among the checklist of diagnostic criteria, the first publication of PTSD specifically required the individual to have experienced an event that was outside the range of usual human experience, and to have demonstrated at least three characteristics associated with

numbed general responsiveness. As many nurses worked at mobile Army surgical hospitals (MASH) and not on the front lines of fire, few nurses in immediate post-Vietnam studies qualified as experiencing an event outside the range of usual human experience. Their experiences were indirectly associated to the horrors faced by the soldiers, thus not fulfilling DSM-III's criteria³; in contrast, these indirect experiences would qualify as a source of PTSD in today's DSM-V's understanding of PTSD. Additionally, few nurses grew unresponsive to their occupational duties, one of the necessary diagnostic criteria for PTSD, particularly due to the military capacity of their job. In a story recounted from Lorraine Boudreau, she expressed feeling increasingly depressed over the course of her tour, finally approaching the chief nurse in a desperate crying request for a different assignment or to be sent home. The colonel replied, "We'll have none of that, Captain. No, you will not be reassigned. You were specifically chosen for this particular position."⁴ Thus, she could not and was not allowed to, even if she did have PTSD, demonstrate any signs of her symptoms, especially in her role as a military nurse. In fact, many nurses in Vietnam coped with their trauma and depression by suppressing emotional expression, and working even harder by serving more patients, by means of detaching themselves from the patients at hand. In this sense, obvious and outward expression of PTSD was uncommon, and that in itself made the diagnosis of PTSD by the DSM-III standard very difficult and challenging.

Contrary to the previous study, a second qualitative study conducted in 1994 found that PTSD was highly prevalent among veteran nurses, serving as additional evidence that PTSD diagnosis is relatively frequent.⁵ Although a quantitative analysis of Vietnam-era nurses was statistically insignificant because of the small sample size studied,

many qualitative indicators of PTSD were acknowledged. Nurses in Vietnam showed frequent and recurring nightmares, as well as alcohol problems and ineffective coping mechanisms. Feelings of responsibility for the death of another, denial of emotions, inadequate preparation for Vietnam, and sexual harassment all contributed as factors to the development of PTSD symptoms. Due to lack of preparation for Vietnam and the close degree of relationships between nurses and casualties, the study determined that nurses had a high likelihood of developing PTSD. By the last decade of the 20th century, Vietnam-era nurses were acknowledged as a population with potentially high risk for PTSD, as the DSM-IV criteria was now applicable to the “trauma” experienced by these nurses. Nurses experienced the two specifications that defined stressful and traumatic events: they were exposed to “serious injury or threat to the physical integrity of others” and their “response involved intense helplessness or horror.”⁶ Thus, the same experience of nurses in Vietnam that previously did not qualify as PTSD now does, as the definition of PTSD evolved over the course of two decades.

Traumatic Experiences Specific to Vietnam War Military Nurses

Due to the ethical roles and responsibilities of nurses, the stressors they faced in military combat care were highly unique and individual to their occupation and background. Nurses spoke of how they were trained for holistic and compassionate care in nursing school, an aspect of care they felt like they could not perform in war time situations due to constrictions of military protocol, purpose, time, personnel, and equipment. Nurses recounted tales of how they received flak for their actions and were punished or denied promotions if they did not follow Standard Operating Procedures (SOPs) of the military doctrine.⁷ One wom-

an recounted the story of two Vietnamese twin infants who had passed away during a Viet Cong attack. Rather than placing each on its own stretcher, she placed the two together, believing that this arrangement would be preferred by the parents. She was then negatively counseled and reprimanded for this decision. Other nurses spoke of how the emergency nature of many medical situations meant that emotions would often obstruct their ability to critically think and follow SOPs. Jacqueline Navarra Rhoads, a nurse veteran, remembered how she could not ignore pain and how it became her ultimate focus, not only for the patient, but also to relieve her own agony. “We always worried about pain, alleviating pain. We’d do anything to alleviate pain.”⁸ Nurses spoke of how their immediate goals and desires to end suffering often countered SOPs and their duty as military health care professionals. Nurses also noted that they were indoctrinated in school that caring and compassion was the foundation of nursing. Thus, additional stress and pressure was put on themselves to take on roles beyond their professional roles as nurses, especially with such severely injured and young demographic of patients. As a consequence, nurses adopted new roles in Vietnam, representing “their girlfriends, their wives, their mothers.”⁹ This responsibility for the soldiers’ holistic state contrasted further intensified feelings of helplessness that nurses felt throughout Vietnam.

War resulted in conflicts of values, an additional psychological stressor for nurses. Karen Bush was a nurse completing her Psychiatric doctorate degree when she signed to volunteer in Vietnam after her graduation. She had joined for adventure, but quickly realized that caring for this young, vulnerable population was much more demanding than she had anticipated.¹⁰ There were young men who had come into the psychiatric ward on their

own, who merely pretended to be crazy because they were scared of war and losing their lives. Like Rivers in *Regeneration*, Bush acted upon her duty to the military, sending these men back to war and reprimanding their cowardice, yet also questioned the ethics of sending an unwilling boy to a potential death. Similarly, nurses felt conflicted on the dilemma of sending physically recovered soldiers back to battle, a conflict that manifested in personal guilt and shame. Additionally, many nurses questioned the morality of saving patients with multiple amputations, brain damage, or quadriplegia, believing that quality of life would be so significantly decreased that life may no longer be worth living. One unnamed nurse spoke of repeated nightmares where a young man she once saved cursed her for leaving him with such an unrecoverable, debilitating handicap as a spinal cord injury.¹¹ Other nurses suffered moral dilemmas of placing injured soldiers into the 'expectant' section of a hospital, a section for those deemed likely to die. Multiple nurses spoke of the extreme guilt they felt after placing individuals in the 'expectant' category, yet how it was necessary for them to utilize resources on those with a higher likelihood of survival.¹² Soldiers were not called patients because SOPs indicated that they were to be called casualties, creating a falsified distance between the nurse and the patient as an attempt to reduce nurses' guilt.

Nurses in Vietnam were further stressed by suffering from conflicts of interests between their roles as nurses and hatred for the enemy. Lorraine Bourdreau, a lieutenant appointed to take over a ward of Viet Cong POWs, found it difficult to place nursing ethics over her personal hatred and disgust. Other subordinates below her would improperly care for Viet Cong patients, kicking them in the process of care. As the supervisor, she would have to reprimand these nurses and ensure proper care to the Viet Cong

patients, despite despising them herself. Maintenance of moral and professional principles became even more difficult as war wore on, taking the lives of more and more young men.¹³ Bourdreau spoke of her feelings of shame and self-condemnation in taking care of the enemy who were murdering American soldiers and suffered recurring nightmares of enraged, dead American soldiers.

One of the most common stressors recounted by nurses was the physical and emotional exhaustion, and the lack of recovery time between traumatic events. In a qualitative study of interviews collected from a sample of 24 women who served as nurses in Vietnam, cluster themes were formed by coding overall commonalities in these interviews.¹⁴ Most of the nurses in Vietnam volunteered for duty, and recounted being the only female in their 'hooches,' or improvised shelter. These nurses worked 12 hour shifts for 5 days a week, describing the patient load as "heavy and exhausting," with nurse to patient ratios averaging 1:18. Nurses described themselves as a machine that "worked, slept, and went back to work." Besides mere moral and ethical exhaustion, many of the medical and physical aspects of working as a medical personnel in Vietnam was traumatic in itself. Nurses recounted how it was the first time many of them had handled injuries borne from parasitic diseases, malaria, and the plague, which were nonexistent in the United States. One nurse spoke of a particularly horrifying memory of inserting a nasogastric tube to a patient, and watching an intestinal worm slither out of the patient's nose. One of the memories that united almost all the nurses was what they called the "smells of Vietnam."¹⁵ These "smells" consisted of blood, burning flesh, pseudomonas-infected tissue, and burning human waste. Another nurse recounted her contrasting memories of Vietnam: witnessing a beauti-

ful countryside, and standing ankle-deep in blood while accompanying bodies to “grave registration.”¹⁶ Traumatic memories could often be triggered by sounds or environments; one nurse veteran expressed how the whirr of a helicopter could trigger overwhelming panic attacks of past memories of bloodied patients. Yet, these memories became so firmly rooted in the process of self-identification that these nurses refused to let go of these recollections, despite the trauma they caused.

The rigor and trauma of Vietnam necessitated emotional coping mechanisms, resulting in what nurses called the “play hard, work hard” lifestyle. The social atmosphere in the military camps was intensely filled with parties and USO shows. Alcohol, drugs, parties, and sex were rampant among nurses, and they were necessary for stress management in the disheartening war environment.¹⁷ Demoralizing was one of many coping mechanisms for the constant stressors that they faced in Vietnam, which manifested as a concept they called “compassion fatigue.” The more involved and immersed nurses were within the war effort, the more detached nurses would become in order to cope with stress on shift. They would stop talking or looking directly at patients, and obsess over nursing tasks and duties until the shift ended. “You are supposed to be caring and healing the sick, yet you are helpless in the eyes of a soldier whose head is blown off or a patient that dies from malaria.”¹⁸ This guilt was so overwhelming that nurses recounted trying to depersonalize their patients and became increasing workaholics over the course of their duty. Karen Bush had been trained to talk and question patients in a psychotherapeutic manner in her doctorate program. But in Vietnam, she had to place these ethical considerations aside in light of more pressing limitations of time, where she would immediately medicate the patient without question.¹⁹ Overtime, the

suppression of guilt became routine and habitual, and she no longer questioned herself in the process of this immediate medication, another example of nurses’ suppression of feelings. Nurses spoke of how it was psychologically necessary to believe that everyone who left the hospital actually lived, or they would risk losing all hope in continued work in Vietnam.

During the Vietnam War, there were few immediate psychiatric services available for soldiers, and even less for medical personnel. Nurses were not seen as a population who had experienced “real enough” trauma to culminate in physical and psychological symptoms. An unnamed nurse described her difficulty in seeking counseling from an Army psychiatrist, despite her symptoms of extreme depression, hopelessness, alcoholism, and detachment from work and comrades. The Army psychiatrists who met with her said that they did not have time for her as they had too many patients of a higher priority. She then booked herself with a non-military affiliated psychiatrist by paying out of pocket, yet found that many of these psychiatrists were Freudian-oriented and wanted to look back at childhood memories. This specific nurse felt more frustrated, believing that these Freudian methods were inconsistent and entirely unhelpful in assisting her with psychiatric problems that arose directly out of the war.²⁰

The threat of death was also a constant source of stress. In a series of letter entries to his family by Lt. Odom, a nurse who was in Vietnam from November 1967 to August 1968 speaks of multiple close incidents to death. There is a very real fear, that in the case of an attack to their MASH or medical facility, the nurses would be of more use to physically fight to protect patients than to be caring for the patients themselves. In one particularly dismal letter,

he speaks of a night when all the nurses collected together after a shift and spoke of how they “would react if we had to fight and how we felt about death,” only to realize that he “might have to.”²¹

Military nurses also faced unique stressors when coming back to civilian life and work as consequence of their war experiences. The lack of medical personnel in the military during Vietnam meant that nurses often worked independently, supervised large numbers of people in over-packed wards and hospitals, and performed duties above their scope of practice. Upon return to the U.S., nurses who had served in Vietnam were often scolded for acting like a ‘mini-doctor’ and not ‘being in their place.’ In combat zones, actions such as putting in tracheostomies and chest tubes were all permitted, yet in the States they were considered duties beyond their legal scope of practice. Some military nurses became feminists after the war, as they felt pride in their accomplishments and were angered by the lack of responsibility they were allotted post-Vietnam.²² Nurses also felt a lack of camaraderie and teamwork in civilian hospitals, especially because they viewed the hierarchy and nurse-doctor feuds as hindrances to their ability to provide care. Back in the States, “my main job was to get coffee” and “you weren’t allowed to do anything... Your judgment wasn’t trusted, you didn’t have any smarts.”²³ This transition to State-side nursing was difficult. Many missed the excitement and challenge of Vietnam, while others felt underutilized, devalued, and under appreciated in peacetime nursing. In retrospective studies of Vietnam-era military nurses, nurses averaged over 17 years in active duty, as many opted to return to the military and serve time post-Vietnam. Vietnam-era military nurses are also highly educated, with 53% of Vietnam Army nurse veterans holding a Masters degree.²⁴ This has been attributed

to an ambition to work harder in order to prove that they were capable, a drive that they credited to working as a nurse in the army.

The camaraderie and teamwork was professionally satisfying and completely unique in Vietnam. Nurses spoke of intense bonding and closeness with patients similar to that of the ‘philia’ described in “War of Nerves.” Nurses experienced a closeness greater than ‘brotherly love,’ as their occupation necessitated them to be closer than comrades, closer than family, in order for them to fulfill their duty and profession. Veteran nurses strongly identified themselves with the military. They were unable to explain their experiences to their friends at home or the other nurses in civilian hospitals, who often dismissed their experiences in Vietnam. Shirley Menard recalled how the other nurses did not understand that the stress of a mere five patients admitted in one night in a city hospital was very different from having 100 patients delivered at once in a war zone with limited supplies. They were angered that no one seemed to be “proud of the soldiers and nurses and doctors there.”²⁵ Many nurses also felt a sense of guilt about going home when so many others had to stay. Feelings about the war tended to be favorable before nurses were deployed, and support for the war generally increased during and after their service.²⁶ While many did question the intent, there is only record of one nurse who became fully disenchanted by war, while all others recounted becoming more supportive. Despite the horror, stressors, and aftereffects of war, nurses were generally proud of their military experience. Regardless, there is strong evidence from a variety of sources that military nurses exposed to war stress have the potential for mental health problems related to their experience, due to their consistent exposure to severe combat casualties, self-blame, death, workload extremes, personal

deprivation, loss, and danger.

Post Traumatic Stress Disorder in 21st Century Military Nursing

It has only been a little over a decade since the start of the War in Afghanistan, yet extended studies on the lived experiences of U.S. military nurses have already been published. These accounts have been similar to the lived experiences of nurses in Vietnam. For example, caring for the enemy and POWs remains as difficult an ethical decision for nurses in the 21st century as it was in Vietnam. A nurse reported having a severely injured U.S. soldier in one bed and an Iraqi insurgent on the next to him.²⁷ Both were on different ends of the same firefight, yet due to her ethical duties as a nurse, she had to care for both with equal detail and compassion. Like Vietnam, the blood and gore could be too much for the nurses to handle. One nurse recounted how she and her comrades would attempt to “wiggle my way out of ER” because of the traumatic memories that resulted from the large amount of shocking trauma they had to see. An army reservist nurse recalled a memory where she arrived on scene to a soldier as young as her son inside a blown up Humvee, and watched him panic stricken, look down at where his legs used to be and scream “Oh my God, I don’t have any legs.”²⁸ She had to take a few steps away, vomit, and immediately return to the scene to care for him. This nurse had to suppress her maternal feelings and detach herself from reality in order to take care of immediate duties, a suppression reminiscent of that of Vietnam-era nurses.

However, there are also distinct stressors in Afghanistan that did not exist in Vietnam. America’s war in Afghanistan has resulted in extended and lengthy interactions with the local population, resulting in many medical interac-

tions with local civilians. While communication through language and interpreters has improved, cultural barriers have remained a huge stressor for military nurses. Nurses recounted how Afghan nationals expected the American medical personnel, with their greater technology and services, to be capable of solving any medical issues. Thus, nurses felt escalated guilt and frustration when an individual passed away, as their personal feelings of guilt and responsibility were exacerbated by blame and accusations by Afghani families.²⁹

While there has only been one published study on the correlation of PTSD and military nurses in the War in Afghanistan, experiences from the Vietnam War can serve as both a predictor and basis for understanding future PTSD diagnosis in military nurses. In 2013, the American Psychiatric Association published an updated understanding of PTSD in DSM-V. The criteria for the origin of stress, or ‘stressor’ in DSM-V now encompasses an even more vast selection of events than those illustrated by DSM-IV; new criterion may potentially increase the number of diagnoses in military nurses. For example, “Repeated or extreme indirect exposure to aversive details of the event, usually in the course of professional duties” now constitutes a potential stressor and fulfills the criteria for PTSD.³⁰ In contrast, the criteria in DSM-III for a ‘stressor’ was limited solely to an individual who had “experienced an event that is outside the range of human experience and that would be markedly be distressing to almost anyone.”³¹

Alternatively, it may be suggested that SOP improvements in the War in Afghanistan have decreased the presence of risk factors for PTSD development. Nurses reported better and more adequate training in Basic Officer Leadership Course (BOLC) for potential stressful situations before

deployment, whereas nurses in the Vietnam War reported that they were flown out within 15 days of volunteering for the military.³² Many nurses who served in the Vietnam War volunteered out of a nationalistic sense of pride or duty that may have contributed to idealistic naivety about War. In contrast, the 21st century military nurse corps consisted of nurses who were already either in active duty or activated from the reserves. Despite increased preparation and maturity, nurses still felt that they were in “harm’s way more than I bargained for” in Afghanistan. Now that the combat operations in the War in Afghanistan have officially ended, perhaps retrospective studies on active duty nurses can be completed, and a modern day conception of military nurse diagnoses and risk factors of PTSD can be evaluated.

Conclusion

Military nurses have only become a recent focus in the past half century, with studies expanding simultaneously with the developing understanding of PTSD. This is seen in the rapid evolution of the prevalence of PTSD diagnosis and risk factors in military nurses. Military nurses are an easily overlooked population with enormous potential for PTSD due to their distinct experience and role as a nursing professional in highly stressful combat situations. As the military continues to expand and fight in future wars, proactive approaches in the prevention, identification, and treatment of PTSD in nurses must be developed. Proper training before responding to traumatic events on field, as well as conducting debriefings after intensive combat care and mass casualty incidents are steps towards proper coping mechanisms for these military nurses. The Army Nurse Corps is the backbone of any military unit. Thus, the military must adapt to view nurses as individuals with potential military service related PTSD and develop nursing specific

PTSD treatments and strategies. Only then, can the Nurse Corps remain strong and resilient in performing their ultimate duty of care for those who protect this nation.

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SOCIALIZED MEDICINE: A HATE STORY

MEGAN FICKES

Choke down your bile, suppress your shudder—we're using the dreaded “s” word. I implore you: before you have a violent conniption, just consider the following.

For years, politicians have warped into oblivion the purpose of socialized medicine: to provide universal health care by means of public funds. Socialized medicine is not socialism, nor is it communism. It certainly is not a dire threat to the United States, although conservatives would doubtless have it that way. How has governmental catering to the health needs of a population become so heinous?

Our intense aversion is the result of propaganda dating back to the 1930s; however, this is not the Red Scare, nor the height of the Cold War. This is 2016, and we should know better by now. In America, we profess to espouse lofty values of equality, opportunity, and justice for all, yet our current healthcare system frequently denies those rights to those most in need.

The bottom line is this: a nation cannot proudly laud its status as the “Land of the Free” while failing to ensure health—a basic human right—for all of its citizens. Socialized medicine is not the enemy: it is a solution.

It's time to reconsider where our priorities lie, especially in light of Colorado's upcoming referendum on universal health care.

Americans tend to cling to the fallacy that we are number one. Take one look, however, at the numbers depicting our health care system and its effectiveness, and that one quickly evaporates. The current fee-for-service system of health care delivery follows a capitalist model that, quite simply, has proven time and time again to fall perilously short.

We tend to treat any consideration of the potential for other systems of healthcare surpassing our own as heresy. It is an attack on the well-established “American way,” a way defined by willful ignorance and obstinacy. I beseech you to consider, if you could be so kind, the systems of some of our European counterparts.

The United Kingdom's system of socialized medicine, the National Health Service, is funded through centralized taxation and in return provides comprehensive universal health care at little to no cost for its citizens.¹ Sound good? That's because it is.

In a comparison of the US to 10 economically similar countries, The UK surpasses the US in just about every measure of health—it is ranked first on measures of quality care, access, and efficiency. The US, by stark contrast, is ranked 11th in overall care, 5th in quality care, 9th in access, and 11th in efficiency.²

Compound this with the fact that the United States grossly overspends, devoting a whopping \$9,255 per capita on health expenditures, and it's clear something has to give.³

Another economically similar country, Germany, employs some aspects of socialized medicine to great benefit. Its “sickness funds”⁴ essentially operate on a socially and economically conscious axis of “rich paying for poor,” a statement that would doubtless ignite the rage of any self-respecting Republican. Social welfare? Universal access? Be still, my beating heart!

It's clear that socialized medicine in other countries proffers universal access and quality with much lower costs than in the United States. Could aspects of this system be adaptable to the US? Although I do concede that economic considerations must be taken into account, given that the US devotes more of its GDP (17.4%)⁵ to healthcare than any other nation, it seems that our method of spending at present is not effective or efficient.

There is no clear cut answer to the pressing problem of health care reform, but blindly rejecting aspects of socialized medicine for purely political or pejorative reasons only serves to hurt the vast majority of citizens who would benefit from its services.

It's time to stop playing catch-up with the rest of the industrialized world. It's time to take a long, hard look at how we treat healthcare.

It should be regarded as a matter of deepest shame that the United States is the sole wealthy, developed nation in the world without universal health care. So let us remove the cloud of misinformation and bias; let us go beyond political diatribe. Let us move toward a system of equitable and affordable medicine for all, not the few.

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NOT YOUR WORTH

Samantha Ng



FIFTEEN GOING ON ZERO

SARAH RAMSEY

It was the summer before high school started.

Bye Bye Miss American Awkward Pre Teen,

 Skin breakouts,

 Dances wearing khaki polo's,

 Eating alone at lunch,

Hello Ms Taylor Swift,

 Snagging that upperclassman,

 Wearing that kissable lip gloss,

 Easy, breezy, Covergirl.

Soccer tryouts are the first attack.

 Training all summer.

 Lifting, running, pushing.

 Push it to the limit.

Bye Bye fifteen pounds.

 You should never have been there.

 Curse you sucker.

 I look good.

On the fields.

 Damn Miss you look fine.

Off the fields.

 Random mom asks

 "What diet did you use, you look so skinny!"

I look good.

 I am confident...

 In my thunder-less thighs.

Maintain the number.

 Embrace my lack of space.

 Feel my body crunching in.

Lower the number.

Skip meals.

Weigh myself.

Lie about it.

Weigh myself.

Considering puking.

Weigh myself.

Feel good.

Weigh myself.

Feel bad.

Drink water. More water.

Concave and eat every little sugar filled morsel I can get in my sight.

Ice cream, check.

Hot fudge, check.

Home-baked cookies you made for my family a few days ago and refused to eat then, but I'll eat two at a time now, check.

Feel disgusted, check.

Unhappy, lies negative, pain, concern, hiding, for what?

For whom?

For when?

For why?

PLEASE stop.

OK

MEGAN FICKES

The fear that came then was insidious. It crept up within me and took hold, almost without me noticing. A slow burn extended from my core outward until I was locked within its grasp. Helpless. Something long dormant—or maybe simply subdued, silenced—filled my veins, infiltrated my bloodstream, stopped my heart and crushed each of my lungs, a caress that became a chokehold. I watched from some distant place, the land of unreality, as my body—my cage—betrayed me. Immobile, locked in a labyrinth with no exit, gasping desperately, seeking a reprieve that wouldn't come. My limp body was dragged along by the force of a wave too big, and I was small, I was nothing. Did I exist anymore? *I don't care, make it STOP—you win. I'm mute and deaf and blind isthiswhatdeathfeelslike? I don't—I can't—please—help—*

“How was the weekend?”

Emily inquired, looking up from her book and surveying me with keenly alert blue eyes. I responded blithely, positively serene, mask securely in place. It was good, it was always good, how could it be any other way? What a ridiculous idea.

Every nerve ending in my body was aflame, electric pulsating shockwaves reverberating with no release, coursing from the very tips of my fingers curled in tightly clenched fists and down the hunched line of my spine. I was consumed by it, devoured by it, the fear was in me as it was me, was *me*. My eyes had been squeezed shut—darkness was easier than light when light only served to blind. Peering through wet thick eyelashes, the room was blurry. I watched the stale yellow paint start melting off the walls, Salvador Dali-style—was it hot in here? Thick, shuddering gusts of oxygen forced themselves out of my throat in rapid succession, one after the other—*gaspgaspgaspgaspgasp—I can't breathe—I can't breathe—I felt my airways constrict and shrink and fold gently into themselves. An ocean of me poured out from behind my eyes, the dam burst, the levy broke—the strongest walls are only as strong as their weakest point. Hot, salty wetness, melancholia streams and liquid nightmares. My hands were soldered to my chest and they had to be, they had to or my heart would fall out. The pounding, it's inside my skull it's loud and full and my heart might really explode, I might really explode—that pounding, that pounding!*

I sat down at my perpetually cluttered desk, sifting through readings for that week and running through the laundry list of things I had to do, always a nagging fear that I was forgetting something. *Finish that sociology paper—status attainment and*

social reproduction, was it? E-mail your advisor and set up an appointment, you need to figure out your class schedule for next semester. Do your laundry. Eat. Shower. Sleep. Clambering into bed—one of the few things I really did miss while away—I set to work on my paper. Everything in order. Everything as it should be, as always.

The room pitched and swayed, a woozy psychedelic dream, as I blindly groped for the door handle through the thick film of sensation, adrenaline, *attack*. It was 1:30 am, but I knew they would pick up. “What’s wrong?” No hello—my mom didn’t have to ask, already knew. I spluttered incoherently, words dripping out of my mouth in a cacophony of cluttered syllables. *I need dad. I just need dad.* Still groggy, he asked what was going on—“Are you OK?” The guttural sobs that ripped through me, cleaving me in half, must have been answer enough. As a psychiatrist, my dad was well versed in how to talk his patients down, but I was not his regular patient. “Hey. Listen to me. I need you to breathe. Meg—breathe, slowly. In and out, that’s right. Good. Just like that. Keep going, in, out, in out.” *In. Out. In. Out.* I clung to his words like I had never heard him speak before, like those words would be my deliverance. And they were. The radiator thrummed against my leg, aching to prove just how much it was alive. Looking out the window onto the silent street, my lips pursed in a small “o,” I forced myself to do what my dad said. Slowly but surely, I unwound, the chokehold of panic releasing me, free, at least for now.

You are OK.

I am not OK.

S HACKLED:

HOW THE US IS TIED UP BETWEEN POLICY AND LEGISLATION REGARDING PHYSICAL RESTRAINT OF INCARCERATED PREGNANT WOMEN

SYDNEY KANJUPARAMBAN

I. Introduction

A quick Google image search of the word “pregnancy” fetches approximately 262,000,000 results in 0.26 seconds. The search engine’s algorithm sifts through incomprehensible amounts of data to bring the most relevant and important hits to the surface, selecting four pictures as the winners to be featured on the top line of the first results page. Each of the four pictures shows the nude, white, rounded stomach of a different woman. She cradles her bump lovingly, sometimes holding a red paper heart, an ultrasound picture, or a little black chalkboard that reads “Coming soon!” in pretty white script. These are images of love, anticipation, joy. The faceless women in these pictures aren’t scared— they’re excited! They know who their OB/GYNs will be because they handpicked them. They are confident in their birth plans and are attending prenatal education classes. They have been over exactly what to expect in the maternity ward and their “birthing bags” are already packed and waiting by the door, just in case. The women in these pictures embody everything pregnancy represents in our culture-- a time to glow, to nest, and to prepare.

But of course, things are not always as they seem. This type of pregnancy—the glowing, showing, happily growing type— really only applies to women who have access to quality healthcare, a disposable income, and free time. For many other women, pregnancy is far less glamorous. And

for approximately 9,000 American women in correctional facilities across the United States, pregnancy can be terrifying. They are allowed to exercise little to no autonomy over their obstetric health care decisions, most notably those surrounding their inevitable delivery.

As there is no actual federal legislation prohibiting this practice, many incarcerated women are deemed a “flight risk” and are shackled to the delivery table with heavy metal chains around their wrists, ankles, and waists when they give birth, restricting their movement and thus making it very difficult to escape—but also very difficult to birth a child. This paper will explore several cases that exemplify use of physical restraints on pregnant prisoners during labor, explain the deep concerns associated with such practice, examine existing public policy surrounding the practice, and argue for federal legislation in the United States prohibiting the use of shackles during childbirth.

II. Selected Cases

A. Villegas v. Metropolitan Government of Nashville, 2012
In 2009, a Mexican woman named Juana Villegas sued the Metropolitan Government of Nashville and Davidson County after being shackled at the wrists and legs while in labor and immediately after delivering her child. Villegas claimed that the restraints (as well as her being denied access to a breast-pump) violated her Eighth Amendment

rights.¹

After being arrested for driving without a valid license and detained for her illegal status, Villegas had been only been in medium-security for three days before she experienced amniorrhexis (“water-breaking”) and went into labor. She was then transported to the hospital via ambulance but prison officers mandated that she be shackled to the stretcher the entire ride to prevent her from escaping. Villegas’ shackles were not removed until her cervix was dilated to 3cm and after multiple requests from hospital staff and the attending physician, over an hour into labor. Villegas was then re-shackled at the ankle six hours after delivering the baby.²

The United States District Court for the Middle District of Tennessee decided in the Plaintiff’s favor, ruling that her shackling was conducted deliberately indifferent to her medical condition, thereby being considered an unconstitutional act, as “The Eighth Amendment prohibition on cruel and unusual punishment protects prisoners from the ‘unnecessary and wanton infliction of pain.’”³ Villegas was awarded \$200,000 and the Metropolitan Government of Nashville and Davidson County quickly appealed the ruling.⁴

The decision was subsequently reversed by the US Court of Appeals for the Sixth Circuit. The appellate court ruled that the treatment Villegas received by the prison officials and hospital staff could not be considered “deliberately indifferent” to her condition because her shackling supposedly did not interfere with her medical treatment— “for example, the shackles are not removed so that the medical treatment may proceed unimpeded; however, such were not the circumstances in this case.”⁵ The court’s decision also stressed

that it cannot be assumed that the Defendant (here referring to the officers who ordered that she remain shackled) possessed “knowledge of a substantial risk of serious harm” by the restraints and therefore it could not be established that the actions of the Defendant were *deliberate* in their interference with her medical treatment.

B. Nelson v. Correctional Medical Services

In September 2003, nonviolent offender Shawanna Nelson was serving time in a Florida correctional facility when she went into labor. She was transported to a nearby hospital and then shackled to a bed at 3:50 PM by Correctional Officer Patricia Turensky. At this point Nelson was already at 7 centimeters cervical dilation, which is considered a final stage of labor. According to the maternity ward nurses, “each time a nurse needed to measure Nelson’s dilation, that nurse had to ask [her correctional officer] to unshackle her, although [...] no one on the hospital staff ever requested that she be reshackled.” Officer Turensky would apply the restraints again each time. Nelson remained shackled while pushing the child through the birth canal at 9 centimeters cervical dilation without an epidural (even though she had requested anesthesia upon her arrival at the hospital). By the request of the attending obstetrician, Nelson’s shackles were finally removed at 6.15PM, only eight minutes before the birth of her child at 6:23PM.⁶

Nelson claimed that her shackling not only restricted necessary movement during labor and caused her extreme emotional trauma but resulted in more permanent musculoskeletal injuries as well. She brought claims against Officer Turensky as well as Turensky’s supervisor, the director of the Arkansas Department of Corrections, Larry Norris. Both Defendants moved for summary judgment, requesting not to stand trial and arguing that they should receive

qualified immunity on the grounds that their conduct did not violate “clearly established statutory or constitutional rights of which a reasonable person would have known.”⁷ Although the district court denied these motions, a later appellate court granted Norris the immunity. Eventually a second appellate court ruled in the Plaintiff’s favor, stating that “the majority proclaims Nelson had a clearly established constitutional right to be free from restraints during labor.”^{8,9}

C. Women Prisoners of District of Columbia Department of Corrections v. District of Columbia

A group of female prisoners serving time in three DC correctional facilities sued the District of Columbia on grounds that the District violated Title IX and the Eighth and Fourteenth Amendments of the US Constitution. The Plaintiffs claimed a myriad of violations, ranging from sexual abuse to general living conditions. Their suit was successful at the district court level and the Defendants quickly appealed the ruling. One part of the original ruling that was never contested in the appeal, however, stated that “the use of physical restraints on women in their third trimester of pregnancy” constituted a condition in violation of “the Eighth Amendment guarantee against cruel and unusual punishment.”¹⁰

III. Arguments for the Use of Physical Restraints During Labor and Reasons for Their Invalidity

A. Inmates Outside of a Correctional Facility Pose Flight Risks

The principal reason for shackling women in the maternity ward is out of concern that the unshackled prisoner/ patient could more easily escape the hospital and pose a threat to community at large.¹¹ It is not uncommon for prisoners receiving other forms of medical treatment (including surgery) to be placed under physical restraint while in the

hospital. Violent and nonviolent offenders alike can be placed in physical restraints, typically at the discretion of the attending correctional officer.¹² In most cases, this precaution is reasonable. A prisoner in relatively good health who arrives a hospital for a non-life threatening condition would most certainly pose a flight risk if allowed to venture outside the prison walls unrestrained. The same hypothetical prisoner would not be in any extreme discomfort while handcuffed. Thus, this practice of restraining prisoners who are legitimately capable of escape is justifiable and even advisable.

Pregnant and laboring inmates, however, present a completely different situation—if a woman is in active labor, she is under immense physical stress and is extremely unlikely to be able to run from a situation. In the completely improbable case that she were, in fact, able to run from the delivery room, she would soon be stopped by the *inevitable* delivery of the infant. The prisoner in labor is different from any other prisoner receiving treatment because her debilitating condition has an end that cannot be postponed. Once labor has started, her body will push the infant out. Hindered by not only physical stress but also the rapidly progressing timeline of her condition, she cannot be subjected to the same concerns a prisoner coming to receive a splint for a broken arm or for chemotherapy would have, namely those who could actually make it out of the hospital and escape. These assumptions are further corroborated by both medical logic and the fact that “there have been no reported escape attempts among female inmates who were not restrained while giving birth” ever in the United States.¹³ In light of these facts, it is apparent that the pregnant woman does not pose a legitimate flight risk to correctional officers.

B. Shackling During Labor Prevents Prisoners from Using Physical Violence to Harm the Public

A second claim commonly used to advocate for the continued use of physical restraints during childbirth is that said restraints prevent the prisoner from physically attacking the people around her.¹⁴ This reasoning stems from a pervasive cultural belief that prison inmates are dangerous, violent people who pose a serious safety risk anytime they leave the walls of the correctional facility. It is not fundamentally wrong; naturally there are a number of violent offenders in US prisons.

However, the statistics of incarceration weaken this claim considerably in its application to laboring mothers. Violent offenders in US prisons are overwhelmingly male—by more than a 75% margin in 2012.¹⁵ Women are far more likely to be imprisoned for nonviolent crimes like drug abuse or fraud than they are to be for violent offenses.¹⁶ Combined with the physical toll a woman in active labor is already experiencing, the odds of her becoming violent and hurting a member of the hospital staff, correctional officers, or general public during labor are incredibly slim, rendering such argument for restraint use as nonsensical. In fact, not a single incident of harm to medical staff by an inmate in labor has been reported in New York City since the city restricted the use of physical restraints during delivery in 1990.¹⁷

IV. Arguments Against the Use of Physical Restraints During Labor

A. Physical Restraint During Labor Places Medical Judgment in the Hands of Correctional Officers When It Should Be Left to Physicians

To better visualize the additional unnecessary strain that

such physical restraints put on a woman while in active labor, it helps to understand what these restraints imply. Heavy metal clamps, or irons, can be placed around the legs. Wrists are typically restrained by metal handcuffs. The movement of the entire woman may be inhibited via the use of a waist shackle, a weighted belt of sorts that chains the woman to her delivery bed.¹⁸ The use of one or more of these restraints are left to the sole discretion of the prisoner's correctional officers. Because only the correctional officer has the ability to remove the shackles, the woman's medical team must request them to be removed when medically necessary, as seen in cases like *Nelson v. Correctional Medical Services* and *Villegas v. Metropolitan Government of Nashville*. In both cases, the attending hospital staff had to seek out the correctional officer for removal of the restraints, a nurse even testifying in *Nelson* that Officer "Turensky 'hooked [her] right back up' to the bed rails after each cervical measurement was taken."¹⁹ It is important to note that the hospital staff in *Nelson* requested the removal of the shackles multiple times, but not once did they ask for Nelson to be reshackled. This uncomfortable shifting power dynamic between hospital staff and correctional officers is not only frustrating for the attending medical providers but is also dangerous for the patient—if the patient or the baby's condition rapidly deteriorates during labor and the key-holding correctional officer cannot be reached quickly enough or refuses to cooperate in a timely manner, the two lives at stake may be lost.²⁰ Physical restraints during labor are dangerous because they effectively place medical decision-making in the hands of correctional officers when such judgments should be left to the physician. These restraints therefore interfere with the treatment of the patient during a time when such treatment is crucial to the health and survival of the patient and child.

B. Physical Restraint During Labor Poses Extreme Discomfort and Legitimate Medical Threat to the Patient/Prisoner

The protocol shackles present not only an indirect impediment to the patient's health but a direct one, as they can cause actual physical harm to the patient in active labor. The shackles restrict the movement of the woman as she delivers the child. Such movement is necessary to aid in the movement of the child down the birth canal. If the woman is restrained during the process, she will experience even greater pain with delivery; her restrictions will prolong the birth process and prevent her from making movements that can reduce the inevitable pain.

A medical expert consulted in the *Villegas v. Metropolitan Government of Nashville* testified that shackling during labor actually "increases her risk of developing a potentially life-threatening blood clot."²¹ Pregnant women are already prone to developing blood clots, but their risk peaks immediately postpartum. Dr. Torrente, the testifying expert, maintained that the patient should be "ambulatory... as often as possible" right after she delivers. It follows that the woman should not be reshackled immediately after delivery as she is at high risk for developing medical complications (such as blood clots) that would need emergency treatment.

The expert in *Villegas* was not an outlier in her concerns. The American College of Obstetricians and Gynecologists issued a statement in 2011 regarding the matter, stating:

[P]hysical restraints have interfered with the ability of physicians to safely practice medicine by reducing their ability to assess and evaluate the physical condition of the mother and the fetus, and have similarly made the labor and delivery process more difficult than it needs to be; thus, overall put

ting the health and lives of the women and unborn children at risk.²²

Finally, multiple reputable associations of medical practitioners and ethicists, including the American Medical Association and the American College of Obstetricians and Gynecologists, have condemned the use of physical restraints during delivery because of the psychological distress and risk of lasting emotional trauma this practice poses for the patient. They collectively reiterate that the lack of mobility during birth can be particularly traumatizing for the mother, as it increases her pain and risk of complication and prevents her from properly and safely handling her newborn.²³

C. Shackling During Labor is a Form of "Cruel and Unnecessary Punishment" and Is Therefore Unconstitutional

The Eighth Amendment to the United States Constitution guarantees any person who has been convicted of a crime freedom from "cruel and unusual punishments."²⁴ Such criteria condemns the shackling of a prisoner during active labor, as it intensifies the pain of an already extremely painful process by inhibiting her natural movement and prolonging the birth.²⁵ The prisoner has been sentenced to serve time at a correctional facility, but not to submit to the pain associated with physically restrained childbirth. Correctional officers should not be empowered to worsen a prisoner's punishment for her crime by inflicting unnecessary pain on her by administering leg, wrist, or waist shackles when she poses no flight risk or safety risk to those around her. By this logic, the use of physical restraint of prisoners during childbirth is indeed "cruel and unnecessary punishment" and therefore a violation of the Eighth Amendment to the United States Constitution.

The rulings of several courts have supported this conclusion, including those issued in *Villegas v. Metropolitan Government of Nashville* and *Women Prisoners of District of Columbia Department of Corrections v. District of Columbia*. The court opinion in *Villegas* stated that “the shackling of pregnant detainees while in labor offends contemporary standards of human decency” in its violation of the Eighth Amendment.²⁶

D. The Use of Physical Restraint During Labor Is Considered a Violation of Human Rights

The practice of shackling pregnant women to delivery tables has sparked global conversation surrounding the concept that the offense of the procedure transcends mere state and national law and can be considered a violation of universal human rights. The United Nations, the world’s leading organization devoted to the idea of universal human rights and their protection, has issued two declarations regarding the matter: *U.N. Standard Minimum Rules for the Treatment of Prisoners (1957)* and *U.N. Rules for the Treatment of Women Prisoners and Non-custodial Measures for Women Offenders (2010)*. The latter elaborates on the basic tenet of the former: that sentencing to prison should never infringe on the prisoner’s U.N.-declared fundamental human rights, such as the right to be free from “cruel, inhumane, or degrading treatment.”²⁷ The 2010 publication explicitly states that “instruments of restraint shall never be used on women during labour, during birth and immediately after birth,” yet the United States is still yet to fully comply with this policy.²⁸

The protection of prisoner/ patient rights during childbirth is of special concern when one considers how the patient, by delivering a child while in correctional custody, has already forfeited a great deal of patient autonomy. She is

granted medical care but allowed to make very few decisions regarding her delivery and treatment. Her labor will be inherently more traumatic than that of a free woman because she can exercise only a fraction of control over the circumstances of the child’s birth— she did not get to pick the doctor or the hospital; it is unlikely that she will be accompanied by friends and family; in most cases she will not allowed to keep the child for more than 24 hours.²⁹ To place this woman in shackles during birth is to allow her helpless condition to come to physical manifestation. It violates her last shred of dignity in childbirth—the physical control over the movements of her body.

V. Existing Policy Addressing this Problem and Why It has Failed

Publicity surrounding lawsuits such as *Villegas* and *Nelson* has brought public awareness to the practice of shackling during delivery and instigated sweeping policy changes across the country. Physical restraint during childbirth has been condemned (as noted, previously) by human rights protection groups like the United Nations, medical practice and ethics associations like the American Medical Association, and civil rights advocacy groups like the American Civil Liberties Union Foundation. Even correctional institutions and groups have begun to examine the practice and suggest policy reformation.

In 2010, the National Commission on Correctional Health Care issued a position statement regarding “Restraint of Pregnant Inmates” in which it listed conditions where restraints are not always necessary and outlined ways to minimize their use during pregnancy and delivery.³⁰ The statement acknowledged ways shackling harms the mother as well as the fetus and safety precautions that can

be taken when using physical restraints on the patient. A similarly-minded publication called *Best Practices in the Use of Restraints with Pregnant Women and Girls Under Correctional Custody* was released in 2012 by the U.S. Department of Justice. The document addresses the fact that “the use of restraints can interfere with maternal and fetal health care during pregnancy, labor, delivery, and maternal and newborn health care during the postpartum period” and seeks to establish guidelines for new protocol that will minimize the health risks associated with restrained delivery.³¹ Although it does not call for complete abolition of the practice, the publication states that restraints should be used only when absolutely necessary “when there is an imminent risk of escape or harm [...] and these risks cannot be managed by other reasonable means.”³²

If the policies and official positions of so many relevant entities have changed in the last ten years to condemn the use of traditional shackling of pregnant prisoners during labor, why is it still a matter of concern? Why are incarcerated women still being forcibly restrained during childbirth across the US? Why was the decision in *Villegas* overturned to rule in favor of the correctional officers who refused to take off Villegas’ restraints until the last minute? The answer lies in another frustrating reality of US law —policy and advocacy alone are insufficient to ensure that pregnant inmates will not have to deliver their children while shackled to a hospital bed. Instead, shackling of pregnant, nonviolent offenders during delivery needs to be made illegal by federal legislation.

VI. Reasons for the Need for Federal Prohibition of the Use of Physical Restraint on Pregnant Women in Labor

A. Existing Policy Does Not Sufficiently Protect Pregnant Inmates in a Court of Law

In 2013, after considerable pressure from various human rights advocacy groups, the United States issued a report emphasizing the importance of policy (not law) in “regulating the shackling of pregnant women” and several US Departments updated their policies to include a section about avoiding the use of physical restraint on pregnant women.³³ Unfortunately, however well-intentioned and progressive these new policies may be, they are not enforceable. They are only recommendations, in actuality holding very little weight. Physical restraint during birth is still legal under federal law even if the US Department of Justice strongly advises against it. These policies do little more than wag a pedantic finger at the correctional officers still shackling women across the country.

The case of Juana Villegas is an excellent example of why the United States needs definitive, enforceable legislation rather than policy statements. Her case is very recent (2013). By the time it was filed, several similar cases had already proceeded through different district courts.³⁴ The district court ruled in her favor, citing violation of the Eighth Amendment to the US Constitution and awarding Villegas \$200,000. The defendant, however, successfully appealed the case and the ruling was reversed.³⁵ An examination of the opinion of the appellate court reveals why current policies can be subverted by flawed interpretations of the situation, exposing the legal gray area of policy without law.

The opinion, written by Justices Clay and Gibbons, acknowledges that shackling Villegas during labor “offends the contemporary standards of human decency” in violation of the Eighth Amendment and that “a reasonable person could nonetheless conclude that the Plaintiff was not a flight risk.”³⁶ Now the court has acknowledged that the actions of the Defendant were both unconstitutional and unreasonable. But here is where Villegas loses her case-- the court continues on to say that it cannot be concluded that the Defendant truly understood the effects of the use the shackles during labor nor the necessity of removing them, and therefore it cannot be established that the Defendant was *deliberately* indifferent to the Plaintiff’s condition.³⁷

The court clearly agrees with current US policy that shackles should not be used to restrain a nonviolent offender during labor. But without an actual law criminalizing the use of physical restraint in this scenario, the court appears to be stuck in minutia, allowing officers who have forced women to deliver in shackles to slip through legal loopholes (like the vague wording of deliberate indifference) and get off scot-free. If there were federal legislation prohibiting the use of physical restraints during childbirth and delivery, offenders could be prosecuted on the grounds of their actions, not gaps in legal jargon, and there would be a significantly smaller discrepancy between policy and law.

B. State Laws Prohibiting the Use of Physical Restraint on Pregnant Inmates Represent Progress but Not Perfection in the Protection of Human Rights

As of now, only eighteen states in the U.S. have adopted anti-shackling laws for pregnant inmates. 24 U.S. states have written policy on the subject, but this policy still carries little weight in way of actually preventing the continued

practice of shackling or prosecuting correctional officers who use it when unnecessary.³⁸ These policies generally “only apply to prisons and correctional departments that adopt them,” essentially rendering them optional guidelines.³⁹ State law, on the other hand, is enforceable and transparent; it applies equally across the entire state and can only be changed by democratic process.

The primary advantage of adopting federal anti-shackling legislation is to account for incongruences and inadequacies among different state laws. Currently Pennsylvania law mandates that all uses of restraint be reported so that the attending correctional officer can be held accountable for their misuse. California, however, has no requirement to report the use of restraints.⁴⁰ Therefore, offending correctional officers in California are much more difficult hold accountable for their violations in inappropriately shackling pregnant women. A federal law could require the same protocol across all 50 states in order to eliminate these inconsistencies.

Finally, the fact that the use of physical restraint on pregnant inmates during labor represents a violation of human rights that should be enough to prompt federal legislation alone. The United States should take a united stand against procedural violations of human rights instead of leaving it up to each state’s legislature to decide the value of the dignity of a pregnant inmate. These cases of inappropriate shackling violate core tenets of American law, specifically the Eighth Amendment to the Constitution, and federal legislation needs crack down on penalizing these breaches of the federal constitution. A violation of American constitutional rights should be treated with equal attention in *all* fifty states.

VIII. Proposed Parameters for Federal Anti-Shackling Legislation

In order to prohibit the use of physical restraint on non-violent offenders during labor, delivery, and postpartum recovery, the legislation would need to strictly define “labor” to avoid outcomes like *Nelson v. Correctional Medical Services*, in which Nelson was shackled to the hospital bed during the vast majority of her labor but technically not during the delivery, as the restraints were removed a mere seven minutes before her child emerged from the birth canal.⁴¹

According to the Mayo Clinic and the American College of Obstetrics and Gynecology, labor can be separated into two phases: early (or latent) labor and active labor.⁴² Early labor is characterized by mild regular contractions, slight cervical dilation, and the loss of the cervical mucus plug.⁴³ Inmates in early labor should be examined by the attending prison physician. Active labor is next, and its beginning is marked by regular contractions, five minutes apart.⁴⁴ Inmates should be transported to the hospital as they experience contractions of this timing and enter active labor, as this is the traditional protocol outside the penal system as well. At no point in the labor process (experience of any of the qualifications above) should the inmate be shackled at the wrists, legs, or waist.

To prevent worsening potential postpartum complications (see Section IV.B) and endangering the infant by restricting the movement of the mother, the inmate should remain unrestrained during her entire postpartum stay at the hospital.

To promote accountability and honesty among correc-

tional officers, the law should include a reporting mandate like those already in effect in Pennsylvania, Arizona, and Illinois.⁴⁵ Correctional officers will be required to document any use of physical restraint on the pregnant inmate. The International Human Rights Clinic at the University of Chicago Law School has proposed the following requirements for said reports:

The report should include (1) the reasons the officer determined extraordinary circumstances existed requiring the use of restraints, (2) the kind of restraints used, (3) the reasons those restraints were considered the least restrictive and most reasonable under the circumstances, and (4) the duration of the use of restraints.⁴⁶

The effect of this mandate is twofold: First, correctional officers who are fully aware that their actions are being recorded and subject to scrutiny will be less likely to abuse their power. Knowing that they are ultimately being supervised (and perhaps even fear of punishment for violations) promotes honesty and appropriate judgment on the job. Second, the record will serve as court evidence for any violations that may occur anyway—the claims of both the prisoner and the correctional officer can be checked against the record.

IX. Conclusion

The use of physical restraint on pregnant incarcerated women, although legal in the United States, represents a dangerous overstep of prison officials into territory where their power should not be exercised. The pregnant prisoner has already forfeited much of her medical autonomy by being incarcerated—she has very little ability to make her own decisions during her pregnancy and will only receive

the level of care that is provided to her by her correctional facility. Proponents of the continued use of physical restraint of pregnant and laboring inmates argue that pregnant patients pose a flight and safety risk to the community and hospital. To claim such points is to ignore the reality of the medical condition of the inmate in labor; her pregnancy and the inevitable, unstoppable delivery of her child make it nearly impossible for her to attempt an escape.

Shackling these laboring women to their hospital beds also poses serious medical and ethical consequences. Physical restraint during labor prevents the body from taking its natural course of childbirth, therefore putting the woman in an unnecessary additional amount of pain and violating the United States' Bill of Rights, which states that prisoners must be guaranteed freedom from "cruel and unusual punishment."⁴⁷ Correctional officers must be prevented from interfering with appropriate medical care during labor through the use of shackles.

Changes in US policy and new state laws prohibiting the use of physical restraints on pregnant women are certainly signs of movement in the right direction, but this violation of the human rights of a population with very little voice must be taken seriously enough to create a prohibitory federal law. Federal legislation would allow all prisoners, regardless of facility or state, freedom from unnecessary, additional inflicted pain during childbirth and hold correctional officers accountable for their mistakes. The United States must be firmer in its commitment to defending the dignity of these patients and guaranteeing them equal protection under the law and affirm the values expressed in the Bill of Rights.

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WHEN A DISORDER IS NOT A PUNISHMENT

CRISTINA LOPEZ

The beauty of the brain lies in its complexity. No two human brains are wired the same way, nor should they be. Our unconscious human judgment focuses on weaknesses rather than strengths especially when discussing the attributes of individuals with autism spectrum disorders (ASD) and other neurodevelopmental delays. In the grand scheme of things, does the wiring of our brains really have more value than our overall contribution to society?

About 1 in 68 children are on the autism spectrum according to the Center for Disease Control and Prevention (CDC). Autism is a particularly difficult topic to discuss because its neurological basis largely remains a mysterious combination of genetic and environmental factors. People still believe that there is a link between childhood vaccinations and autism. Everyone is entitled to his or her opinion about the vaccination debate, and discussing this issue is not my primary purpose. However, stating that vaccinations could possibly cause autism despite plenty of evidence against it contributes to the greater public perception of autism as a negative side effect or a preventable disease. Therefore, a shift in the way we perceive neurodevelopmental differences is necessary. A raise in awareness begins here.

Back in elementary school, we learn that some of our peers are better at sports while others are better at art. An outgoing student receives more attention than a quiet, socially awkward one, possibly resulting in a lower sense of self-esteem. As a society, we need to reconsider what we value and remember that children, adolescents, and adults with autism are functional human beings with their own intelligence and virtue. In fact, over 40% of those diagnosed with an autism spectrum disorder are said to have above average intellectual abilities (CDC). For many, understanding the gist of a conversation or getting the punch line of a joke may be difficult, but oftentimes their music or art skills are impeccable.

Trouble with social interaction is common among people with ASD. Nonetheless, we must remember that just because somebody cannot communicate effectively does not mean that they are not having plenty of thoughts. *The Reason I Jump* is a book by a nonverbal thirteen-year old boy named Naoki Higashida, who is considered to have a severe case of autism. Through the use of an alphabet grid, he heartwarmingly forms words and sentences to respond to questions about autism that he assumes people want answered. In doing this, Naoki proves that the language his caregivers and loved ones use around him indeed affects him. Temple Grandin, another famous author on the autism spectrum, takes pride in the idea that she sees the world in pictures. These minds have a unique way of seeing the world and these senses should not go unnoticed.

In recent years, there has been a rise in the amount of autism cases. ASD currently affects over 3 million people here in the United States alone (CDC). Professionals attribute this surge in autism to better methods of diagnosis. What most people do not consider, however, is that many of the most brilliant figures in history may have been diagnosed with an autism spectrum disorder if they had lived with today's modern technology. Albert Einstein was said to have difficulty in social situations and exhibit hyperactive senses, which are both common ASD behaviors. Similarly, Wolfgang Mozart was said to have extreme sensitivity to loud noises despite his composition of many influential classical pieces. The world would be quite monotonous if there was nobody like Einstein or Mozart and everyone had the same skill set.

All brains are equally important in contributing to the greater good of society, and this is the kind of thinking that promotes acceptance for those whose brains are wired differently than our own. Let us strive to think inclusively rather than citing autism as a negative side effect. Although difficult to navigate at times, autism is not a punishment. Individuals on the spectrum may suffer from physical health complications, but it is our job to ensure a supportive community to foster the minds of all kinds of thinkers. Their minds are far from shut down, so we must not shut them out.

WHAT MATTERS IN THE END

COLLEEN BRADY

We ask *how we can help you?*
and *where does it hurt?*

We are taking vitals, making sure your lungs
are breathing, that your heart is beating, holding
your hands, those lands of blue-green
veins, with sun spots scattered like
rain drops, that's the first sign
of your collection of years, a process

of stages, of new normals, of changes.
so what do we do when your own words
begin to taste like a mouthful of ginger,
milk gone sour, and your own voice
your own voice when you speak is a foreign
country, a lost helpless country, etching out
unfinished stories:
you remember your Air Force
days, the baseball games, the first time
you saw Annie

Forgive us, there's nothing we can do when
your home's burning down, the home
your soul rests in is burning down, festering
that fire, anger you can't control, and
when visitors come in and you push them away,
you are sleeping more than you are awake,
we tell you it's normal to feel this way, it's
the new normal, not easy, and we don't know
when you can accept that
you are dying you are dying you're *dying*.

forgive me, it isn't easy to let go and maybe mortality
is an illusion, some haze makes us forget that
because our thoughts will sing back to you every day
haunting is something people seem to know how to do
but right now, we can hold your hands.

CAUTION: AT YOUR OWN RISK

A Collection by Samantha Ng



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FEATURING:

DOCTORS AND WRITING

GUEST CONTRIBUTORS

Rita Charon, MD, PhD

Author of “The Writer’s Quest”

Rita Charon is a general internist and literary scholar at Columbia University in New York. She received her MD from Harvard in 1978 and her PhD in English from Columbia in 1999. She originated the field of narrative medicine in 2000 and has been directing the Program in Narrative Medicine at Columbia since. She writes and lectures extensively on the role of narrative skills in caring for the sick. She is the author of *Narrative Medicine: Honoring the Stories of Illness* and co-author of the forthcoming *The Principles and Practice of Narrative Medicine*.



Caleb Gardner, MD

Author of “Undiminished Somewhere: Medical School and Philip Larkin”

Born and raised in the Boston area, Caleb Gardner is currently a resident physician at The Cambridge Hospital. As an undergraduate, he majored in English and completed an MFA in Creative Writing before receiving his MD from Johns Hopkins Medical School.



Perri Klass, MD

Author of “Listening For Stories”

Perri Klass is Professor of Journalism and Pediatrics at New York University, where she is Director of the Arthur L. Carter Journalism Institute. She attended Harvard Medical School and completed her residency in pediatrics at Children’s Hospital, Boston. She has received numerous awards for her work as a pediatrician and educator, and has written extensively about medicine, children, literacy, and knitting. Her most recent books are *Treatment Kind and Fair: Letters to a Young Doctor*, and *The Mercy Rule*, a novel, which appeared in 2008. For five years, she wrote the monthly “18 and Under” column for the Science Section of the *New York Times*.



Danielle Ofri, MD, PhD

Author of “Skills of Discovery”

When Danielle Ofri isn’t seeing patients at Bellevue Hospital, she’s writing about medicine and the doctor-patient connection for the *New York Times* and other publications. She’s a founder and editor-in-chief of the *Bellevue Literary Review*, and is the author of four books about the world of medicine: *What Doctors Feel*, *Medicine in Translation*, *Incidental Findings*, and *Singular Intimacies: Becoming a Doctor at Bellevue*. Her newest book, about how doctors and patients communicate (or don’t) will be published in January 2017.



THE WRITER'S QUEST

RITA CHARON, MD, PHD

A playwright and actor who teaches in the Master of Science in Narrative Medicine graduate program at Columbia University told me about the new Russian-language production of Chekhov's "Cherry Orchard" at the Brooklyn Academy of Medicine. "I told all my Narrative Medicine students to go see it, even if the director decided to leave out the first act. It is pure Chekhov." And then she reminded me of the last words of the play, the last words that Chekhov wrote before he died. The dying house-servant who refuses to leave the estate, knowing it is about to be destroyed, says to himself as curtain falls, "Oh, you old good-for-nothing."

Whatever the connection between Chekhov's doctoring and his playwrighting, it is the case that doctors can—if they choose to and are gifted to—see things others do not see. Either our eyes are opened to the ultimate mysteries of mortal life or we are attracted to doing this work because the ultimate mysteries beckon. Either way, those of us doctors who gingerly place our hands on other people's intestines in the midst of abdominal surgery or those of us who listen, as we sit in the semi-dark behind the patient, to memories that are recalled only because they are being told to us are all privileged and cursed to see straight into the face of the radical doubts of life.

I recently announced a Creative Writing Workshop for Faculty on the health sciences campus at Columbia. Within a few days, I had 4 or 5 times as many applications as positions in the workshop. The applicants were nurses, public health professionals, psychologists, physicians, environmental science professors, clinical researchers, and psychoanalysts. Some said they wanted to improve their writing. Others said they had for years harboured a secret desire to write but never thought they'd find a way to do so. Many said simply, "What else can I do with all the stories I see and hear but write them down? How else can I be faithful to what I know?"

I will suggest to the participants another dividend to their writing when I meet with them. Not only can their writing keep fresh the memories of patients' stories and confirm the gravity and power of these stories. By writing them, they will also perceive them. The better we can represent what we see, the better we perceive it. Time and time over, as I teach close reading and creative writing to clinicians, I witness the profound epiphany of the writer who says, "I didn't know that until I wrote it down." They thus join the countless novelists and poets—Flannery O'Connor, E.M. Forster, Robert Frost, Joan Didion, George Orwell—who declare that they write in order to know what they think. As one writes creatively, freely, expansively, letting things happen in the writing that are not fore-ordained, he or she achieves a meta-cognitive experience

of whatever “knowledge” is. Using our imaginations and bodies and deeply stored hence unavailable memories, we create something *new* to ourselves. We surprise ourselves. We don’t know what we know until we represent it.

A corollary to this realization is that the writer needs a reader. In a writing workshop, the listeners tell the writer what he or she has written. The writer needs an *other* to read or listen to what has been written in order to be able to see what the writing holds.

As a doctor and as a writer, all these years, I think I have seen more about my patients by virtue of my writing and I have seen more about writing’s quest—those ultimate mysteries—by virtue of my patients. When the curtain falls, life’s good-for-nothingness might be seasoned by the satisfaction of having gotten some of it down in words.

UNDIMINISHED SOMEWHERE: MEDICAL SCHOOL AND PHILIP LARKIN

CALEB GARDNER, MD

When lecture classes ended about halfway through medical school and we got ready to begin our clinical rotations, my classmates and I were filled with a sense of excitement and possibility. In fact, so much seemed possible that I could hardly sleep. As I thought about the future it felt like time was rushing ceaselessly by me, and that to embark upon any one thing was to forgo countless others. In the middle of the night, when the hours passed most quickly, I picked up Phillip Larkin's collected poems and read over and over passages of regret and indignation at opportunities not taken, happiness withheld, and the infinite disappointments of a life measured against expectation, imagination, and desire. He sees the things we hope for as ships approaching in the distance and writes:

*We think each one will heave to and unload
All good into our lives, all we are owed
For waiting so devoutly and so long.
But we are wrong.*

In another passage, the same predawn moon that illuminated my bedroom beyond the need for lamplight was for him not the conventional source of wonder, but rather “a reminder of the strength and pain / Of being young; that it can't come again, / But is for others undiminished somewhere.”

Larkin's outlook is bleak, no doubt, but there is a certain defeated satisfaction in his resignation and self-reproach. The poem “Wild Oats” presents a prolonged and ultimately failed engagement from which he wryly takes away “that I was too selfish, withdrawn, / And easily bored to love. / Well, useful to get that learnt.” But the other part of the story is that perhaps he never really gave himself, or wanted to give himself a chance, ending the poem with a reference to a different girl who he met only twice: “In my wallet are still two snaps / Of bosomy rose with fur gloves on. / Unlucky charms, perhaps.” What is tragically moving here is that Larkin knows what he is giving up by fixating on something essentially imaginary, and does it anyway.

To me, poetry and medicine, humanities and science, have always been distinct yet inseparable. Most of the time they complement and reinvigorate each other simultaneously, but I have also looked to one at moments when the other has seemed inadequate or incomplete. So, when the euphemisms and superficialities of daily life become particularly intoler-

able, I often seek an antidote in the nuance and understatement of art and poetry. And, conversely, when the inner world with all of its complexities and contradictions feels especially vertiginous I almost always find more solid ground outside of myself in medicine and science.

Every morning after I began my clinical rotations, as I walked from the garage to the main hospital building, I passed the entrance to the outpatient center. If it was early, things would still be quiet, and I would fall into step with doctors, nurses, and other hospital employees arriving for the day. If it was a little later in the morning, or if I left campus in the middle of the day, I would see patients arriving, walking out, or waiting by the benches just outside the large rotating glass door.

Most of them were older. Many used canes or walkers, and some of the more disabled patients needed to be helped along by family members, or friends, or others who were paid to do it. There would be kids coming and going as well. Sometimes I couldn't tell if they were patients or just along for the ride. Sometimes it was painfully obvious. I remember one adolescent boy in a wheelchair refusing to be pushed by his parents while his younger sister walked behind the three of them listening to her noise-cancelling headphones with a look of profound boredom.

A few years later, early in my residency, I came home after a day in the ICU during which one of our patients had died at the end of a long hospital course. I sat down on the couch in my apartment and absentmindedly picked up the book of Larkin's poems and flipped to "The Building," his poem about a hospital.

After finishing, I paused and read the last lines one more time: "nothing contravenes / The coming dark, though crowds each evening try / With wasteful, weak, propitiatory flowers." I thought of the purple hyacinths that had remained on the windowsill of our patient's room that afternoon after everything else had been removed. I felt a momentary pang of sadness for Larkin, and then I closed the book and haven't opened it since.

L ISTENING FOR STORIES

PERRI KLASS, MD

I teach in two settings--in the Journalism Institute at New York University, and in the medical school, where I work with medical students and precept pediatric residents in clinic. I've been struck by the ways that both curricula emphasize the art of the interview--the professional skill of making a connection with a stranger and proceeding fairly rapidly to a conversation which goes well beyond standard casual discourse. Clinical training in medicine is in many ways an education in story-telling, though the stories can be extraordinarily specialized, and I think that the draw of those stories, and the pleasures and challenges of the storytelling are certainly part of my own continuing connection to clinical medicine.

I am certainly a different writer because I am a physician--I think that medical training has shaped my voice, my perspective, my eye for a story, and certainly my window on human experience. I believe that writing, for me, has shaped me as an observer and as a storyteller, and therefore certainly affected me as a clinician--but that may be to say that for me, writing has been a path into imagining and understanding lives that I have not lived. I don't think it's the only such path, and I hesitate to claim that I am in some way a "better" doctor because I am a writer--I just know that these disciplines have shaped both my perceptions and my practices.

The skills that you acquire when you study journalism, the practices of reporting, verifying, observing, are closely connected to many of the skills that you use in clinical medicine. I write both fiction and nonfiction, both reported journalism and personal essays, and I enjoy the process of thinking through the different formats and possibilities when there is a story that I want to tell. Writing gives me a chance to think about the value of language, to explore the possibilities of word choice and rhythm and syntax, choices and decisions which are not necessarily important when you are making clinical choices and clinical decisions. But I think that part of medical training is in fact to come to grips with the many elements of assembling and observing stories of so many different kinds, collecting details, listening carefully to other voices, and finding ways to hear--and tell--the stories in the world around you.

S KILLS OF DISCOVERY

DANIELLE OFRI, MD, PhD

If you think about what distinguishes the great physicians from the merely competent and ordinary, it is the ability to listen astutely and think creatively. These great doctors pay very close attention to what the patient says and does; they examine the patient carefully. These doctors think broadly, and are comfortable challenging accepted wisdom. These are skills that we can gain from the humanities in general and writing in particular.

Writing is a much slower process than the practice of medicine. So often, the daily work of medicine is rapid-fire, with hardly any time to think and reflect. This is a set up for medical error, as well as burnout and disillusionment. Writing, and especially revising—I happen to love revising!—forces us to revisit the situation, to go back several times and rethink our approach. It teaches us that our first thoughts may not necessarily be correct. Writing affords a luxury of discussion not measured in time or feeling. In our typical day, we work fast, we talk fast, we eat fast, we walk fast—often all at the same time. Writing is an almost sacred experience because when you think “on the page,” you are forced to slow down and engage in discovery.

I am not sure if writing makes me a better physician, but experience with writing and humanities makes me realize that there is always more to consider about a given situation. Most of the medical facts we learn now will become quickly out of date. (Thank goodness for computerized databases like UpToDate!) But the ability to think across disciplines, the ability to listen wisely, the ability to tolerate ambiguity, the ability to question and revise our first drafts – these are skills that stay with us for life.

THIS IS WHAT YOU'RE HERE FOR

ERIN ANNUNZIATO

This was our second time at Missionaries of the Poor. *Okay, you can do this. God, just go in. This is what you're here for.* I quickened my pace to combat the impulse to turn around and run. Run back to the school we had just come from, back to the dormitories we were staying in, back to the airport. *Stop being scared; you're terrible; stop. Stop. STOP. Just keep going. This is what you're here for.*

The bright blue building itself was beautiful, but subdued with age. A few young boys standing on a balcony on the second level peered down through the colorful foliage lining the walkway guiding us to the entrance of the first floor. Inside, three large rooms housed around fifty children aged a few weeks to thirty years who had willingly or reluctantly been abandoned by families unable to care for their extremely debilitating disabilities. They were instead cared for by a Catholic order of residing Brothers, a small group of locals, and a rotating host of ambitiously joyful foreign volunteers – supposedly including our group.

Through the gate to the first level, I immediately saw the boy who I had held at the end of our first visit. His short stature and permanently pleasant boyish face constantly begged for attention, and was currently targeting a white female volunteer from another group visiting the center. I impulsively turned my face away and walked closer to my group members. *Hey. What are you doing. He means no harm; he didn't mean to...* Last time, when I returned him to his crib before leaving, this boy had completely overpowered me: clinging to my neck and back and torso, begging without words to be held longer, pulling the V-neck of my sweaty cotton t-shirt down to my skirt waistband. Exposed, exhausted, and embarrassed, I had burst into tears in the middle of the room – in that moment I had hated that boy. *Hated.* Despite his severe disability, innocent intentions, affection-starved face, and despite the fact that I had actively and knowingly prepared for months to interact with and 'serve' others just like him, I hated him for his desperate, physical request for love and attention.

I hate myself.

This time, I walked into the room with the 'babies,' stroking their heads, rubbing their backs, and telling them someone was here. This room was set up like the other two: cribs lined four walls surrounding two rows of more cribs that created aisles. I absorbed their unregistering faces attached to curling bodies of frail limbs and malformed appendages. *Oh God, what are you doing, don't/don't/DON'T cry again... good. Keep going. This is what you're here for.*

One of the children restlessly flailed her arms and contorted her face in pained expressions. I rubbed her back. “Hi there, what’s bothering you?” I barely whispered, knowing I wouldn’t get a response. But moments later, she lay still, her face calm, eyes closed. Impulsively thinking I had hurt her, I withdrew my hand. She opened her eyes and her spastic movement resumed. *It can’t be that simple...* but as soon as I started rubbing her back again, she calmed once more. I was astonished. *This is what you’re here for...*

In the other two rooms, I repeatedly greeted blank faces and gently touched my skin to theirs. I hugged a few children in their cribs, but maintained my ground and refused to pick any up, remembering the boy from last time. *You’re terrible.* Walking out of the rooms and into the foyer, I was alone for a moment.

If this is what you’re here for, what is this?

It was a question I had been asking myself frequently since I deplaned in the Kingston airport. I had arrived with a group of 25 students who had also spent months preparing for the Jamaica Magis service trip led by Father Michael. In his hometown, he wanted us to experience God; he wanted us to see those we served as equals without pity, without thinking of ourselves as ‘us’ and the poor as ‘them.’ On my first day, I had stepped off the plane with the clearest eyes I could manage and began to simultaneously absorb and feel both everything and nothing.

As I walked through the foyer and back onto the patio where I had seen the boy-who-made-me-cry when I arrived, raw questions fired off in my head. *Where is God, where is He here? What if I had been born into poverty with a severe disability? I could be like them, exactly like them. Do they know they could have been born into something else? Into my world? Do they know this when they see me? Do they see me? What do they know? What do they think? They cry, they must feel, they must think. I must do something, if I could just...*

Most of the children on the patio were with volunteers, but a boy and girl placed in wheelchairs were sitting by themselves. They were completely immobile, and their eyes glazed over; they – whoever they really were – were trapped deep in bodies that bound from rather than bridged to the world.

No. This is exactly what you’re NOT supposed to be thinking: there’s no ‘us’ or ‘them’, no ‘us’ or ‘them’, no ‘us’ or ‘them.’

I walked over to these two children, greeting them quietly and grazing their twig-thin arms. As I stood over the boy, my nose then my gaze immediately followed the trail of flies buzzing around his shorts: he was sitting in his own feces. I immediately took a step back, horrified – he couldn’t even cry out like newborns with full diapers, let alone walk himself to the bathroom. Despite the Brothers’ sincerest efforts, this center was underfunded and understaffed relative to the amount of attention and supplies each child truly needed. I wondered how often this kid sat in his own excrement. Retreating, I left

the patio. *How old is he? Who else has this problem? Probably so many, all the time, everywhere. STOP you're pitying them... God, I'm pitying them, I'm not supposed to be pitying them. Ok he's probably one of the lucky ones, to be cared for here... maybe it's not so bad... maybe he doesn't feel it...*

Upon stepping into the foyer, trying to shun these thoughts by wondering how long it would be until we were whisked away and moved on in our itinerary, I almost laughed at my instant feeling of dumb clarity. *He's human. Like you. He feels it. Like you.*

I stopped one of the group leaders. "Hey, um... there's a boy on the patio who went to the bathroom in his pants. It seems like he's been sitting there for awhile. Should I...?"

"Oh. I'll go tell one of the Brothers."

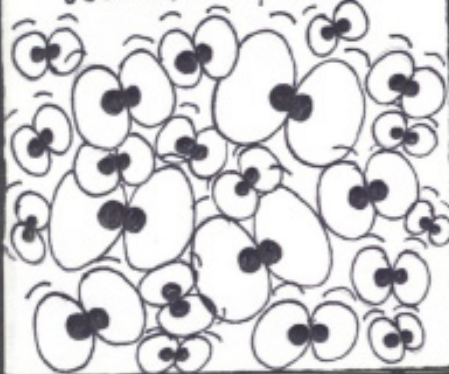
Within minutes, the boy was wheeled past me – presumably to be cleaned so he could sit more comfortably in a fresh outfit.

God, this is what I'm here for.

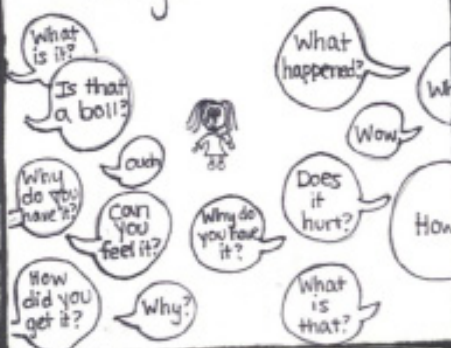
STARLING

KAROLINA MIECZKOWSKA

This was a common scene in my life:



And the questions ranged from:



"Actual"
Karolina



"What People Made Me Feel Like"
Karolina

There's only so much that a young girl can take...



... before you start to worry about the important things in life.



So when my mom gave me some advice, I thought I'd go with it.



(Although, I was thinking something along the lines of :))



Her advice seemed to work sometimes...





END

UGANDA'S "KILLER NURSE" DESTROYS COUNTRY'S FIGHT AGAINST HIV/AIDS

HUNTER NEWMAN

"Rosemary Namubiru, 64, a nurse with 35 years of experience, was working at the Victoria Medical Centre in Kampala, Uganda. On January 7, 2014, Namubiru was attempting to give an injection to an ill 2-year-old patient. Neither she nor the mother could calm the distraught child. With the child writhing and kicking, the needle accidentally pricked Namubiru's finger; she stopped what she was doing, washed and bandaged her pricked finger, and returned to the child. She was eventually able to administer the injection.

Uncertain about whether the same needle was used throughout, the mother became concerned about the possibility that her child had been exposed to HIV (Human Immunodeficiency Virus). It was confirmed that Namubiru was HIV-positive and on anti-retroviral drugs. The child was given an HIV test; the results were negative. A precautionary 2-month post exposure prophylaxis regimen was initiated, after which the child was retested.

Rosemary Namubiru was arrested in front of a bevy of journalists. She was held by the Criminal Investigations Department for four days before her first appearance in court. She was charged with attempted murder, which carries a sentence of up to life imprisonment, and remanded to Luzira National Prison to await trial. On February 7, 2014, she was denied bail and returned to prison to await trial. Minutes before the trial began on February 11, 2014, the prosecutor announced the charge would be changed to "negligent act likely to spread infection of disease." Namubiru's attorney appealed the case

and she was released 5 months following the trial, with the judge stating she had already served her sentence to the full. The child has not tested positive for HIV."¹

The case of Rosemary Namubiru is shocking at first glance. Reading the summary brings attention to Namubiru's questionable practice as a nurse. The reader considers the case as one implementing excessive charges, but, in the end, having justice rightly served. But was it? Delving deeper into the story, the details of Namubiru's societal treatment become horrifying. This simple misunderstanding wrongly accused the nurse of unsafe medical actions and revealed the hidden issues of stigma for people living with HIV (PLHIV) in Uganda.

In order to better understand this case, it is vital to be contextually informed about life in Uganda in a time of AIDS. According to the GAP report, four-percent of the global HIV population and seven percent of all new HIV cases globally are located in Uganda.² Uganda is one of two sub-Saharan African countries to have the number of new HIV cases rise since 2005. Although 2005 to 2013 saw a nineteen percent decrease in AIDS-related deaths in Uganda, it was accompanied with a twenty-one percent increase in novel HIV infections. The decrease in AIDS fatalities may be due to the fact that about forty percent of adults are on antiretroviral treatment (ART).³ However, it is unnerving that Uganda has experienced the third larg-

est increase of infections in the world. In the past, Uganda has been recognized as one of the leading countries in a progressive acceptance of AIDS; from 2005 to 2013, there was an increase of 175% in accepting attitude of PLHIV.⁴ While this seems promising, there are still setbacks that have taken place, including the Anti-Homosexuality Act of 2014. This act increased the punishment for performances of homosexuality by sentencing the offender to life in prison.⁵ Bills of this nature exemplify societal rejection of men who have sex with men (MSM), causing social stigma among those with HIV and thus degrading the accepting attitude. The case of Rosemary Namubiru is yet another example of those vital setbacks that Uganda has faced in HIV acceptance.

Namubiru's case seems as though it may have been linked to politically charged responses to HIV/AIDS. The Ugandan Parliament had recently passed a bill criminalizing attempted and intentional HIV transmission.⁶ This bill was awaiting the President's signature, and Namubiru's case may have been a perfect conviction to influence his decision. There are some signs of the case which bring this argument to reality. First, Namubiru was the only person to be charged under a law passed fifty years prior that criminalized negligence in risking the spread of an infectious disease.⁷ It is not coincidental that as soon as Parliament sought a Presidential signature for a HIV transmission bill, the first HIV negligence charge arose.

Secondly, Namubiru's case is based off of hearsay. The immediate arrest and conviction of Namubiru is constructed off of two contrasting viewpoints.⁸ The sixty-five-year-old pediatric nurse, with thirty-five years of professional experience, has her voice in a medical experience heard second to the mother's. Not to declaim law officials, but it seems

quite difficult to convict a nurse with such experience on hearsay; especially from a non-medical professional's claim, where the child tested negative for HIV. At first the authorities may have desired to appeal to the mother's concern, as one can understand. But to allow such convictions to continue following the child's outcome is flabbergasting.

Furthermore, the chance of exposure to HIV via a needle puncture or prick to subcutaneous skin, as in this case, is only about 0.32%.⁹ This chance is less likely than one's cause of death being due to firearms in the United States.¹⁰ Understandably so, this little opportunity seems like ninety-nine percent likelihood to the parents. One can understand the parental concern, but to continue conviction of the nurse after learning the child's negative status is unjust. The father was quoted stating that he had hoped the case would spur the president to sign the bill criminalizing HIV transmission.¹¹ This fed directly into Parliament's hands, the bill finding support without much effort. The Ugandan public took over Namubiru's case, displaying its emotions to the president.

How long can a politically driven response go before it is considered too far? The ethics of this question cannot be overlooked. It is unethical to use a human being in order to influence political legislation. Namubiru's life is taken away due to something that may have occurred, but did not. Who is the president, public, parliament, or anyone for that matter to make the decision to take one's life? On a broader scale, how unethical is it to evaluate the value of one's life based on its benefit to another cause? Think about the effect this bill, incriminating attempted and intentional HIV transmission, would have on pregnant women. Would women want to get tested after becoming

pregnant? If they are HIV positive, and infect their child, they would be incarcerated. There is no ethical reasoning to take a mother away from her newborn child, simply because the child acquired HIV. Now, this child, having a lifelong disease most likely requiring special assistance and attention, would have no mother in his or her life. Mothers can pass on diseases such as herpes, syphilis, or chlamydia, yet there is no legislation affecting these cases. Thus, ethical concerns arose once Namubiru's case was influenced by outward factors.

This case cannot be analyzed without discussing the role of stigma surrounding HIV in Ugandan society. The treatment of Namubiru sets an example for other healthcare professionals, especially those living with HIV. Healthcare professionals battle stigma for their patients, but as PLHIV they also fight stigma against themselves. One of the few researchers who studies this topic in Uganda is Margaret Kyakuwa. In her work, "Ethnographic experiences of HIV positive nurses in managing stigma at a clinic in rural Uganda," Kyakuwa explored the workplace experiences of HIV-positive nurses. She saw that HIV-positive staff in Uganda live in hiding for fear of facing stigma. This case study is appealing since the health clinic in which these nurses were working is dedicated to treating HIV/AIDS patients. All of the nurses in the study feared disclosing their HIV status to fellow colleagues or patients. Such stigma is seen in Waliggo's writing. Noerine and her husband, Chris, who discovered he was HIV positive, felt as though the staff did not want to take care of him at the hospital where they both worked. Chris' disclosure of his HIV status completely altered his working relationships and environment.¹² The nurses in Kyakuwa's study feared stigma to the point where they visited various clinics to receive ART. They claimed to have witnessed drama or gossip regarding those with HIV,

and thus wanted to have their private lives separated from their professional work. Although the nurses were simply protecting themselves, they were aware of the contradictions by which they were living: in the HIV/AIDS health environment, disclosing one's status should be considered virtuous. Clearly, the healthcare system failed to provide HIV/AIDS workers with the support they need. Nurses are in a position to help others and save HIV-positive lives in Uganda, and yet the care they provide is not reciprocated. HIV stigma is extremely real and powerful in Uganda, even for those who fight against it.¹³

Unfortunately for Namubiru, the media and news promoted the HIV stigma mantra during her trial. As police were escorting Namubiru, she had her head down, not displaying her face. Since the media was attempting to obtain a photograph of her, the police officer grabbed her by the hair and lifted her face towards the cameras.¹⁴ Her image surfaced across the televisions and newspapers in Uganda. This situation is unique in Uganda, exhibiting the influence of stigma. There was a Belgium case in 2000 where an AIDS-infected nurse transmitted HIV to a patient. The only media coverage the case received was an article featured in the Yahoo Daily News, originally written as a manuscript for the Journal of Virology.¹⁵ The article does not report the nurse's name, or discuss incarceration, but instead focuses on the contraction of the disease, and how hospitals could improve practices to minimize the risk of transmission. There were no news trucks or trials to destroy an individual's life, but instead presentation of the case a learning experience.

The way that Namubiru's case was reported both endangered and devastated the nurse, exemplifying the GAP report stating that media reporting of HIV in Uganda is of-

ten incomplete, misleading, or incorrect.¹⁶ Articles surfaced with phrases such as “Killer nurse,” “the fiendish nurse,” “Baby Killer,” and “HIV-Injection Nurse.”¹⁷ Some articles went even further to accuse Namubiru of withdrawing her own blood from her arm and deliberately injecting the child. These falsehoods continued to grow, blowing reality out of proportion. Namubiru was essentially tried and sentenced by the media,¹⁸ the police, and the public. Regardless of the outcome of the trial, this poor nurse already had her life claimed by the Ugandan society.

In reference to Kyakuwa’s study, and the media’s broadcasting of Namubiru’s case, the discussion of confidentiality must be examined. One of the nurses, Florence, discussed receiving ART at a different facility in order to remain anonymous, claiming, “Remember the principle of confidentiality still holds!”¹⁹ This principle was not upheld for Namubiru. Not only was her HIV status disclosed to the hospital and family of the child, but to the entire nation. Namubiru’s HIV status was broadcasted globally, spreading virally on the internet, newspapers, and television. The topic of confidentiality and ethics crossed paths here. Was it ethical for Namubiru’s HIV status to be broadcasted to the entire nation, along with false claims of her wrongdoings? Namubiru was never asked to be tested for HIV nor had she signed a disclosure form releasing her information. The new bill clearly addresses this topic and states that any HIV test may be disclosed without consent to any person if they pose a clear and present danger of HIV transmission.²⁰ In terms of ethics this does not seem correct.

In other countries, the concept of confidentiality is held to a higher degree. In Gerald Gleeson and David Leary’s case study,²¹ a HIV positive young man began dating a girl who belonged to his Come In Youth center in Australia.

The center would not break the confidentiality of their patients, and did not inform the girl about her partner’s status. This case was a perfect example of one person’s HIV status posing a clear and imminent threat of transmission. Yet, the ethics of confidentiality were upheld. This goes to show the specific influence of HIV stigma in Uganda relative to other countries. Due to this stigma, the confidentiality should be held to a higher standard, protecting those with the disease. Keenan writes, “AIDS has forced us to recognize that respecting individual rights is a critical safeguard for the health of the community as well as for the person.”²² By the government owning power of HIV disclosure, it is also claiming power over lives of PLHIV. In a society with stigma as strong as Uganda’s, disclosure may ruin a life. Who is the government to control the quality of one’s life? Once a person obtains this morbid disease in Uganda, it seems as though all of the “rules” change. In Namubiru’s case, the police illegally broke into her house and obtained her bottle of ATR, using it against her in court. Had she not been HIV-positive, this would never have occurred. Uganda needs to recognize the ethical implications both its laws and actions have upon its constituents.

The question of gender arises in Namubiru’s case; if she were male would the situation have been different? Statistically women are more affected by HIV in Uganda than men, with 8.2% to 6.1% prevalence of women to men, respectively.²³ Women in Uganda need to be better protected, and the government needs to address the powerlessness and vulnerabilities that enforce gender based violence for PLHIV women. This has to do with women’s economic dependence upon men in Uganda, where women accept the violence in order to stay alive.²⁴ According to the GAP report, over thirty-percent of married

women in Uganda receive spousal physical or sexual violence. Namubiru is somewhat of a rare case; she is a female who not only completed secondary school but also went on to receive a college degree in a society where there is only about a twenty-percent retention rate of women in the first year of secondary school.²⁵ Ugandan society's treatment of Namubiru's case demonstrates the phenomenon that even women who have overcome significant aspects of society's female suppression are not safe. In a male dominated society, such as Uganda, it can be argued that no man would have lived through this nurse's experience. The government claimed to have given her justice by freeing her from jail, but this did not free her of the emotional scarring. Legal policies such as the HIV Prevention and AIDS Control Act continues to suppress women, putting them in a vulnerable state.²⁶ Because healthcare providers can disclose HIV status to sexual partners without consent, women are at an increased risk of physical violence, including domestic violence if husbands discover the positive status of their wives. This issue needs to be addressed by the Ugandan government, and public displays of mistreatment to upstanding, high status women place the female gender in danger.

After examining Namubiru's case, it is alarming how this sixty-five-year-old woman was treated both by her government and society. One could understand how, as a parent, it would be upsetting to think that your child may have contracted HIV; but after discovering the negative results, would it not be just to sympathize with the nurse? This woman's intention had been to assist the child medically, not to hurt him. It is quite shocking that not one person in Uganda attempted to help Namubiru. She worked as a pediatric nurse in the same hospital for thirty-five years and yet she received no support from the institution. No statement was released by the hospital regarding this situation;

it needed, but failed, to stand up for its employee.

The Namubiru case is extremely dangerous for HIV populated African countries. The Ugandan government is unaware of this danger, and it is quite ironic that a country recognized for being a leader in battling the HIV/AIDS epidemic is now regressing. This country has devoted billions of dollars and an insurmountable amount of time encouraging its citizens to act responsibly with this disease.

However, the situation surrounding Namubiru's case will discourage those who were acting conscientiously. Why would an individual choose to receive testing with the knowledge that they run the risk of experiencing what this sixty-five-year-old nurse endured? This woman should have been focusing on retirement²⁷ and spending time with her family, rather than watching her life disrespectfully be thrown away. Good people will now avoid testing for HIV in order to prevent others from knowing their status, thus protecting themselves. Arguably, the government set a threatening precedent for those living with HIV/AIDS. The fundamental rights that PLHIV have in Uganda are clearly different than others. It is understandable that the government is attempting to prevent further spreading of the disease, but its naïve reckless reaction may cause some of its most successful HIV programs to self-destruct. The bill that was passed will promote HIV ignorance and thus enable the spread of the disease.

Namubiru was simply doing her job, what she loved to do: helping children in distress. Due to the government's political drive and the stigma of PLHIV in Uganda, Namubiru's life was ruined. This case calls for necessary change in Uganda. There is a reason the country is on the rise in terms of new HIV infections per year. Without a change

in societal judgment and government decisions, HIV/AIDS will continue to win the epidemic battle in Uganda.

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CARETAKER

CAROLINE HONE

It's okay, it's okay. Everything will be just fine.

These phrases, as if echoed by a broken record player, repeated continuously in my head—or so I thought. They reached my lips and I whispered the assertions under my breath, as if speaking them out loud would make them true.

Hurry, book the car service. Faster. She's in pain.

I could hear these thoughts, not wanting to reveal the pit I sensed in my stomach or the breathlessness I felt, as if the air had been shoved out of my lungs. I could hear the music surge back to life; intermission had ended. Clearly we were not staying for the second act.

Okay, done. Car is on its way. How's mom?

She sat hunched over to my left, arms clutching her side, eyebrows furrowed, teeth clenched. My two younger sisters hovered next to her. “Will mom be okay?” “Yes of course, it's mom.” She's strong, she's invincible, she's our mother.

How can this be happening?

Just a few hours earlier in the day, the four of us huddled around a table at that Italian restaurant; in between forkfuls of cheesecake, we declared it the best day of summer. Chatting on the train ride into the city, wandering along Fifth Avenue, wiping away the tears from laughing at the displays in the SNL exhibit—I guess a Broadway show to end the day would have been too perfect.

Was it something she ate? Too much physical exertion? Any relation to her colon surgery just four months prior?

I strapped her into the front seat, and we began the grueling forty minute drive back to my grandparents' house. I alternated between stroking Natalie's shaking hands and drying the tears streaming down Grace's cheek, rarely removing my eyes from the car's side mirror, in which I could glimpse my mother's pale face.

*It's okay, it's okay. Everything will be just fine.
But would it be just fine?*

Back on campus the following week, my mother called to declare that she needed to have her gallbladder removed.

Another surgery? This soon after the last? Hadn't she spent enough time in the hospital, enough time feeling sick, enough time being the patient?

A mother is meant to be the caring one, not the one in need of care. Visiting her daily in the unfamiliar New Jersey hospital the week prior, I felt like the mother.

I'll get some ice for your ginger ale. Let me put the socks on your feet, they feel cold. Need to use the bathroom? I'll help you stand. How are Nat and Grace coping?

For a moment, I could understand my mother in a way I never had before. I understood why she lies sleepless at night when Natalie is stressed about homework—she assumes the tension Natalie feels. I understood why she gives Grace Motrin at the first mention of a headache—she doesn't want her to feel any more pain. I understood why to this day, she insists on coming to my annual doctor's appointment and listing the items of concern that she has documented since the last visit: she wants no symptom to go unrecognized.

I understood what only a mother can truly feel: the worry, the fear, the love. I understood that when my mom assures me that "it is okay" and "everything will be just fine," that there may be a piece of her that doesn't wholly believe it. I suppose that no one, not even my mother, can truly know what to expect, because sometimes, life is as unpredictable as a gallbladder attack in the middle of a musical.

S LICES

MAISIE KISER

“Good Morning, Jack, how are ya honey?”

My rowdy, red-headed friend approached the window, giving Nurse Antonelli a playful wink before taking a paper cup that looked more like a thimble in his varsity-football-big hand. Hair a mess, backpack unzipped, and collar partially upturned, he raised the cup to his lips, throwing the two pills back as enthusiastically as a college freshman takes a vodka shot. He turned to face me and opened his mouth: “All gone! Catch ya later, Doodles,” calling me by an unfortunate nickname I acquired at boarding school. This was Meds Line, and we were the Meds Line Crew. There were at least forty students on meds at any given time, probably closer to sixty. We joked about making T-shirts, our dosage numbers on the back.

It was easy to tell why certain kids were there. Jack was an obvious ADD child. Alden took meds for ADD and depression. Emma took every anxiety medication under the sun before being expelled for harboring a supply of prescription drugs that would make any pharmacy proud. Boarding school was a difficult place to keep secrets and they were harder to keep if you went to Meds Line. Everyone there had *something*. I always wondered: *Did they know? Could people tell what I had?*

Every morning for almost three years I looked through the window to the other side, to the tidy rows of bottles and labels—towards my salvation. It’s strange to think I always said thank you for those two pills, but I did.

Sip. Swallow. Smile.

“It’s hard to explain,” I told her. The school psychologist, Dr. Ferns, sat across from me in an armchair with her feet tucked beneath her, just as she had the first time we met. It was the reason I knew I could talk to her—the way she sat on her feet. “Well, just try and walk me through what happens.” I loved this woman, who knew more about me at the time than my own family, yet I still had trouble looking her in the eye when I told her the truth. I had to look up. Up and out through the floor to ceiling window, with a diamond shaped pane at the top. I would look out the window, watching the leaves change week by week, and tell her my truth.

It was as if I watched myself do it. Hunched in the bathroom stall, I’d start with a few cuts on my right arm. Then I would

switch to the left. It wouldn't feel like enough. It wouldn't feel like I had tried hard enough to *make* myself feel. So I would keep going, working my way up my arms until my skin was hot, stinging, swollen. I would cut until I was tired. Sometimes panting. Frantic to prove that the age old adage was true, that it was in fact better to feel pain than nothing at all. I would stop, throw the razor onto the windowsill and look out into the night, wondering each time what I had done.

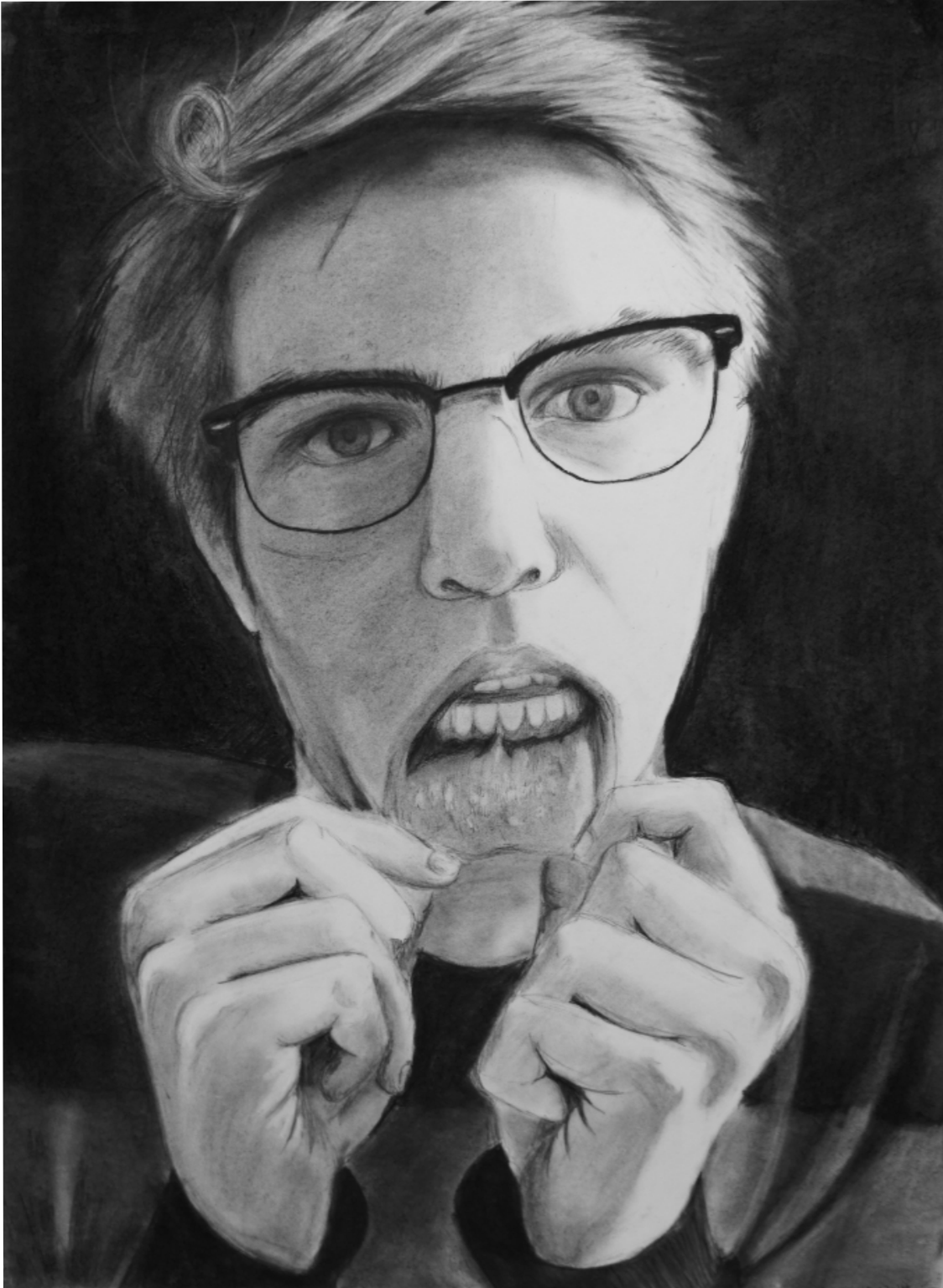
"I'm coming," read the text. I pressed my face against the frosted window, as if I could see him running to get me, hold me, save me. When I realized I would never be able to see him coming, I slid to the floor against the radiator. Willing the seconds to pass more quickly, I cried until I heard banging on the door. "Mai, open up." When I hugged him I put my elbows around his neck, my forearms crossing over one another, facing up. I didn't want to ruin his sweatshirt.

One day while on health leave from school, I went to the Metropolitan Museum to get lost. After wandering around for a bit, I went to the ladies room. I opened the door only to see the reflection of Mrs. Andrews—our headmaster's wife—in the bathroom mirror. Without hesitation, I turned and bolted. I hoped she hadn't seen me. I walked quickly and aimlessly until I ended up in an unfamiliar wing of the museum and sat down on a lacquer bench.

That was so weird. What is she doing here? I looked around. I was alone in a windowless room with enormous engraved tablets on each wall. *Why did you run away?* Mrs. Andrews was famously affectionate, and had I not turned and run she would have hugged me right there in the bathroom. *What are you doing here?* I had left school for a few weeks, supposedly, to get better. In doing so, I had left the love that kept me afloat: my friends, Dr. Ferns, the dorm that was my home—all the people who had fought for me when I could not muster the strength. *What the hell are you running from?*

Seeing Alice Andrews in the ladies bathroom of the Met, 263 miles from campus, was proof of how futile my attempts to run away from my problems were. Because no matter where I went or what I did there was one person I could never escape. I carried my fears, my anxieties, and my suffocating desire to be the most loved, the most beautiful, and the most perfect with me everywhere, the way I carry my scars today.

I didn't want to get lost anymore, so I stood up, walked two miles down Fifth Avenue, and went home.



CECILIA DOLAN

FREEDOM TO DECIDE: THE ROLE OF AUTONOMY IN MEDICAL ETHICS

LESLIE PERLERA GONZALEZ

“It is our choices that show who we truly are far more than our abilities.” –J.K. Rowling

So ingrained has the notion of self-determination become in our society that it has seeped into a realm that for centuries was dominated by those we once considered god-like in their expertise. Where at one time physicians made all medical decisions on behalf of their patients, patients can now decide for themselves whether or not to accept a physician’s recommended intervention. In fact, this transition of power to the patient is evident in the passage of the 1991 Patient Self-Determination Act, which requires that “hospitals, nursing homes, and other health-care facilities...provide patients with written information about relevant state laws and the rights of citizens under those laws to refuse or discontinue treatment,” and in the host of cases that have been disputed over issues of consent.¹ Put simply, patients now have the right and responsibility of managing their own health. This newfound autonomy has given rise to efforts to control even the ways in which we die. With advances in medical technology, it is now possible to evade death for longer periods of time, and more and more human beings are choosing to prolong the inevitable. At the same time, this emphasis on free choice has left those who are unable to choose stuck in the dominion of neither the living nor dead.

The art pieces that I chose to examine through the lens of autonomy and medical ethics included a painting by Childe Hassam, “At Dusk (Boston Common at Twilight)” and an untitled photograph showing a nicely-dressed couple standing on a sidewalk, selected by Peter J. Cohen as a part of an assortment of unfinished works. The painting of Boston Common drew me in because of the stark divide between the greenery of the Common on the right hand side and the rising buildings lining the block on the left-hand side. The painting depicts a then modern mid-19th century Boston Common, which at the time of the painting’s conception had already been transformed from a cattle grazing field into a park of elm trees and promenades.² At that time, the scene would have been seen as distinctly modern due to the distinguished building facades at the side of the park and the bustling street full of horse-drawn carriages and an orange trolley. Several figures, including one well-dressed woman and her children feeding the birds in the foreground, can be seen in the painting. The scene is not only one of tranquility, but also of prosperity. There is a certain ease with which the mother and her children, with their little fur muffs and fur capes, regard the birds. The city lights shine bright in anticipation of the coming gloom. To me, the traffic on the left side of the painting is representative of how humanity is constantly running against the course of nature. The streak of progressivity captured in this painting is the same element reflected within our current society, which largely encourages the expansion into greater and greater unexplored biological territories.

What was once impossible is now a reality; human beings can now linger among us even when they are beyond the capacities of breathing and normal brain functioning. The rise of machinery, such as the ventilator, spawns questions of what it means to really be dead and what qualifies us as living. We can now distinguish between several categories of dead, such as “total brain dead” in which there is no electrical activity in any part of the brain, or “traditionally dead” in which there is irreversible cessation of the heartbeat and respiration. There are those of us who would choose to be kept “alive” by any standard or definition and who would seek all possible means to avoid the unknown. The choice now exists: to continue on in whatever possible form even after we have lost consciousness, or to pass away. We get to decide in the form of advanced directives and verbal communications to our peers and health care workers. Before the modern age of medicine there was little we could do to resuscitate our patients once the heart or lungs stopped. Now the possibility to push our lives beyond our natural means is readily available to us.

The nature of medicine and the goals of the physician have changed. Until the 20th century, the role of the physician was, if not to cure, then to care for the patient and promote the patient’s comfort. Now physicians make value judgments concerning their patients’ lives, actively aid in the extension of human life, and even sometimes help to promote the cessation of certain lives. Many issues affecting our lives have commonly become medicalized and fall under the purview of the physician or other practitioners because physicians and practitioners can be “expected to have developed special sensitivity and skills regarding the judgments to be made, and are an identifiable group that can be readily held accountable for serious error.”³ For example, in *Belchertown v. Saikewicz*, the Probate Court largely deferred to the doctors’ expert opinion. In this case, sixty-seven-year-old Joseph Saikewicz, a mentally retarded patient who has been diagnosed with a particularly lethal version of leukemia, must have his future decided for him. The Court explicitly inquired of Dr. Mying Cho whether, given the nature of the Mr. Saikewicz’s illness and the risks and benefits which treatment would incur, it was his opinion that treatment should be administered at the present time.⁴ When both Dr. Cho and Dr. Melnick stated that they would not give the treatment at the present time in light of the discomfort Mr. Saikewicz would be likely to experience and his inability to understand the situation, the Probate Court deferred to their opinion and held that life-saving treatment would not be given.

Mr. Saikewicz passed away without pain or discomfort due to a complication of the leukemia.⁵ In this case, no attempt was made to solicit an opinion that would most closely confer with that of someone in Mr. Saikewicz’s condition. Instead, Judge Jekamonksi reflected on what he himself would want, which is to go ahead with any treatment if it had any chance of prolonging his life. In presenting their evidence and stating what they believed the average rational person would want, the doctors had almost total determination over the results of this case, and therefore Mr. Saikewicz’s life. Before the invention of life-saving treatments such as chemotherapy, the doctor would not be put in the position of having to decide whether to treat a mentally retarded, terminally ill person. The patient would simply die as an effect of the disease.

The problem becomes identifying when medicine should no longer be employed in the effort to extend a person’s life. In

Atul Gawande's piece, "Letting Go," we learned about the consequences of continuing treatment in spite of the futility of the intervention. In the case of Sara Moore, who had been diagnosed with terminal cancer, the benefits that were to be derived from treatment would be very slight (only a few extra added days of life); however, after it became clear that remission was not likely, she was given not one or two, but three rounds of additional chemotherapy. In this case, the data showed that after the failure of second-line chemotherapy, lung cancer patients rarely gain any additional survival time from further treatments, and instead often suffer significant side effects.⁶ Sara's last days were spent in a hospital when she could have been enjoying her young family in the comfort of her home. The problem that our society faces is recognizing when it is time to let go. It is often only after we have extended millions of thousands of dollars in health care, and we have exhausted every available treatment option, that we stop trying to save the lives of our loved ones. Much like the Common in Has-sam's painting, we have clipped and boxed nature into one remote area of our lives while medical technology courses on ahead.

In the United States, a great portion of our GDP goes to paying for expensive medical care. Between 1960 and 1983, private and public expenditures on health care rose from 5 to 11 percent of the GDP. The greatest amount of our health care expenditures goes to end-of-life care, and specifically treatment for those with terminal illnesses.⁷ Five percent of Americans account for half the total we spend on health care. A ten-day visit to the ICU can cost as much as \$326,000.⁸ It is clear that expenditures have to be cut. Unfortunately, with the transition of autonomy to patients such as Sara Moore, who cling desperately to their lives, doctors often fall prey to ill-advised courses of action. Doctors who know full well that medicine cannot fend off death forever and that at some point the "letting go" process becomes far more beneficial to the patient in question than allowing him or her to continue treatment. However, our society continues to hold fast to the notion that John Stuart Mill expressed so eloquently one hundred years ago: "Over himself, over his own body and mind, the individual is sovereign."⁹ With notions of freedom and self-determination pervading the medical ethos, doctors find it hard to say no to the dying patient, such as 11-year-old David Stewart. The demands of the desperate, terminally ill population is changing how medicine operates because the more money that is expended on futile care, the more our premiums are raised and the more expensive health insurance becomes.

Modern medicine has the power to sustain a person's body long beyond what the average person can bear. In the effort to extend life, we destroy it. It is with horror that Karen Ann Quinlan's family regarded her withered body,

"They had her uncovered, because of this new machine, and Mama could see what I never thought she would have to see—Karen's little figure, shrunken and twisted in a position that seems inhuman, with a blanket stuck between the legs so the bones don't cut into the flesh, and the gauze pads between her toes to keep them from bruising each other, and the bedsores that go so deep you can see the hipbone exposed."¹⁰

In seeking to gain control over the medical realm, we expose our own humanity, our limitations, our mortal boundaries, and trudge forward with an unseeing eye. The photograph I chose represents this curious phenomenon of erasure. Though

the photographer intended to capture the likeness of the subjects, for they clearly looked posed and artfully arranged (the couple's feet is angled towards each other and theirs touch carefully at their sides), there is a crucial part missing from the frame: The couple's heads have been cut from view. The camera is not level with their faces; it is instead pointed at the couple's bodies and the surrounding space of the sidewalk. I think this photograph does an extraordinary job of representing what happens when a human person enters a medical establishment and falls under the medical gaze. People cease to be human beings and instead are viewed simply as bodies—without souls. A person becomes an injured limb, a faltering heart, or a cancer-riddled pair of lungs. Though the object of medicine is to promote healing, we often destroy ourselves by removing the person from the life we are attempting to save.

I included the quote at the beginning of this paper because it accurately captures the preoccupation of our society with personal choice. We believe that to be a person is to have the freedom to design our own lives. In the popular Harry Potter series, the protagonist is even able to choose whether he would like to return from the dead and rejoin the living or continue on into the afterlife. Daniel Callahan writes, “to be self is to live with perpetual tension of dependence and independence. The former is as much a part of us as the latter. . .it still remains only half the story of our lives, however.”¹¹ Human beings do not exist in a vacuum. Though we may emphasize individualism and self-determination, we do not operate as singular machines in the cosmos. Because we live with others, and we come from others before us, we cannot keep choosing courses that are detrimental to us all. If Americans do not stop the ridiculous expenditure on health care costs, America will bleed to death, both figuratively and literally. Furthermore, if we continue to push the boundaries of death with no regard for the destruction of the natural body, we risk changing the face of humanity to the point where it is no longer recognizable.



At Dusk (Boston Common at Twilight)¹²



Untitled¹³

ENDNOTES

1. Introduction, 389.
2. "At Dusk (Boston Common at Twilight)," Museum of Fine Arts, Boston. Web.
3. "President's Commission," *Deciding to Forgo Life-Sustaining Treatment*, 406.
4. *Belchertown v. Saikewicz*, 467.
5. *Superintendent of Belchertown v. Saikewicz* (Supreme Judicial Court), 473.
6. "Letting Go," 30.
7. "Lester Thurow," *Learning to Say No*, 537.
8. Lisa M. Krieger, "The Cost of Dying: Its Hard to Reject Care Even as Costs Soar."
9. John Stuart Mill, "On Liberty," 151-A.
10. Joseph Quinlan and Karen Ann, 486-496.
11. McCormick, 22.
12. Childe Hassam, *At Dusk (Boston Common at Twilight)*, 1885-86. Oil on Canvas. Museum of Fine Arts, Boston.
13. Unidentified photographer, *Untitled*, 1950's. Photograph, gelatin silver print. Museum of Fine Arts, Boston.

WOUNDED WARRIORS SENT BACK INTO BATTLE

HUNTER NEWMAN

After a wounded soldier returns home from war, the battle never ceases – it now means fighting the United States government. Soldiers head off to war, become injured in battle, and return home to a nation where it is difficult to access health-care.

From the wars in Iraq and Afghanistan, there are over fifty-thousand physically disabled and over five-hundred thousand mentally injured veterans. These are simply the reported numbers, with an estimate of seventy-five percent of all veterans struggling with memories from combat. Despite the great services these veterans provided for our country, forty percent report difficulty in receiving physical care from Veterans Affairs doctors. Also, thirty-five percent of veterans seeking access to mental health services in the past year were unable to obtain it. On average it takes the VA about nine months to complete a single medical compensation claim; in some major urban areas that number increases to six hundred days.

What message are we sending our veterans? And furthermore, what are we demonstrating to those who desire to serve in the future? That you can protect us now, but we cannot necessarily protect you later? This is entirely different from our roots following other wars. In 1944, the Servicemen's Readjustment Act was passed by President Roosevelt, which provided a range of benefits for veterans returning from World War II. So what has changed? Well, nowadays we tend to look strictly at the economic perspective of providing benefits to veterans, and not the humanitarian aspect. We, in a sense, look down upon veterans needing help and care. About twenty-eight percent of veterans claim they worry about seeking mental health care due to the stigma associated with these issues. This is absurd; we expect soldiers to have a wall up while away on the battlefield, but also in their home country.

It is difficult for these veterans to assimilate back into civilian life. When applying for jobs, their disabilities often hinder them from landing the position. Veterans used to be the “most qualified” for obtaining occupations following the war in the 1900's, and now service is often looked at with caution. Employers worry about such things as Post Traumatic Stress Disorder (PTSD), which could keep these servicemen unemployed. Most of the jobs veterans seem to obtain are minimum wage occupations, as if they were just as qualified before they left for war. I guess employers overlook the “Fought to protect the freedom of our country” line on their resume.

We as a country need to recognize the importance of the soldiers' experiences, and also the traumatic effects they cause.

With these occupations, it is difficult for the wounded soldier to afford the care they need. Outside third-party organizations attempt to assist the Veterans Affairs program in attending to the soldiers. The most prominent group is the Wounded Warrior Project. This organization raises hundreds of millions of dollars a year to help aid wounded veterans in all aspects possible.

Even though this provides great hope and assistance in our country, more still needs to be done. The United States government needs to reevaluate its spending towards our veterans. Some of the money designated for helping foreign countries or spent in medicare should be specifically redirected toward our wounded warriors. Doctors could be paid specifically by the government to treat these veterans, so they do not have to wait for compensation. Our healthcare professionals can lend a helping hand by giving to those who gave for us.

As for the rest of society, we can assist by erasing the injured veteran stigma and giving veterans more opportunities to reintegrate into society. Come on America; we claim to support our troops, so let's not send them into another war at home.

POPULAR MYTHS: THE IMPACT OF THE HYPER-SEXUALITY TROPE ON BLACK WOMEN'S HEALTH ACTIVISM IN AMERICA 1900-2000

NATHALIE LAVOIE

The trope of hyper-sexuality has immeasurably affected African-American women's health; this paper will explore discourse on reproductive health in two overlapping historical periods that mark specific interactions between dominant stereotypes about sexuality and black women. In the late 19th and early 20th centuries, many African Americans used social organizations to address their need for health services. Sanitary hygiene campaigns, promoted by these organizations, can be understood as a reaction to the perception of sexual immorality tied to the African-American community. These groups focused on moral purity as a means of advancing the race as a united whole. A critical examination of medical discourse on cervical cancer mortality from the late 20th and early 21st centuries offers an example of the continuing impact of the trope of hyper-sexuality. The presumed sexual availability of black women is implicated in the epidemiologic tracking, diagnosis, and treatment of cervical cancer in the African-American community. In contrast to movements of the past, the reproductive health activism born from the feminist movement, in response to the HPV vaccine controversy, relied on a community health model that empowered black women to voice the role of racial identity in women's health. Thus, the early health activism from 1890-1920s, the increasing cervical cancer rates of 1930-1970s, and the participation in post-1970s feminist health movements represent different ways in which black women interacted with the trope of hyper-sexuality: in which *middle-class black activists*

used the trope to pursue a project of racial uplift, in which *the medical field* used this trope to reconcile health data and redirect illness blame, and in which *black feminists* rejected the trope to empower community-centered health activism.

To understand the way that early health activism and the escalating rates of cervical cancer intersect with this trope, it is important to consider the origins and historical impact of the myth of promiscuity. In her article, "Some Could Suckle Over Their Shoulder," historian Jennifer Morgan recounts the tales of European travelers who encountered African women for the first time. In observing these women, men struggled to find a cohesive understanding of both their blackness and femininity: "Femaleness evoked a certain element of desire, yet travelers depicted black women as simultaneously un-womanly and marked by a reproductive value dependent on their sex."¹ These traveler accounts, compiled from the 15th to 17th century, stoked the imagination of European men as they were reported back to the continent. The women became more and more mythical, elusive, and "exoticized." The African women existed, in the minds of many men, as the antithesis to the white, pure, women of Europe. They became creatures who sought to seduce men to satisfy their "obsessed . . . craving for the love of mortal men."² This specification of mortal men seems to indicate that

these women were other-ly, perhaps non-mortal, but most certainly different. This perception did not dissolve over time, but instead took on different meanings in different societies.

During slavery, the power dynamic between white male slaveholders and black female slaves often perpetuated this dangerous myth. White males justified sexual access to black female bodies, under the pretext that those women were the descendants of the creature-like sexual objects described by early European travelers. Following this precedent, the notion that black women were by nature sexually promiscuous had long served as justification for white male access to black female bodies.³ Noma Roberson, a nurse and sociologist, emphasizes the inconsistency between the characteristics of many West African family models, such as “respect, restraint responsibility, and reciprocity” and prevailing stereotypes about slaves.⁴ She describes the way that slavery broke down this value system for slaves. Historian Michele Mitchell describes Post-Emancipation as a “mainstream discourse generally portrayed black women as indiscriminate and insatiable, black men as oversexed and bestial, and black children as so sexually precocious as to preclude innocence.”⁵ Jim Downs argues that Emancipation resulted in a complete deconstruction of community and cultural resources, not entirely unlike the resulting values reconstruction following the dispersion from the slave trade.⁶ In an attempt to seek economic autonomy, black women obtained positions as domestic servants. These women became the target of racist health awareness activities. Domestic servants were labeled as contagious and charged with bringing disease into their employer’s home, by employers and public health officials.⁷ However, the historical precedent for black female health advocacy can be seen in the Colored Benevolent Societies, which

were predominantly women-led and sought to provide resources for freed men and women.⁸ Contrastingly, there was not much focus on sexual ethics in these groups.

However, a presumption about black female sexuality continued to integrate itself into the American social fabric. Nearly a century later, in the 1950s, sociologist Charles Spurgeon Johnson noted an irony in the famous Alfred Kinsey sex study that the recorded behavior of white women – half of whom were not virgins when married and a quarter of whom were unfaithful at least once after marriage – “approximate[d] many of the popular myths about Negro women.”⁹ Johnson’s retort was made in response to the exclusion of black females in the study because of their presumed deviant sexual behavior. The belief was so prominent that in 1953, sociologist Edward N. Palmer called for a similar study for African-American women to determine “once and for all” if there truly existed a deviance in sexual behavior between the two races.¹⁰ Palmer’s use of the phrase “once and for all” is significant in emphasizing the historical longevity of these beliefs. Worse still, the impact of these beliefs is still prevalent in the treatment of black women by medical professionals. The preconceived notion of access to black women’s bodies is seen in a story told by a medical resident in 2003 in the journal *Focus*. During rounds, the medical team examined the abdomens and breasts of two female patients of similar ages. Unlike for the white patient, who was fully draped, had her permission requested, and her curtains drawn, the examination was performed on the black patient without any of these standard procedures.¹¹ This account is published in the book *Seeing Patients: Unconscious Bias in Health Care*, which dedicates itself entirely to the impact of underlying racism on modern medicine.

At the end of the 19th century, a prominent shift can be seen in the medicalization of the hyper-sexuality through the discourse on venereal diseases. For example, a medical research paper from Dr. Holmes included the commentary, “[i]f by any miracle venereal infections could be completely eradicated” when discussing the African-American population.¹² This subtle reference to the particular relationship of the African-American community and venereal disease indicates a prevailing notion of deviant sexual behavior. The collection that published Holmes’s piece, *Germes Have No Color Line: Blacks and American Medicine 1900-1940*, plays on the slogan “Germes have no color line” used by federal public health officials to alert white Americans of the threat that ignoring black health had on themselves.¹³ In 1896, Frederick K. Hoffman, a health statistician for Prudential Life Insurance, more overtly gave “particular emphasis on the idea of the physical and moral deterioration of black people due to sexual immorality.”¹⁴ Heather Prescott draws attention to the use of the word venereal in medical literature, which “signaled the sinful origin of these afflictions” due to its origin in theological conversations about sins involving lust.¹⁵ The focus of biomedicine on venereal diseases encouraged the presumption that African Americans were both physically and morally diseased.

To understand the role of the hyper-sexuality trope in early 20th century health activism, it is important to understand the creation and goals of the health activism of the 1890s-1920s. At the turn of the century, black mortality rates were 70% higher than the mortality rates of whites in the southern city of Atlanta.¹⁶ Throughout the country, black communities’ living conditions often lacked paved roads or piped access to water. Until 1886, there existed no nursing institutions that admitted African-American nurses, indicating the unequal number of African Americans in

the health professions.¹⁷ This compounded with racial segregation policies resulted in what has been termed medical apartheid.¹⁸ This lack of services and wariness of white physicians, alongside the emergence of the black middle class, played a crucial role in the development of the social clubs that assumed the role of health educators and advocates. The National Urban League, founded in 1910, worked to secure equal opportunities for African Americans through “solutions to problems of income, employment, education, housing, health, and civil rights for the masses of black and brown Americans who want a better way of life.”¹⁹ The group also focused on education, housing, and childcare. As unemployment and homelessness were understood as factors in overall health and thus named “social ills,” nearly all of the organizations’ work focused on health. In addition, the groups practiced more overt health policy activism, such as testifying before Congress on health insurance coverage of minorities.²⁰ The National Urban League and many others classified much of their work as sanitation promotion. This hygienic movement was offered as “a euphemism for the control of venereal diseases and a new approach to the prevention of these afflictions.”²¹ Underlying the health movement of these groups was a moralistic agenda about sexuality. This is especially true for the women-led organizations.

The Tuskegee Woman’s Club, for example, considered it their mission to spread the “gospel of cleanliness.”²² These women described themselves as “sex crusaders in service to the race,” a particular terminology that deepens the association of this health work with a moralizing racial uplift agenda.²³ Within the work of the National Association of Colored Women, founded in 1896, the uplift and alleviation of poverty existed alongside “concerns about sexual morality.”²⁴ There existed a clear contrast between

the progressive reform element and the conservative overtones regarding sex. To understand why these women adopted this stance, it is useful to examine the prescribed roles of women in health. At the Annual Tuskegee Negro Conference, it was established that “women’s irresponsibility, not financial constraints, had jeopardized the lives of their children” as an explanation for high rates of infant mortality in the African-American community.²⁵ Even in the *Journal of the National Medical Association*, an African-American inclusive counterpart to the American Medical Association, editor Charles Victor Roman blamed the high rates of mortality and morbidity on “‘sexual relations, diet, and unsanitary housekeeping,’ and in all of these, he pronounces that ‘woman is the determining factor.’”²⁶ In doing so, Roman and many others denoted the moral, sanitary, and sexual practices the result of women’s misconduct. Thus, righting these wrongs also became women’s work. Additionally, the medical field marked this kind of social work as primarily “feminine” and turned its attention to the innovative fields of bacteriology and epidemiology.²⁷ Because of their exclusion from formal medicine, the medical fields disregard for women’s health, and in reaction to the assertion that women were to blame for unsanitary conditions and diseases, women began to assume the work of sanitation and hygiene.

The construction of black female bodies as promiscuous has undoubtedly contributed to the sexual purity stance of racial advancement. This historical presupposition was manipulated by middle-class black women for a racial advancement agenda. Finding themselves defined by the “lowest common denominator,” many upper-middle class African Americans felt the need to both distance themselves from lower class blacks and elevate lower class blacks for the sake of the race.²⁸ Thus, the ultimate goal of moral

purity became “an appropriate solution to racial advancement.”²⁹ This goal required, in the minds of these reformers, a moral refurbishing of African-American women. Historian Susan Smith, in connecting the 1920s activism to these stereotypes, writes, “[t]heir assertions of sexual respectability were black middle-class women’s responses to racist sexual stereotypes.”³⁰

It is important to note however, that there exists no singular motivation for the women of these groups. It is most likely that they “sought simultaneously to alleviate the urgent medical ills of a community and to implement greater internalized social control.”³¹ This is clearly exhibited in the efforts of the Tuskegee Women’s Club, which worked to stop sexual abuse and expose sexual myths. Shame and secrecy around sexual activity continued in the public sphere, even as these women worked towards improved sexual education. However, the turn-of-the-century activism marked an important change. What had been a continuum of stereotypes generated about and describing African-American women was now being actively engaged by the African-American community, for better or worse. This engagement was positive by indicating that African-American women could assume authority over their own categorizations. However, it also compounded the stigmatization of the trope for lower-class African-American women, to whom the trope was predominantly applied. Despite this diversity in motivation and intention, the application of the hyper-sexuality trope to the lower class for the purpose of uplift adds to the ugliness of its legacy by integrating a classist perspective to this health work.

In the 1920s, physicians approached cancer as an opportunity to act as moral agents, using their position of

authority to constrict women's choices.³² Cervical cancer offers an interesting case to understand the immortality of the promiscuity myth, because unlike other cancers, it "brought researchers into a new thicket of speculation about intimate lives and sexual matters across the color line" especially as cancer was considered a woman's disease for much of its early history.³³ This was in part because cervical cancer stood as the only cancer with higher mortality for blacks than for whites.³⁴ In medical discussions of sexually transmitted diseases, women remained "at the center of causal narratives for most of the twentieth century" not unlike the message of sanitation campaigns which isolated women as the source of disease.³⁵ Perhaps as a result of this narrative, "[f]or many women, cancer continued to be associated with dirtiness and shame, failures of hygiene, and implicit accusations of a tainted morality."³⁶ The proposed etiology of the disease over history reflected the medical field's use of presumptions about African-American sexuality. The difference in the rates of cervical cancer for white and black Americans recorded in the 1930s was tied to poor care after childbirth and different labor practices.³⁷ This speculation is reminiscent of the historical construction of black women who birthed children without pain and continued working with their children strapped to their bodies.³⁸ However, it also spoke to contemporary conditions in which black women continued to have limited health access. By 1949, it was determined that the various effects of poverty might have an effect, "perhaps due to a combination of diet, the trauma of multiple births and poor obstetrical care, and possibly some racial influence."³⁹ Whereas this attitude addressed certain risk groups an important turn was made in the 1950s, addressing the disease as the result of behaviors in place of belonging to certain social groups.

The story of Henrietta Lacks exemplifies how race affected cancer diagnosis and treatment, and how cancer of the cervix was viewed in a particularly moral context, especially for black women.⁴⁰ Henrietta Lacks, a poor black woman from Virginia, died at thirty years of age from a cancer she first identified on her cervix. However, her legacy and much of the controversy surrounding her life is in regards to a sample taken from her tumor, without her knowledge, which went on to become the HeLa cell line, infamous in biology studies. This abuse of her body and deceit of her family offers one more compelling case of the medical communities presumed authority of black women's bodies. However, the focus for this paper is on Henrietta's experience of cervical cancer in the 1950s in America as an African-American woman.

Henrietta visited the segregated John Hopkins Hospital with the self-described condition of a "knot in [her] womb." She had kept her symptoms silent for some time because she feared a doctor would render her sterile if she complained of the issue. When she finally visited the local doctor, he "figured it was a sore from syphilis," but after negative tests he recommended a gynecologist. The healthcare environment for Henrietta and other blacks was bleak and reminiscent of the post-emancipation conditions of nearly a century earlier: "David drove Henrietta nearly twenty miles to get there... it was the only major hospital for miles that treated black patients. This was the era of Jim Crow – when black people showed up at white-only hospitals, the staff was likely to send them away even if it meant they might die in the parking lot."

Upon entering the hospital, Henrietta expressed discomfort at the medical atmosphere. Her medical history

reflects a continued preference to avoid treatments or tests that seemed unnecessary. Her commitment to this appointment was like most black patients in that “she thought she had no choice.” Upon telling the physician she knew there was something wrong with her womb, he doubted her experience noting she would have had to palpate the area to know this. Later, in reviewing notes, Dr. Jones also questioned why during her pregnancy a few months prior, no note was made in her medical history about the lesion.⁴¹

Rebecca Skloot’s telling of Henrietta’s story highlights a few important elements that are relevant to the post 1950s discussion of cervical cancer in African-American women. Primarily, the interactions between Henrietta and her doctor are marked by Henrietta’s fear that the doctor would perform unwanted contraceptive surgery and the doctor’s presumption that any reproductive issue was linked to syphilis. The discussion of sterilization and contraception have extremely complicated histories that are extremely relevant to the construct of hyper-sexuality, but ultimately beyond the scope of this paper. The suspicion of syphilis, assuming that Henrietta did not raise this as a concern, more blatantly infers a belief about Henrietta’s sexual behavior. Additionally, the Lacks’s journey to the facility and Henrietta’s resistance to complete any treatments represent the conditions that contributed to the characterization of the American healthcare environment as medical apartheid.⁴² The physician’s commentary in doubt of Henrietta’s health narrative as she tells it reflects a power dynamic in the relationship and thus distrust in Henrietta as a knowledge-bearing patient. Additionally, from his note about her self-examination and his special attention to the idea of Henrietta touching her cervix implicates a broader commentary on the acceptable limits of black female sexuality.⁴³

Henrietta’s story exists in contrast to the archetypal cancer patient, a “middle-class white woman who trusted and turned to medical doctors for guidance.”⁴⁴ In addition, this woman was expected to practice self-examination of her breasts for malignancies. Motion pictures regarding breast self-examination cast Hollywood-ready white women to encourage others to engage in the practice. In this way, “cancer was cleaned up and recast for popular consumption.”⁴⁵ This clean up approach to sexually linked health behaviors is reminiscent of the hygiene campaigns that restrained African-American women’s sexuality. The medical practitioner’s reaction to Henrietta’s practice of self-examination indicates her behavior is deviant. The greater sense of shame demanded by black women about their sexuality is related to the presumption of promiscuity. The pervasiveness of the trope is apparent in the mainstream media’s exclusion black women from the autonomous practice of self-examination.

This racial disparity recalls other sources of historical trauma on black women’s health. It wasn’t until the 1970s feminist movement that voices like Roberson, a nurse and sociologist, cited the sexual assaults by slave masters and the other dangers of slavery as “no doubt, key factors to the introduction of cancers of the female reproductive organs.”⁴⁶ Roberson selects three influences that need further consideration in the discussion of African-American women’s health in the 1970s. These are African-American women’s placement in social structure, social stereotypes about black women’s health and health-related behavior, and health status.⁴⁷ This highlights the impact of both the accessibility of health services, as well as social influences, particularly stereotypes. Roberson forges a causal link between the sexual exploitation of black women and thus the myth of promiscuity and the reproductive health

for African-American women. Many medical papers list the “reproductive behaviors” of African-American women as a cause of their increased risk for many reproductive disorders, but Roberson digs into this point. She questions what assumption about the particular sexual behaviors of African-American women is implicated in these medical documents.⁴⁸ She is not alone in questioning the connection, but her criticism is ahead of the work of contemporary feminist movements in the 1970s.

Facing medical exclusion, women were mobilized in 1974 to form the National Women’s Health Network. Unlike the segregated organization of the turn of the century, this organization “gave the women’s health movement a unified voice.”⁴⁹ The incorporation of African-American board members like Byllye Avery who spearheaded the Black Women’s Health initiative in 1982, support this claim of inclusion. Differences clearly existed between the black women’s and white women’s health groups. While white women promoted self-examination of their cervixes, African-American women sought a platform to share the struggle and story of their health narratives. For black women, self-help was promoted as an opportunity “to explore our collective history, to analyze our past and to identify our struggles and triumphs as we move to wellness.”⁵⁰ This difference is important in understanding the different positions from which these women stood in society. A description of the 1983 National Conference on Black Women’s Health highlights a beneficial change since the health activism of the early 1900s. An observer described the participants in the conference: “They came with Ph.D.’s, M.D.’s, welfare cares, in Mercedes and on crutches, from seven days old to 80 years old – urban, rural, gay, straight.”⁵¹ This inclusivity is in line with the movement’s focus on engaging women in the community through self-help groups to

work towards self-definition of health needs.⁵² Julie Scott, who worked with the Black Women’s Health Project and Boston Family Planning Project, drew from her lived experience as a black woman in the United States, when she opposed performing pelvic exams on patients under anesthesia who had not explicitly granted consent.⁵³ The story in particular, as well as the complicated network of issues revolving around reproductive health, highlight the positioning of African-American women in society, such that a special care towards sexual health lingered from the legacy of the trope of hyper-sexuality.

Another black women’s health activism movement emerged in response to the release of Gardasil in late 2006. Merck, the pharmaceutical company behind Gardasil, advertised using a “generalized risk and universal girlhood” based approach that ignored the risky circumstance that some girls faced while others did not. This increased discussion around some preventive health practices but silenced the discussion of racialized risk and certain preventive actions such as Pap smears. The controversy surrounding the HPV vaccine has tended towards discussion of Merck’s, the pharmaceutical company that produces Gardasil, “colorblind racism” in advertising.⁵⁴ In addition, Merck published an advertisement in *Ebony* article which placed the blame for cervical cancer on black mothers for not protecting their daughters with the HPV vaccine.⁵⁵ In doing so, the pharmaceutical company “effaces the social and economic context that surrounds the women in the United States who have the highest rates of cervical cancer.”⁵⁶ In particular, one of the risk factors for the development of HPV into cervical cancer belongs to an ethnic minority group.⁵⁷ The medical community has insolently accepted that people of color continually fell into the grouping of “at-risk teens.” This was true in

various diseases and can be seen in 1995 based campaigns about HIV.⁵⁸ Even into the 21st century, African-American women are at 60% higher risk for developing an invasive cancer and at twice the risk of dying than Caucasian counterparts.⁵⁹

In constructing explanations for this epidemiologic gap, researchers and clinicians have employed, intentionally or not, age-old presumptions. The Down There Health Collective (DTHC) asked what doctors truly mean by listing race as a risk factor. They asserted that doctors are not making a claim about a genetic connection, but instead that, “living in a country founded on racist principles that continue to undermine access to health care” poses a serious health risk.⁶⁰ This connection between ethnic or racial minorities, and worse of cervical cancer outcome, has been attributed to “financial restraints, poor access to health care... substance abuse”, as well as “language problems, cultural and social differences, and poor compliance.”⁶¹ When physicians implicate cultural or social differences, it is interesting that the lasting stereotypes about substance abuse and poor compliance are stated overtly. It does not deviate far from historical discourse about black female bodies to understand that this claim of cultural difference may reflect a presumption about increased number of sexual partners and earlier pregnancies, conditions which exacerbate HPV and have a historical precedent in the presumed hypersexuality of African-American women. This connection, vocalized by Roberson twenty years prior, is rearticulated in more contemporary health activism.

In the work of such organizations as DTHC, Gardasil can be seen as more than just another implication of the hypersexuality trope, but also an opportunity for the incremental growth of black women’s health activism. In addition to

critiquing the HPV vaccine’s advertisement and focus, DTHC released their own pamphlets with independent information about the vaccine and reproductive health. These pamphlets were written for teens and posted on the MySpace page of the organization. These community-based movements more overtly reject the hyper-sexuality trope as it is implied in explaining and compounding racially disparate rates of cervical cancer incidence and death. Recently, the defunding of Planned Parenthood has reignited the debate over claims that such abortion-clinics promote black genocide.⁶² This issue is complicated by the role of Planned Parenthood as a primary health care provider. Planned Parenthood has been considered a source of health autonomy for women, by providing Pap smears and birth control. This access to and use of birth control stands in stark contrast to the early 20th century activism which accepted the trope as a means of racial uplift.

Though it is clear that the myth of promiscuity has a clear and lasting impact on the health of black women, so too has the legacy of health activism. As early work reflected existing societal pressures to “clean up” the race, activism represented the autonomy of middle class black women to affect the health of individuals within the broader African-American community. In reaction to the impact of racially disparate health outcomes, as seen in HPV and cervical cancer, women have questioned the authority and bias of male physicians in diagnosing and talking about reproductive health. Various voices have drawn connections between the lasting impact of presumed availability of black female bodies and differential health outcomes based on race. However, the Black Women’s Health Network and the Down There Health collaborative indicate that health activism offers a parallel story of autonomy that stretches beyond its origin in sanitation campaigns. Many other is-

sues are implicated by this discussion - such as perceptions about African-American male sexuality. Additionally, the current Flint water crisis calls into question the additional health burden for childbearing aged women exposed to lead and other environmental injustices.⁶³ As such, this overview of particularly reproductive health related issues and activism welcomes further exploration and discussion. In telling the story of a century of black women's health activism, the trope of hyper-sexuality is implicit in contextualizing the different approaches of health activism and in part culpable for the health outcomes for black women.

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I T IS EASY TO FORGET

SARAH RAMSEY

He is tall, 6'5".
His presence used to dominate the room when he bent under the door to enter.
Now he is thin.
All of the muscles he built up,
After years of slamming, hitting, and lifting,
Are breaking down.
His knowledge,
Vast from books taken out of the Princeton Library,
Documentaries on PBS,
Intellectual conversations and observations,
Is leaving.
He is fed up,
With his body for playing games and causing confusion.
He no longer trusts his own thoughts.
Are they constructions or the truth?
He is viewed as hopeless, pathetic, weak, waiting.
He is not a fighter.
He is forced to separate his identity from his body.
You are not that.
You are trapped in prison.
There is no battle.
It is a defeat.
White flag waving.
This is bullshit.
It sucks. End of story.
It feels as if each day, his sense of being is diminished.
What did I just lose?
A day at the beach? A conversation between brothers?

Gone.
This is bullshit.
He is a fighter.
There is a battle.
He is my hero.
Strong, smart, loving, wise.
Faced with an end,
But not treating it as such.
He smiles, talks, laughs, loves, eats, ponders, shares.
He still lives.
Don't treat him otherwise.
Don't forget or diminish his existence,
While he is right there.
It sucks. End of story.
He is my hero.

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Erin is a junior in the Morrissey School of Arts and Sciences, majoring in Biology and English, minoring in Medical Humanities, Health, and Culture. She would like to dedicate this piece to the children she worked with in Kingston, Jamaica during her Jamaica Magis service trip (Summer 2015) led by Father Michael Davidson.

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Colleen is a senior in the Morrissey School of Arts and Sciences, majoring in English, minoring in Biology. This piece is featured in The 2016 Medical Humanities Conference at Boston College. She wrote this piece as a reflection of her time volunteering at hospice, in which she visited and comforted isolated patients at nursing homes.

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