Life, Liberty, and the Pursuit of Health: An Ethical Approach to Non-Biological Disparities in Health Care

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Abstract
In this non-traditional project, I have highlighted some of the most significant non-biologically-based disparities in health care that currently plague our nation. My primary inspiration for the project came from my time as an intern at Catholic Charities Free Health Care Clinic of Pittsburgh. The completed project consists of nine large-scale artistic representations of specific disparities in health care and short, corresponding narratives. This unique project will allow students from the schools of health sciences, nursing, pharmacy, and natural sciences to deconstruct the pieces out loud and, as a group, derive meaning from them. My hope for the project is to actively engage my fellow classmates and peers by educating them on the ways in which we, the next generation of health care professionals, can better fulfill our responsibility to advocate for our patients and fight against injustice by minimizing non-biologically based disparities from affecting our future patients and medical practices.

Step up 1’ 11” x 2’ 4”, acrylic and graphite
In school we are taught that biologic agents like Inflixamab, brand name Remicade, are the most efficacious agents for autoimmune and rheumatologic conditions like Ulcerative colitis and Cohn’s disease because they are “capable of interrupting the inflammatory cascade underlying” autoimmune diseases, and they show the most promising results for treatment of patients long-term. However, because of how expensive biologics are, many insurance companies will not pay for agents like Remicade initially, even in situations like pediatrics where the agent “could be used in the initial stages of the disease to interrupt and cease the inflammatory process” deeming the agent clinically indicated. Instead, insurance companies insist that patients try alternative methods of therapy, termed the “step up” approach, which consists of aspirin, NSAIDs, corticosteroids, and immunomodulators and document failure to respond to these treatments before agreeing to reimburse prescriptions for biologic agents like Remicade. While this method of treatment makes financial sense for insurance companies, it can result in terrible clinical outcomes for patients because biologic agents are sometimes only effective within a narrow window of time, meaning that even if biologics are eventually given, they may not work because they were not given soon enough. In a perfect world, biologic agents could be used prophylactically in pediatric patient populations to prevent the extent of inflammatory bowel disease progression and therefore prevent the patient’s need of bowel resection surgery and consequential short gut syndrome, a serious medical condition that they will have to endure for the rest of their lives. But because the bureaucracy of our healthcare system allows insurance companies to take advantage of patient’s reliance on financial coverage, this alters patient care negatively and prevents the most efficacious treatment from reaching the patient which ultimately results in avoidable negative outcomes. Therefore, education among health care providers is necessary, because poor patient outcomes due to bureaucratic oversight is a failure on the part of the clinician to advocate for their patient. It is our duty as future clinicians to work to prevent this type of carelessness from taking place. There is a possibility of laws being passed under state legislatures that aim to prevent insurance companies from disregarding physicians’ medical advice when it comes to treatment. However, state legislature is not good enough; we must do everything that we can to push for federal mandates that prevent these types of situations from occurring.
Toska Saudade 1’ 11” x 2’ 5”, acrylic and graphite
In the United States approximately 1 in 5 adults, which equates to 43.8 million people, experiences documented episodes of mental illness in a given year.\(^5\) However, the average rate of adults who have a diagnosed mental illness and are also uninsured is roughly 3.5 percent.\(^6\) While it is almost impossible to find pro bono mental illness care regardless of state, in states like Arizona, Mississippi, Washington, Louisiana and Nevada it can be nearly just as difficult to find insurance-covered mental health treatment centers, even though these states average the highest prevalence of mental illness in the country.\(^6\) Renowned psychologist Tanya Luhrmann suggests that the social environment of our country, unconcerned with the financial burden that this illness has on patients, may in fact deeply affect the course and the outcome of serious psychological disorders.\(^7\) Furthermore, Luhrmann suggests that in the near future her research may suggest that “our standard model of care not only does not help but may even make these illnesses worse”.\(^7\) We trap mental health patients in an endless circuit of hospitals, transitional housing, and shelters, which eventually ends with prison.\(^7\) Many mental health patients endure hospitalizations in “overburdened public institutions until they are then discharged to the street, to family or to supported housing, from which they are eventually evicted or electively leave due to being unmedicated”.\(^7\) This terrible psychiatric care is grounded in America’s federal health care system’s lack of concern with the prevalence of mental health and patients’ inability to pay for care due to denial of help from their health insurance. American Parity law “does not require insurers to provide mental health benefits,” and health plans that on the surface appear as though they offer coverage for mental health services are lawfully allowed to “specifically exclude certain psychological diagnoses” from receiving even partially funded treatment or care.\(^8\) This piece of art is therefore entitled Toska Saudade, both words being untranslatable to English. Toska, a Russian word meaning the deepest and most painful sensation of great spiritual anguish without any specific cause\(^9\), represents the struggle that mental health patients feel as a result of their condition. Saudade, a Portuguese word meaning a pleasure you suffer and an ailment you enjoy\(^9\), represents the way in which our country’s lawmakers perceive America’s current state regarding mental health. This Saudade is also depicted in the piece with the reference of the Uncanny valley effect utilized in the faces of the two physicians. While the faces look human, the audiences’ response to them is uneasy because they do not match the environment in which they are depicted in, just as our lawmaker’s decisions do not seem to match what these patients really need. The patient is depicted with two faces as a metaphor for partly suffering from their illness while also partly suffering from the financial burden and circuit of care that their illness ensues.

CHIP On Your Shoulder 2’ 4” x 1’ 11”, acrylic and graphite
The Children’s Health Insurance Program was established in 1997 with bipartisan Congressional support in order to provide insurance coverage to uninsured children who are classified as low-income but above the cut off for Medicaid eligibility.\(^10\) Combined, CHIP and Medicaid cover nearly one-third of American children.\(^10\) These two programs have significantly expanded health coverage among U.S. children.
and “provided a coverage safety-net for children in working families during economic downturns”.

The CHIP program is so important because reducing the uninsured rate of children means that following enrollment into CHIP, “children are more likely to have a source of care that provides them with primary care and prophylactic medicine and are less likely to have unmet medical needs”. Evidence collected indicates that removing barriers to timely accessing primary care leads to a reduction in unnecessary emergency department visits, which ultimately leads to better patient health long-term and saves states money. In addition, CHIP has reduced disparities in populations of low income children and racial/ethnic disparities, as well as increased coverage for children with special health care needs. Improvements in providing access to care “lay down the foundation for gains in school performance and educational attainments” and ultimately lead to long term health and economic well-being.

However, by the end of 2017, most states came close to running out of funding. If Congress had not passed a six-year extension to CHIP on January 22, 2018, all of the children receiving coverage would have lost access to their insurance. This piece symbolizes the legislation that we, future health care providers, must actively endorse to ensure that an extension to CHIP funding occurs again within the next six years. The triangle, the universal symbol of strength and stability, symbolizes reliable access to health coverage for children. The hands are just barely touching the triangle because without coverage, children will be without access to care, symbolizing the position that so many children will be in if the CHIP program is not reinstated. The hanging light bulbs represent the fragile state of these children’s future, which we have the ability to positively impact. Being that the future of CHIP could be in danger, the lights are not lit, suggesting that a more hopeful future for these children would be present if a more significant extension to CHIP were enacted into law.

**Autonomy vs. Paternalism**

Patient autonomy is the fundamental principle of medical ethics. Autonomy is the concept that patients should have the ability to understand the details of their treatment and the freedom to make choices regarding their medical care. Overall autonomy aims to equip patients with the power to control what happens to their own bodies. Research documents instances in which patient’s participation in the treatment process of chronic disease is a “critical determinant of successful disease management”. The counterpart to autonomy is paternalism, the concept that grants physicians and the clinician team ultimate responsibility over the care of patients. Paternalistic views argue that medical professionals should have the ultimate say over treatment because of their professional training and breadth of knowledge. While paternalism has its place in healthcare, we as clinicians should do everything in our power to advise our patients and deliver patient education, while leaving the power to make the final decisions over treatment and care to the patient. There are many deterrents and barriers to patient autonomy including illiteracy, low health literacy, language barriers, and physical disabilities. These barriers make communication between the health care team and patients more difficult, resulting in patients not being able to fully understand the route of care in which they are choosing to partake. When clinicians do not recognize the presence of barriers to communication, patients are not truly able to provide informed consent for procedures or treatment.
This piece symbolizes the many instances in which limited health literacy is recognized and responded to in a counterproductive manner because sometimes “providing more information may actually cause patients to feel more confused and powerless instead of empowering them”\(^\text{14}\). By no means should clinicians provide less information; they just need to be cognizant of the way in which they deliver patient education. Patient education needs to be delivered in terms that an average person, without a medical degree, could easily understand. Explanations presented as long-winded medical jargon comes off just as that to patients and their families and ultimately does not communicate what it intended to. The infant represents the completely helpless reality that some patients face when attempting to make ill understood decisions regarding their health. If poor explanations are given and true informed consent is not obtained, participating in any type of procedure or treatment, even if beneficial for the patient, is still considered unethical.

**Prioritize** 1’ 5” x 11”, acrylic and graphite

Due to ever-increasing administrative requirements, physicians and physician assistants face mounting demands on their time\(^\text{15}\). Administrative requirements include filling out a patient’s electronic medical record, reading nurses’ notes and completing various other paperwork necessary to keep a medical practice going. Of a group of surveyed physicians, around 60% were found to spend only 13-24 minutes with each patient\(^\text{16}\). The more time that clinicians are forced to spend doing administrative tasks, the less time they have to spend with patients. While decreasing the time that clinicians spend with patients is known to increase the frequency of malpractice suits, decrease patient satisfaction and impair the patient-provider relationship, spending less time with patients can also result in serious consequences\(^\text{15}\). These serious complications include completing less comprehensive physical exams, collecting less medical history information from the patient and communicating less information to the patient. All of these consequences lead to an increased amount of diagnostic testing and an increased probability of unintentionally missing a key symptom and therefore failing to reach the correct diagnosis. The more mistakes that are made on the part of the clinician lead patients to lose faith and trust in their providers, ultimately making communication between the pair more difficult. A breach of ethics also has the possibility of occurring if providers are too rushed when explaining treatment options and procedures to patients. If patients are not actually understanding clinicians, true informed consent is, in turn, not actually being attained.

**Embracing New Ideas** 1’ 5” x 11”, India ink and Prismacolor pencils

This piece is inspired by photos taken of an electronic prosthetic hand created in the Johns Hopkins Applied Physics Lab\(^\text{17}\). The design is meant to represent the spirit of medical and technologic research: embracing new and foreign ideas that lead to advancements. The hands symbolize integration of technology and the application of new research into clinical practice. While the integration of groundbreaking technology into clinical practice is exciting, a disparity exists regarding what patient populations have the ability to actually utilize the new technology, as well as health services in general. Access to health services requires both the ability to pay and geographic availability\(^\text{18}\). Barriers to accessing care include a high cost of care with inadequate or no insurance
coverage and lack of availability of services. When patients lack adequate insurance coverage, “financial matters become integrally intertwined with biomedical considerations in the process of clinical decision making”. These barriers to access are even more exaggerated in attempts to access new technology in clinical practice. Often, only those with access to personal funding or those with the most costly insurance will be able to afford utilizing new technology without going bankrupt. Clinicians’ responses to these barriers impact the quality of care that patients receive and have the ability to impact patients’ health outcomes long-term. Overall, the most ethical way to approach these barriers requires “an understanding of billing regulations, a commitment to informed consent, and a beneficent approach to finding individualized solutions to each patient care/financial dilemma”. Our role as future clinicians is to remember that in order to insure more of the population and afford more patients with access to current care, as well as new advancements in care, we must “address the issues of social justice outside of the office through political and social activism”.

**CRISPR** 1’ 11” x 2’ 4”, India ink and graphite
CRISPR stands for Clustered Regularly Interspaced Short Palindromic Repeats, which is the way in which bacteria defend themselves. Research of this defense system has led to the creation of the CRISPR-Cas9 genome editing technology. CRISPR technology allows scientists locate and alter pieces of DNA in any species. This technology has been used to alter genes in “vegetables, sheep, mosquitoes and human cells,” ultimately leading to “a worldwide race to push the limits of CRISPR’s capabilities”. While the ultimate goal of the technology’s creator is to prophylactically treat genetic human diseases, many fear that the technology will eventually be used to manipulate the laws of nature to create “designer humans, forever changing the course of future generations”. Designer babies serve as the “slippery slope” argument against utilizing this technology. If we start to allow people with the financial ability to alter the genetic makeup of their offspring in vitro to prevent disease, what is stopping them from altering other genetic components that code for physical appearance, athletic ability and even intellectual capacity? Ethically, this practice would not be permissible because it would create a disparity between patients who were able to afford this genetic manipulation and those whose could not afford it. The never-ending tunnel appearance that serves as the background of the piece represents the “slippery slope” argument that so many in the scientific community have defended. The background is intended to invoke the questions that critics of CRISPR technology have voiced: “where is the line, where do we stop, where is the end”. The elephant represents the aspect of luck in the natural conception of a child. Assuming that the fetus in the piece has not received genetic manipulation, the final configuration of the child’s genetic make up and the chance of that child inheriting a genetic disorder, as well as all of its other intellectual and physical attributes, are left completely to chance.

**Scoliosis** 1’ 11” x 2’ 4”, acrylic and graphite
Racial bias within present day health care is a well-documented disparity. Pain management is one domain in which several studies have supported the notion that racial bias is associated with health care providers’ pharmacologic recommendations. These studies provide evidence that the treatment patients get is dependent upon his or her race/ethnicity, and in many cases, African American
patients are not receiving the standard of care because of the false belief that there are biological differences between blacks and whites regarding the perception of pain. Research suggests that if a patient is African American, his or her symptom of pain will likely be underestimated and undertreated compared to a Caucasian counterpart, even after controlling for age, gender, and pain intensity. Relative to white patients, “black patients are less likely to be given pain medications and, if given pain medications, they receive lower quantities”.

It has also been thought that for many years African Americans have been diagnosed with schizophrenia at higher rates than Caucasian patients. This disparity in diagnosis has been attributed to “clinician’s association of poverty, blackness, and poor outcome,” rather than to the patient’s actual illness. Research has argued that “black men are overdiagnosed with schizophrenia” and that similar symptoms often only lead white men to be diagnosed as bipolar because “the lower-status person is simply associated with the lower-status label.”

In both instances, this unequal treatment of patients, and thus unethical behavior, is not due to overt racism, but rather a collection of biases grounded in erroneous stereotypes of African Americans. Because this behavior is not overtly racist, it is easily overlooked and therefore the cycle of deviation of care silently continues. My piece utilizes the condition of scoliosis as a visual metaphor for the disparity in care attributed to practitioners’ racial biases. The fluctuation of vertebral bodies away from midline is representative of the deviation of treatment prescribed away from the standard of care. The deviation in spinal anatomy that is the hallmark of scoliosis is not clearly visible by viewing a patient, such as the patient depicted, from the sagittal plane. However, the condition is blatantly obvious when attempting to view the condition in the coronal plane. While the slight deviation in care that creates the disparity may not be overt when looking at the situation from an outside view, the pattern of deviation becomes more obvious when looking at the situation from a different, more retrospective perspective. This slight deviation in care will continue until clinicians begin to become cognizant of the biases that exist within their own practice and recognize that the unequal care is indeed unethical.

Passage of Time 1’ 11” x 2’ 4”, acrylic and graphite
This piece was inspired by photographs taken of Ron Mueck’s Mass instillation at the National Gallery of Victoria’s inaugural triennial showing. Mueck’s instillation consists of 100 fiberglass and resin skulls arranged with the intention to insinuate that they were at one time “stacked neatly against the rear wall of the gallery, but owing to the passage of time or to some seismic event, they slipped and rolled one by one until they resembled an unkempt scree of cascading craniums”.

I choose to draw inspiration from Mueck’s instillation because the concept behind his rolling skulls serves as a perfect metaphor for illustrating exactly how these disparities in health care have come into being. The concept of the skulls being stacked perfectly mimics the unsullied state of medical ethics at the time of the Hippocratic Oath’s establishment. However, with the passage of time, medical ethics became unintentionally polluted with biases, injustice, and prejudice resulting in non-biological disparities in health care, a state personified by the image of the disordered and displaced skulls.
The subject of each piece in the collection is depicted in shades of graphite to once again reinforce the concept that as time went on, medical ethics became less and less straightforward, and therefore the disparities created by this ethical turbulence would not be fit to illustrate in plain black and white. Shades of gray also serve as a symbolic equalizer of race, ethnicity, level of education, and socioeconomic status, which are often the source of significant non-biologic disparities in health. The stark juxtaposition of color in the background of each piece represents the attention that should be drawn to each of the disparities depicted.

The child in this piece, who has walked into the situation and is now staring intensely at the skulls, symbolizes the position of future clinicians. Like the child, we are walking into this environment and are expected to deal with the disparities that already exist. The only way we can prevent these disparities from continuing in our own practice is by educating ourselves on the inequalities that exist, becoming more cognizant of the biases that exist within our own clinical practice, and doing everything that we can to advocate for our patients’ best interests.
References


