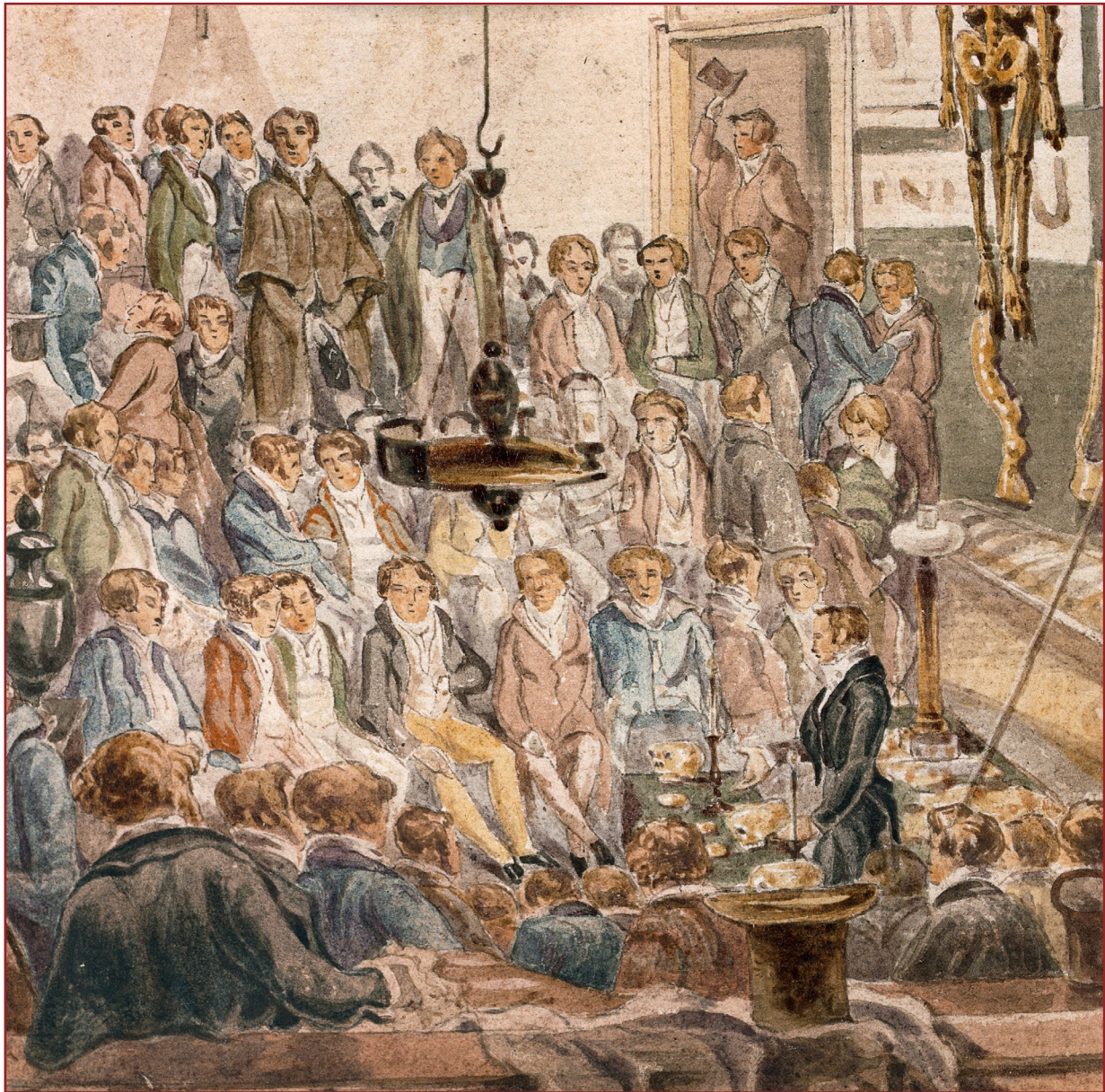


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Ethics in the Flesh

Penn Bioethics Journal

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The Penn Bioethics Journal (PBJ) is the premier peer-reviewed undergraduate bioethics journal. Established in 2004, the Journal provides a venue for undergraduates to make contributions to the field of bioethics. Embracing the interdisciplinarity of bioethics, PBJ reviews and publishes original work addressing debates in medicine, technology, philosophy, public policy, law, theology, and ethics, among other disciplines. The biannual issue also features news briefs summarizing current issues and interviews with eminent figures in the field. Authors and the editorial staff alike have a unique opportunity to experience the peer-review process through the collaborative, rigorous review and preparation of the Journal. With an audience ranging from undergraduates to scholars in the field to the broader public seeking unbiased information, the Penn Bioethics Journal occupies a unique niche in the field of bioethics.

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Content

Letter from the Editors

Emma Balaan and Laura Whelan 4
Editors-in-Chief

Bioethics-in-Brief

Ethical Concerns Surrounding 5
Medicaid Work Requirements

Approaching Direct-to- 6
Consumer Genetic Testing
with Caution

Interview

A Conversation with Dr. Peter 7
Reese, MD, MSCE

Articles

Prioritizing the Patient: the 9
Ethical Considerations of
Using Value Sensitive Design for
Upper Limb Prosthetics

Kayla Williams
California Polytechnic State
University, San Luis Obispo

Selling Kidneys: an Ethical and 14
Economical Approach

Iris Jacobs
University of Chicago

Essay and Commentaries

Holistic Dissection: a Course in 18
Empathy

Laurie Yousman
Yale University

Dissection, Empathy, and the 20
Disposition of Our Bodies

Robert D. Hicks, PhD
Mütter Museum of The College of
Physicians of Philadelphia

In Memory of My First Patient 21
Samuel Aidan Kelly, MD, MBE
University of Pennsylvania

Letter from the Editors

Dear Readers,

It is our pleasure to present you with Volume XV, Issue I of the Penn Bioethics Journal entitled “Ethics in the Flesh.” The articles in this issue each discuss how ethics interface with the human body, with topics ranging from designing prosthetics to kidney transplantation and medical dissection courses.

The first article in this issue, “Prioritizing the patient: The Ethical Considerations of Using Value Sensitive Design for Upper Limb Prosthetics,” explores the role of Value Sensitive Design (VSD) in improving access to prosthetics for those living in poverty. Author Kayla Williams from the California Polytechnic State University, San Luis Obispo examines the fulfillment of autonomy, beneficence, non-maleficence, and distributive justice through VSD for upper limb prosthetics.

In our second article, “Selling Kidneys: An Ethical and Economical Approach,” author Iris Jacobs from the University of Chicago discusses the potential benefits of legalizing the sale of kidneys. She argues that a well-regulated market for kidneys would expand access, improve quality of life, and increase human dignity for patients suffering from end-stage renal disease (ESRD).

We are also pleased to present our first commentary section centered around the article “Holistic Dissection: A Course in Empathy.” Author Laurie Yousman from Yale College argues that the gross anatomy course is an essential piece of medical education because it fosters empathy for the donor. Dr. Robert D. Hicks, Director of the Mütter Museum and the Historical Medical Library of the College of Physicians of Philadelphia, responds by sharing his perspective on the place of medical museums in this discussion. Samuel Aidan Kelly, a recent graduate of the Perelman School of Medicine, shares an essay reflecting on his experience in anatomy lab.

For this issue, we had the privilege of interviewing Dr. Peter Reese, a transplant nephrologist and epidemiologist at the Hospital of the University of Pennsylvania and the Philadelphia Veterans Affairs Medical Center, and Associate Professor at the Perelman School of Medicine. Dr. Reese gives insight into organ allocation policies, the ethics of a regulated market for kidney sales, and his research in expanding access to organ transplantation.

Our Bioethics-in-Brief section covers current issues in the field of bioethics. The first news brief discusses the ethical implications of work requirements for Medicaid coverage and the potential ramifications for vulnerable populations. The second brief examines the rising popularity of direct-to-consumer genetic testing. Originally used to trace ancestry, these tests have expanded to include screening for genes associated with cancers and other hereditary conditions.

We would like to thank our faculty advisor, Harald Schmidt, for his support during the editing and publication processes. Finally, we would like to thank the entire staff of editors for their dedication to the Journal. We have been honored to work with the incredible members of the PBJ community, and we look forward to the insight and innovation they will bring to this organization in the coming years. We hope this issue encourages you to explore bioethics and contemplate the important questions facing the scientific and medical communities.

Emma Balaan and Laura Whelan
Editors-in-Chief
University of Pennsylvania C’20

Ethical Concerns Surrounding Medicaid Work

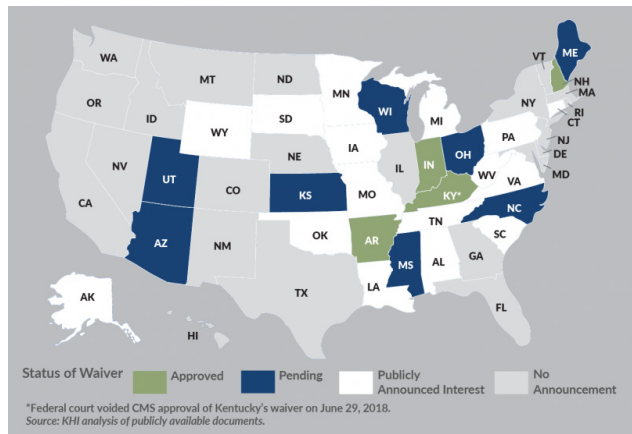
In recent years, several states have begun to implement work and community engagement requirements in Medicaid. Essentially, these requirements state that “non-elderly, non-pregnant, and non-disabled adults” must work, attend school, volunteer, and/or engage in other approved work-related activities for a specified amount of time in order to receive coverage through Medicaid (“A Snapshot” 2019). The hope is that they will promote self-sufficiency and independence, encouraging individuals to improve their socioeconomic situations and to rise out of poverty. Work requirements are highly encouraged by the Trump administration, and the President even released an executive order encouraging his Secretaries to utilize work requirements across various programs (“Exec. Order” 2018).

States can apply to the federal Center for Medicare and Medicaid Services (CMS) for a Section 1115 Medicaid waiver (demonstration waivers that allow states to test different policies and approaches) to implement work requirements. As of March 13, 2019, work requirements are being implemented in Arkansas, Indiana, and New Hampshire, and are approved or pending in several other states (“Medicaid Waiver” 2019). Given that these requirements place conditions on health insurance coverage, a major factor in health care accessibility, they provoke serious ethical questions.

Foremost is the concern that work requirements will severely impact the health and the financial stability of current enrollees, especially low-income and chronically ill individuals who could lose their coverage (Schmidt 2018). In 2018, Kentucky stated that their proposed program would lead to 95,000 enrollees losing coverage within five years (Galewitz 2018). In fact, this initial proposal of work requirements was blocked by U.S. District Judge James Boasberg even after being approved by CMS because Secretary of Health and Human Services Alex Azar “never adequately considered whether Kentucky HEALTH would in fact help the state furnish medical assistance to its citizens, a central objective of Medicaid” (Kodjak 2018). In 2018, 18,164 lost coverage in Arkansas, the first state where work requirements were implemented (Rudowitz 2019).

States utilizing work requirements knowingly, and to an extent purposefully, abridge the ability of thousands of people to receive health care. Some consider health care to be a right, evidenced by the large volume of proponents for universal mechanisms for paying for and/or providing health care, as well as health care systems in many other countries. Under this framework, it is unethical to restrict which low-income individuals may pay for it. Even without that premise, critics consider discriminatory limitation of access to health insurance, such as exclusions of sick individuals with treatable pre-existing conditions, a moral issue. Additionally, work requirements carry inherent themes of deservingness, with those deemed to have contributed a quantifiable number of hours to governmentally-defined productivity retaining their coverage. Given that Medicaid in its inception was built to enable disadvantaged individuals to seek health care, many see work requirements and a refinement of who is “deserving” as going against those base principles and the beneficence of the program.

While there are exemptions under work requirement programs, studies show that there are many nonexempt



individuals who do not meet work requirements for a variety of reasons. For instance, one may have a nonexempt disability or act as a caregiver to a family member (Carroll 2018). Lack of access to technology can inhibit people from reporting their hours or applying for an exemption; furthermore, many people subject to work requirements are unaware of their existence (Sanger-Katz 2018). This further complicates the debate surrounding Medicaid by highlighting added ramifications of work requirements. For instance, why is taking care of a sick parent, especially for low-income individuals who cannot afford to hire a caregiver, not an approved activity? The valuation of different activities, and by extension, different individuals, is at the core of the ethical dilemma in implementing work requirements. The barriers to fulfilling work requirements are often closely tied to vulnerable populations, who are often those most in need of medical care. As such, the harm work requirements cause may be greater than any proposed benefit.

Ultimately, work requirements are spreading throughout states as more waivers obtain federal approval. How states choose to implement the programs and how they will affect populations in jeopardy of losing coverage remains to be seen.

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Approaching Direct-to-Consumer Genetic Testing with Caution

On January 22, 2019, genomics and biotechnology giant 23andMe published an article on an exciting new FDA clearance that would allow them to add a new genetic risk test to their repertoire of products (23andMe 2019). The screening identifies mutations linked to colorectal cancer, which kills 50,000 in the US annually and is the second leading cause of cancer-related deaths in men and women combined (American Cancer Society 2019). The comment section under 23andMe's clearance announcement has filled with questions from their clients, many with family histories of colorectal cancer, asking for the timeline along which to expect updated reports. However, the news has also been met with pushback; for example, an op-ed from the New York Times raised the concern that "F.D.A.-approved" does not necessarily mean "clinically useful" (Editorial Board 2019).

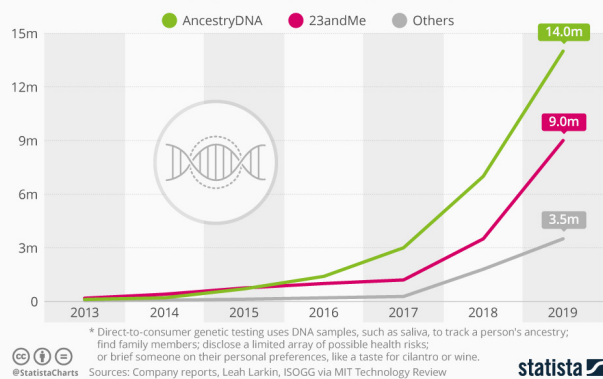
23andMe was a pioneer of direct-to-consumer (DTC) genetic testing, achieving both successful performance of the first autosomal DNA testing for ancestry determination and recognition as Time magazine's Invention of the Year in 2008. However, in 2013, their relationship with the FDA soured after they failed to respond to a notification from the FDA (Wikipedia Contributors 2018). While the ancestry information 23andMe had originally marketed was innocuous, the genetic tests in the Personal Genome Service (PGS) they launched subsequently were classified as medical devices, subject to higher regulatory procedures. This resulted in an FDA ultimatum: terminate marketing of genetic tests or be shut down. 23andMe consequently stalled on PGS marketing until October 31, 2018, when they finally secured FDA authorization.

23andMe has fully complied with the FDA since, exercising due diligence and producing transparent research into both their product user interface and the correlations between identified gene variants and disease risk. They have since been able to implement health risk genetic screening for predisposition on a disease-by-disease basis, from Alzheimer's to Parkinson's, celiac disease to breast cancer, and now colorectal cancer (Wikipedia Contributors 2018).

Breast and colorectal cancer genetic testing, as the only two cancer-related tests currently performed by 23andMe, have been subject to similar complaints and concerns across consumers and regulators. One consistent complaint concerns the limited scope of the genetic tests. The company's breast cancer screening focuses on a select few BRCA genetic variants, most prevalent in those of Ashkenazi Jewish descent, while neglecting over a thousand other mutations which have also been linked to disease risk (Editorial Board 2019). The colorectal cancer tests also fall short on this front, as they determine likelihood that customers are afflicted by a syndrome of colorectal cancer rather than directly testing colorectal cancer genetic variants. This syndrome, MUTYH-associated polyposis (MAP), causes

Commercial Genetic Testing Is Gaining Momentum

Estimated total number of people tested by consumer genetic companies*



cells lining the colon to aggregate into a mass (ASCO Journals 2018). While this condition increases risk for colorectal cancer, it is only a proxy, thus removing their genetic test one step further from actual causal linkage to the disease.

Additionally, in both breast cancer and colorectal cancer, hereditary cases comprise only a small percent of all diagnoses. In colorectal cancer, only 5% of all diagnosed patients have family histories indicating hereditary descent (American Cancer Society 2019). The majority of cases are non-hereditary, which leaves a large margin of cases for which a conclusion of no genetic variants present could paint a misleading picture.

The risk of errors in genetic screening raises concern on two fronts. A misdiagnosis, or false positive, can be corrected through clinical re-evaluation but could be a highly anxiety-inducing ordeal for the patient in the interim. On the other hand, a false negative or lack of a diagnosis when the client is indeed at risk could incite the client to forego clinical diagnosis or make dietary and other lifestyle changes.

However, 23andMe has taken steps in research and practice to address these concerns. Recognizing the potential harms in the DTC model, which allows patients to bypass the physician and other health care professionals in accessing their health information, the company provides a detailed educational module to help clients interpret their genetic health risk results. Additionally, it has assessed the emotional impact of risk diagnosis through phone interviews and demonstrated that anxiety was generally transient and mild (Francke 2013).

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Interview

A Conversation with Dr. Peter Reese

Peter Reese, MD, MSCE is a transplant nephrologist and epidemiologist. His research focuses on: a) developing effective strategies to increase access to transplantation, b) determining outcomes of health policies on patients with renal disease, and c) testing strategies to improve important health behaviors such as medication adherence. He directs Penn's Center for Quality, Analytics and Research in Transplantation (PQART). He also chairs the Ethics Committee for the United Network for Organ Sharing (UNOS), which oversees organ allocation and transplant regulation in the United States.



Photo courtesy of Dr. Reese

Can you describe your career path and how you came to develop interests in organ allocation policy and bioethics?

I had a roundabout career path. I was an anthropology major in college, and the main focus of my energy was community service. I initially intended to be pre-med, but I just found the pre-med environment kind of toxic. It might not have been a representative experience, but I remember people were contesting with the professor over quarter points on a quiz, and it seemed really far away from what my image was of why I wanted to be a doctor. So I was like, "I'm not doing this." Instead, I invested a lot of time in writing, anthropology, English, history, and community service projects. I ran the Big Brothers Big Sisters program; we did a Special Olympics event for people with developmental issues, and at the end of college, I decided, "Well, that's what I enjoy doing." I hoped I could have a social impact. And that left, at least in my limited imagination, the possibilities that I could be a teacher, a social worker, or maybe a policymaker. But then I realized that all the things I was enjoying could be combined with medicine. In trying to alleviate disparities of poverty, it would be really neat to have more technical skills. I thought: Alright, I guess I better go back to the drawing board.

So I did all my premed stuff in a post-baccalaureate year and went to medical school, but I couldn't stand the ethics education. It seemed very formulaic, set up almost so that at the end, they could give you a multiple-choice question with one right answer. I went all the way through internal medicine residency and only at the end did I start getting interested in nephrology, transplantation and the related ethical issues because I just started to realize that it is very hard to take care of these patients and to think about how to make this system better without a familiarity with the principles of allocation of scarce resources. If you want to ration, how should you go about it? Organ transplant is all about rationing on the deceased donor side. And then on the living donor side, living donor transplantation presents these fascinating issues - for example, how much harm facilitated by physicians would you allow someone to take? A unique piece of medicine is the tension between paternalism to protect and autonomy, allowing people control over their lives.

Once I started encountering those issues clinically, I really wanted to know about bioethics. So I think I probably had it different from most people. It seems to me that many people have an experience as if "I woke up when I was two years old and I knew I wanted to be a doctor." They had a straight line. I'm much more of a zigzag.

Can you describe some of your ongoing research projects?

The most interesting work I'm doing right now is a leadership/partnership with a number of other people here like David Goldberg of hepatology, Peter Abt of surgery, and Emily Blumberg in infectious disease. The goal of this group is to expand access to organ transplantation. For kidneys, there are about 95,000 people on the waiting list. If you have blood type O, you might wait seven years. During that time, you're probably going to be on chronic dialysis and unfortunately experience a lot of health deterioration. We're focused on opening up groups of organs to benefit people on the list.

Historically, there were hundreds of organs from potential donors with hepatitis C that were never used; they were just buried or cremated. Those individuals or their loved ones wanted them to be an organ donors, but the treatments for hepatitis C were really ineffective. Long story short, these organs would be offered, and almost all the centers would turn them down. Almost every heart, every lung. Some of the kidneys were accepted, but mostly for patients who already had the infection.

In 2014, some new drugs were developed. The old drug, Interferon, was an injection with horrible side effects- it could give you symptoms like the flu, make you depressed, or make you feel anxious. It was dangerous in organ transplant recipients, and it only cured patients as little as 40% of the time. Suddenly, the situation changed. These new drugs are once-a-day pills with very high cure rates. Our group said, "So the new drugs are here. We don't know how high the cure rates will be in transplant because the patients are immunosuppressed. But they might be high enough that it's reasonable for patients to accept the risk if they want. And we ought to do a trial." The second thought was, "Let's see if we can build a really robust consent process to feel very confident that patients are okay with these risks."

The first step in this informed consent process was doing a bunch of interviews with patients, and it turned out that most of them had no idea what hepatitis C is. So the first thing we had to do was educate patients about the infection and then ask them if they wanted to come in for a face-to-face education session with a family member. Only after that would we consent them for the study. I was the one calling people up, saying, "Hey Mr. Smith, I'd like to give you hepatitis C, what do you think about that?" which is a funny conversation to have. Of course, I was also saying, "I'd like you to have a kidney transplant." About half of the patients were willing to do it.

What's exciting is that all of our patients have been cured. And now many centers are using these organs. Once we published our results, it became very widespread. And to Penn's

credit, it was a high-risk, high-reward study, and it more or less had to be endorsed by transplant surgery and higher leadership. We dealt with the IRB here, we dealt with risk management, even the hospital board was aware of it.

The other thing I would mention is that this is a drug company-sponsored study. There was really no way to do the work without finding a drug company to support it because the drugs were so expensive. We have tried to be very transparent about these interactions with our sponsors with patients and in publications.

What do you think of current policies for kidney allocation?

I think the kidney allocation system is very transparent but also imperfect. All organ allocation systems are principally balancing what you can think of as fairness and efficiency, and those two principles can be in tension. A complicating factor is that we have pretty clear ideas about what we mean by efficiency. For instance, I could have one organ with 10 people waiting. I could estimate - based on who I put that organ into - how many additional years of life each would get. That's one way to think about efficiency: additional years of life gained.

What we struggle with a lot is what is the best definition of fairness. Right now in kidneys they usually allocate within blood type to ensure that people are blood type compatible, but beyond that, the other driver for allocation priority has been how long you wait. So people who wait seven years have higher priority than those who wait 6, 5, 4, 3, 2, 1. And that approach was thought to be an imperfect but decent proxy for fairness, and it was recently refined to make sure that patients are given "credit" for any years that they spent on dialysis before joining the waiting list.

But there are other ways that we advance fairness in the system. For instance, there are many people, including me, who think that children deserve extra priority. They do have extra priority in the current system, but not everyone agrees with this. I agree with it because I think that an additional way to think of fairness is not just first-come first-served, but that the system ought to work to advance the interest of very disadvantaged people. Allocation is complex but essentially we do our best to implement different definitions of fairness to advance certain people's interests.

One approach they take to advance efficiency side is that they take the top 20% of kidneys, and they allocate them to the people who are expected to live the longest. Who is that? It's usually people who are younger, people who do not have diabetes.

One place where I think there will be a revision to allocation is in the problem of geographical inequity in waiting time. For example, if you live in one area of Florida, your waiting time will be a lot shorter than in another area of the same state. I'd like to see that fixed. The concern is, how much of a loss to efficiency would you accept? Say we did 14,000 deceased donor transplants last year, but we changed the system so it is totally agnostic to where people are. You would start flying kidneys all over the United States to the people who have waited the longest. What if this way it was a lot more fair in terms of waiting time, but you did 2,000 less transplants because of the transportation challenges? There is that tension: you want the most benefit from this resource, but you want it to be fair. So what I anticipate will happen over the next two years is that, particularly in kidneys, we're going to have

to have some strong debates over what we are willing to do to make waiting time variation across the country more fair.

Do you think the creation of a regulated market for the sale of kidneys would be feasible, efficacious, and ethical? What are some of the potential benefits and drawbacks of legalizing a trade in kidneys?

I'm not very enthusiastic about it. With risk for living kidney donors, we've come to a pretty good confidence about what would happen to people within 15 years, but we really don't know what will happen after that: We have some ideas, but not much confidence. The first group I would worry about is young people, some of who are impulsive; I would feel uncomfortable paying younger people with many years of life ahead of them. The ethical arguments fall into four categories: The first is undue inducement, which is that people will ignore risk. Number two is unjust inducement, which is that poor people will chiefly come forward and there would be a transfer of organs from the poor to the rich. The third is crowding out, and the fourth is commodification.

If you set up a controlled trial, you could test one and two. But you can't really deal with commodification. Commodification is more of a disgust issue, the notion that people shouldn't sell their bodies for money. Not everyone believes commodification is a real issue: after all, there are already ways in which we can sell our bodies; we can sell our eggs and our genetic material and become surrogate mothers, for instance. However, transplantation exists because the public supports it, and there is a concern because commodification may cast transplantation in a bad light.

With regard to deceased organ donation, as I understand from talking to Art Caplan, who used to be at Penn, is that a key piece of the development of the system of donation with brain death was the endorsement of stakeholders from Catholic, Islamic, and Jewish faith communities. Many of those organizations have commodification concerns, and you might be able to dismiss the ethical objection, but that doesn't mean you can dismiss them from a religious or public perception perspective.

What possible policies do you advocate for in alleviating the shortage of kidneys?

I think a lot of the possibilities are long shots, other than paying donors. Other big ways to alleviate the organ crisis would probably lie down a path to artificial organs or xenotransplantation, which is to grow organs in animals. I think it's feasible during our lifetime that there will be progress in these areas. The heart is a simpler organ, mainly a pump, while the kidney and the liver are more complex. But I think if you could overcome some of the barriers with xenotransplantation, it would probably be ideal. Now with gene editing, it seems like not so far-fetched that 20 years from now we could be trying that. There are two issues with xenotransplantation. One is rejection, because all those antigens are recognized as foreign, but additionally there is something called PERVs (Porcine Endogenous Retroviruses) - animals such as pigs harbor a lot of infections that humans have never seen. If you put that organ into a human who is immunosuppressed, those infections could become opportunistic.

Prioritizing the Patient: the Ethical Considerations of Using Value Sensitive Design for Upper Limb Prosthetics

Kayla Williams*

With the current political administration diminishing the certainty of the future of the Affordable Care Act of 2010, the current number of uninsured individuals is in jeopardy especially those who require financial assistance. Millions of individuals who live with amputations require the use of a prosthesis to facilitate day to day actions and activities, but a significant proportion of them cannot afford to get their own because of the high cost of prosthetic limbs. As a result, many engineering teams have adopted a Value Sensitive Design (VSD) approach in which they prioritize the reduction of the fiscal cost to the patient and their financial support system, while maintaining integrity of the device and ensuring that all stakeholders in the device have their values fulfilled. This paper evaluates the ethical considerations of autonomy, beneficence, non-maleficence, and distributive justice of this methodology in the context of manufacturing upper limb prostheses. All of the shareholders involved in the development and use of prosthetics experience enhanced fulfillment of autonomy, beneficence, non-maleficence, and distributive justice, therefore VSD is a promising methodology for the development of prosthetics.

Introduction

“The Affordable Care Act (ACA) of 2010 contains legislation that declares “a health insurance issuer offering group or individual health insurance coverage may not establish rules for eligibility of any individual to enroll ... based on any of the following health status-related factors” such as “medical condition”, “Medical history”, or “Disability” (2010). This has allowed for many U.S. citizens to be able to afford insurance and access to necessary medical care through government assistance programs such as Medicaid when they are unable to afford private insurance. However, a survey completed in 2016 indicated that approximately 27.6 million people in the US remain uninsured (Budget Office 2017). Regardless of the political solution to undercoverage and who is responsible for healthcare costs, consumer costs of medical goods are often out of reach for those who live with a disability.

According to the U.S. Census Bureau, approximately 50% of individuals registered with a severe disability also require financial assistance from government social programs, and approximately 29% of those living with disabilities report having disability related problems at work (Brault 2010). This means that people living with amputations in a low economic status are likely to not be able to afford prosthetics necessary for facilitating day to day activities.

Prosthetics are financially inaccessible to many people who live in poverty, as “projected unilateral upper limb average costs are [between] \$31, 129 and \$117,440” and many insurance companies will not cover the costs, regarding the devices as cosmetic instead of therapeutic (Blough 2010). Many engineering disciplines seek to adapt design methodologies to consider an end user with a lack of fiscal resources.

This paper seeks to utilize current research, engineering advances in prosthetics, and biomedical ethics reports to analyze the ethical implications of utilizing a method known as Value Sensitive Design (VSD) to develop prostheses for people who otherwise would not have the fiscal resources

to access such technology. I will primarily focus on how each development affects the autonomy, beneficence, non-maleficence, and justice toward all of the shareholders of the prosthetic. VSD methodology stresses the importance of the values of all of the shareholders in a given instance of technology, therefore all of the shareholder groups will be ethically relevant in my argument. I will consider the following groups as the shareholders of this activity: the developers, the patients, and the caretakers and loved ones of patients.

Value Sensitive Design

Mary L. Cummings wrote that Value Sensitive Design (VSD) is a format for developing technology while “explicitly attending to which human values are taken into consideration and integrated into and throughout the design process” (Cummings 2006). To perform this method, designers start with a human value for technology use, “identify indirect and direct stakeholders,” identify harms and benefits to each stakeholder, map aforementioned harms and benefits onto corresponding values, conduct an investigation of the key values to identify potential value conflicts, and then integrate value considerations into the organizational structure of the design process (Friedman 1992). Although Friedman primarily wished to focus on developing this methodology in the field of computer science and engineering, the methodology has garnered the attention from specialists in many other fields. Because of the intimacy of biomedical devices and their stakeholders, VSD also shows significant promise in biomedical engineering developments.

Although the creators of the VSD method did not use an explicit ethical theory as the premise for their instructions, their method regards values such as “participation,” “justice, human welfare, and virtue” as the critical values with which to assess the product’s social impacts (Friedman 1992). These align closely with the Four Principles of Biomedical Ethics from Beauchamp and Childress: autonomy, beneficence, non-maleficence, and

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justice.

Therefore, the prioritization of these values indicates that VSD utilizes moral principles within its foundation and can be used to inform designers how to engage in moral deliberation during the decisions that occur in a biomedical design process.

Even though the following design teams do not always explicitly state that they utilize VSD methodology, many assistive technology developers have design practices that fulfill the criteria of VSD methods, especially with a central consideration about the fiscal welfare of the patient and their support network. I seek to highlight two examples in the biomedical field: a Netherlands group who developed security devices for facilities caring for those living with dementia, and the projects of the organization Quality of Life Plus (QL+).

Example 1: Alzheimer's Technology

Alzheimer Europe released a report in 2010 that addressed the ethical considerations of designing assistive technology for those living with Alzheimer's in an institutional facility. This report stressed that the convenience for managerial staff is insufficient to justify the use of assistive technology, especially if it violates the patients' privacy, so a team in the Netherlands addressed monitoring systems and found a solution through VSD (Schikhof 2010). Residents who live in housing with monitoring systems often complain of the lack of privacy with camera-based security systems, so the designing team conducted small scale interviews with members of the community as well as their family, staff, and institutional managers. All groups valued the privacy of the residents, but the patients and nursing staff reported that they also prioritized the humanity and dignity of the patients. The management team reported that they shared the same values, but also had the added design challenge of preventing false positives in the security alarm system. The designing team incorporated all of these values into their design and created an overall surveillance product that all parties agreed with: an infrared closed-circuit camera would be installed in the rooms in the off setting as a default, only to be turned on when sound and pressure sensors combined to indicate that the patient is panicking and in distress or about to leave. Once the camera is turned on, the footage is sent to a PDA in the night watch station, where a senior nurse or other trained staff person can have the final say as to whether or not the patient was in need of assistance or it was a false alarm.

Example 2: QL+

QL+ is a national organization based in the United States and prioritizes the development of mobility devices to help veterans and other "Challengers" have access to personalized mobility technology. These projects tend to be conducted on 2 to 3 month intervals and stress the importance of customizability to the patients themselves. For instance, one project helped a young child who was born with a partial right hand develop a prosthetic hand that could help him participate in activities such as playing on monkey bars (Mavrommati 2018). Designing for children is a very unique challenge because they will grow very rapidly and no longer be able to fit in the fixture for the prosthetic, requiring many

high functioning iterations. Therefore, the design team for QL+ utilized OpenSource files to 3D print a prosthetic hand to reduce costs and ensure they could easily produce prosthetics for the child as he grew. These teams prioritized the users' value of affordability, interviewed the care team of the Challenger, and guided their design to those values. Another Challenger desired trans-humeral prosthetic for his right hand because he was having difficulty using his left arm to shift gears in his car (Hubbard 2018); the team developed a functional prototype that allowed the Challenger to supinate and pronate the hand, allowing him to shift the gears in his car.

Autonomy

In general, whether or not VSD methodology fulfills or doesn't fulfill the autonomy of the developers depends on who the developers are and what access they have to manufacturing methods. Large companies that manufacture prosthetics through mass production measures tend to claim that a VSD approach is not compatible because of the cost required to manufacture each device. These companies often manufacture these devices in a medium- to large-scale setting with a series of molds to shape medium density polyethylenes into the residual limb, with varying degrees of mechanization to increase the functionality of the prosthetic (Pelliccioni 2013). The VSD methodology has little to do with the manufacturing techniques so long as the techniques produce a device that is sufficient to uphold the values of all of the parties; when this is also considered with the expanse of resources that large-scale developers have, a change to consider human values in the design process has little effect on the autonomy of the developers.

Academic and non-profit motivated developing teams may have a decrease in their autonomy as they tend to have fewer resources for manufacturing techniques, but these developers do not need to produce devices on a large scale to maximize profit, so VSD does not impose upon their purpose of design. Additionally, universities have begun to develop research techniques in the field of 3D printing, so now schematics for designing "dexterous 3D printed hands and sockets are freely available" (Vujaklija 2018). As a result, VSD methodology is compatible with the needs of university developments and the means of manufacturing high quality prosthetics is achievable, so the autonomy of the university developing teams is not restricted.

The most pressing support of using VSD to design prosthetics is that patients have the most direct benefit in autonomous fulfillment. The purpose of the tech is to allow them to directly execute their actions and have an improved quality of life, which is a direct enhancement of their overall autonomy. However, with the current standard of prosthetic design, most people with upper limb amputations report a significant amount of problems with using these prosthetics, including the fitting of the socket and the non-intuitive controls of body-powered prosthetics (Kejlaa 1993). These problems are often so significant that the users even cease to use their prosthetics. VSD in the development of prosthetics could incorporate the patient's unique requirements into their design in order to allow them to customize the technology

Prioritizing the Patient

exactly to their proportions and needs without sacrificing cost effectiveness or quality.

Patients who significantly rely on caretakers, including children and other people with compromised competency, will also be able to have their rights to autonomy fulfilled even if they do not qualify for legal autonomy. Young patients may not be eligible to claim legal autonomy because of their age, so VSD does not account for the legal aspect of autonomy; however, most children above the age of 4 years old who are receiving prosthetics are quite cognizant and can make decisions about their preferences. Therefore, they have the capacity to make decisions about preference, and can convey their desires and values even if they are yet to be thoroughly formed. For caretakers of these patients, an increase in patient autonomy is also respecting the decisional capacity of these caretakers when the devices are developed through the methods of VSD. Proper execution of VSD can account for the values of highly involved caretakers, as they are the ones who must be able to help the patients when problems arise with the devices.

When considering all of the shareholders in prosthetics development, developers and caretakers also get to receive the fulfillment of their rights to autonomy when the device is manufactured through VSD methods. Patients have the most significant fulfillment of autonomy regardless of how the device is designed, but VSD can take additional measures to ensure that autonomy is fulfilled both in theory and in practice.

Beneficence and Nonmaleficence

For industry developers, the benefits of incorporating VSD methodology is that they can reduce the cost of waste products. Although it does not benefit these developers in terms of investment costs as well as quarterly profit, as customizing to smaller subsets of individuals needs takes longer time and can reduce profit, utilizing VSD for the purpose of designing prosthetics means that there will be a larger proportion of their products that will achieve their full product life.

Educational and non-profit developers do not have to be concerned with making a quarterly profit margin, so the benefits are experience in development as well as being at the forefront of technology creation. Especially in academia, having groups conduct these development projects allows students to have first hand experience in developing prosthetics as well as make innovative design augmentations to address the shortcomings of the current industry standard. VSD methodology can be used to guide interdisciplinary projects among students in engineering majors as well as psychology, philosophy, history, sociology, or other majors that are not typically versed in the development of prosthetics. Design companies are currently stressing the importance of interdisciplinary teams due to unprecedented increases in the complexity of technology coupled with its intimacy with the average consumer. Consequences of such interactions are difficult to predict, so using VSD to design products can provide a space for students of many different majors to learn how to collaborate and develop skills that will be beneficial to work in their future fields.

The primary benefit of utilizing VSD for the design of

prosthetics is that the patient is able to be confident that they have a device that reliably works for their needs. As mentioned before, they can experience an increase in autonomy through independence and an enhanced capacity to participate in a wider array of activities. Additionally, many people with upper limb amputations report that they have depression or anxiety surrounding their residual limb because people stare or treat them differently when they realize what it is. Many social justice advocates say that this level of visibility is important for the general public to understand the breadth of demographics of the members of the disabled community, but the microstressors of being treated as “other” in everyday interactions can cause more chronic stress both physically and mentally. Therefore, another benefit to prosthetics as a whole is that patients have an increased sense of self-confidence concerning themselves, and designing prosthetics through VSD can ensure that the form of the prosthetic will complement the degree of cosmetic visibility that best suits the individual patient. For adult individuals who require an upper-limb prosthetic, the utilization of VSD with the primary value of affordability means that they experience a reduced fiscal burden in conjunction with obtaining their device.

In upholding the patient’s autonomy and independence, the caretakers have increased independence as well as less stress in taking care of the patient. They also have a vested interest in the well-being of the patient, so the relationship of care means that they could experience more peace of mind with the knowledge that the patient is more capable of doing the things that they want. If the individuals in the caretaking role are the parents or guardians of the patient, they will be the benefactors of a reduced fiscal burden brought about by the technology.

Large-scale industrial developers of prosthetics have to consider the liability of the safety of their device or the harms caused by the device’s misuse, so designing with VSD may allow them to circumvent misuse or other legal suits. If the developers take documented and deliberate precautions to develop within the declared values and needs of the patients, it is less likely that the patients will eventually sue for negligence. Even if the patients do eventually sue for negligence, VSD in design can bolster the developer’s defense because they have documented proof of value considerations as well as evidence of patient approvals of the design.

Non-industrial developers — especially student or research groups at a university — tend to lack experience in the philosophy of designing to industry standards. If one is merely designing an upper limb prosthetic as a hypothetical or practice project, it is difficult to understand the reasons why the device is being developed and the social consequences of the device’s implementation. Incorporating VSD into the philosophy of designing prosthetics can create a more thorough teaching experience that illustrates the human aspects of the device. Ensuring that the values of all shareholders are considered throughout the entire process allows student developers to become aware of the fact that devices do not exist in isolation, and the users will have experiences with the devices that relate very intimately with their own bodies.

As mentioned before, patients report that one of the most common burdens of prosthetics is that the sockets designed

by developers are highly unpopular with individuals who use prosthetics “due to a sub-optimal interaction between the socket and the residual limb tissues” (Paternò 2018). VSD methodology ensures that the patient’s value of comfort with the device is upheld and prioritized so that the device comfortably fits and they are able to use the device properly. Another consequence of prosthetics to the patient is it may interfere with their relationship to other members of the disabled community who also have upper limb amputations. The variety of people living in the community is so vast that many people have differing beliefs about whether or not prosthetic devices should be used, as well as complaints about how the appearance of the device is more distracting than a residual limb without it. During the interviews with shareholders as part of the VSD process, the designers can ask questions about the individual patient’s values surrounding their social connections and other relationships to be able to minimize the negative effects of the prosthetic on their relationship with their communities.

The caretakers shoulder the burden of learning how to learn the new technology along with the patient, as well as coach through the emotional impacts of the device. If the patient is a child, they also have to often help “troubleshoot” any problems that arise and calm them down should the patient become frustrated with using the device. Incorporating the values of the caretakers and loved ones can help the designers to consider how to address the non-expert use of the device from the perspective of the caretakers, and even consider how to simplify the “troubleshooting” process for them should problems arise. In this methodology, when the caretakers values are considered, they can be less concerned with the working of the device and thus focus on the emotional support of the patient.

Since there are burdens for all shareholders in the design of prosthetics and VSD methodology addresses these burdens in manners that serve to minimize the effects of the burdens, utilizing VSD methods for upper limb prosthetic design upholds the principle of non-maleficence.

Distributive Justice

The right to healthcare and the services it entails is currently debated in many academic circles, with two primary camps fighting along the lines of single-payer versus privatized health insurance systems. Because these services are considered finite, the primary theory of justice that guides the ethics of healthcare is the theory of distributive justice. In simple terms, the burdens and benefits of healthcare should be divided equitably. As Ram-Tiktin writes:

A just society might provide its members with opportunities to acquire education, occupations, and meaningful relationships, among others; however, the potential of human life is limited as long as an individual lacks the basic capabilities to enjoy life opportunities because of some disability or ailment that confines her to bed and limits her access to a good life. (Ram-Tiktin 2012)

This passage reflects the pragmatic nature of distributive justice, as having the right to obtain something means little if one

cannot access that which she has a right to obtain. In the context of prosthetics, this means that the future potential of one who is living with an amputation is limited so long as the person does not have the fiscal means to obtain the prosthetic that best suits her needs. To address this injustice, designing prosthetics through VSD can enhance the fulfillment of distributive justice for people who need a prosthetic limb but cannot afford one.

Industrial developers typically only aim to maximize benefits and do not share the bulk of the burdens of the unintended consequences of the upper limb prosthetic, including social and psychological harms. Many people living with upper limb amputations become frustrated with how prosthetics can increase the complications of performing daily activities, while companies that design the device are so far removed that they do not know of the consequences or comprehend their severity. VSD incorporation in the design process allows all types of developing teams to be able to partake in the social component of how the device performs in the field. For much more intimate design experiences in university teams, many individuals in the development process report that they experience social benefits from interviewing shareholders and working with patients directly. The QL+ team who developed the “Hand for Levi” said that they found the process of establishing a connection with their Challenger personally rewarding, as well as beneficial for prototype iteration with a significant amount of patient feedback. Engineering as a discipline seeks to improve upon the human experience through problem solving, and the intimate relationship formed between the QL+ designers and their challengers allows the designers to directly comprehend the impact of their work.

In standard prosthetic design, patients shoulder the burdens of paying for the device, facing emotional frustrations and physical pain associated with the use of the prosthetic, and having a device that does not fully suit their needs. Ultimately, most people living with uni- or bilateral upper limb amputations pay an extraordinary amount of money only to not even experience the primary benefit of the device. In VSD of prosthetics, the burdens and benefits towards the patients are more equitably distributed. Patients share in the burden of design because they have value input, so they have accountability in the design process and appreciation for the type of labor that is required for developing prosthetics. For example, a common complaint of any design process is that a client or consumer will change the design specifications with an unreasonable expectation that the product will be finished in the same amount of time and with the same level of integrity. In proper VSD methodology, the patient and their care network have thorough initial input of the valuations and needs that are most important for the development of the device, so the developing team and patient have an explicit prompt how the device needs to perform and the values it must fulfill. The incorporation of the external values throughout the process means that the patients and care networks have streamlined the initial conception of the design process in which the function, form, and which values are most important is already decided. Essentially, the consumers have completed the conceptual structure of the design matrix, so the developing team’s role is to utilize the design matrix in combination with their mechanical

Prioritizing the Patient

expertise in order to address the problem. This reduces the burden of conceptual design for the developers and ensures that the patient actually will experience the benefits of the device.

Some burden of caretaking is relieved because members of this group also get a say in values of design; caretakers will also be expected to help maintain the device — especially if the device is for their child — so VSD allows them to express these values and enhance their interactions with the design. The parents of a child who will receive an upper limb prosthetic may request that the prosthetic be very durable and resistant to water since they know that their child is very active and around water. Overall, the burdens of the design process are also now shared with all stakeholders to allow them to have appreciation of the device technology, and the developers have access to an improved connection with those who directly benefit from the technology.

Limitations of VSD for Prosthetics

Although VSD can provide many benefits for the development of prosthetic devices, parts of the method have the potential to be detrimental to the process. VSD calls for extensive research within stakeholder communities to establish a list of values for each stakeholder. This requires significant time and resources that can delay the primary user's access to the technology and prolong the struggles that arise with daily life without the prosthetic limb. Friedman's works indicate that even though extensive interviews can help with the process, they are not the only route that designers can take. She says that VSD permits using previous research to establish a list of values for stakeholder groups, which can help a design team cater their research to their given amount of time for interviews.

VSD also cannot provide a permanent solution to this prosthetics problem, as it cannot alleviate poverty and other systemic obstacles to the development of prosthetics. Having a prosthetic device to perform daily tasks may not drastically increase the ability of a patient to increase their socioeconomic standing or allow all people to have access to the devices they need. However, it does not directly follow that VSD has no place in prosthetics development. Improving the quality of life and providing increased access to necessary technology is better than not addressing the effects of prosthetics at all.

Conclusion

With the improvements in the fulfillment of autonomy, beneficence, and distributive justice, I conclude that it would be beneficial to at least pursue VSD in further manufacturing of upper limb prostheses. Ultimately, the purpose of engineering prostheses is to fulfill the biomedical ethical principle of beneficence and fulfill the valuation of human life as well as the engineering goal of enhancing the human experience. Although this methodology may be time-consuming for developers, the advancements in technology such as 3D printing makes it more feasible to customize the devices to the values of smaller groups of individuals. The deep intimacy of current prosthetic technology with the human body has significant effects on patients' psychological health and interpersonal relationships, so VSD allows for developers to

have comprehensive understanding of these effects firsthand.

The principle of distributive justice is most imperative to address, because simply having the ability to make the technology is insufficient for it to enhance the lives of those who need it. Socioeconomic status is an identity that one has little choice in deciding, so it should not be a limiting factor for the access and use of this technology. VSD allows for design teams to become more aware of the social consequences of their devices and illustrates that they can also be agents in justice in their everyday line of work.

The major obstacle that individual developers will need to overcome in the future of incorporating this design will address how it will affect manufacturing processes, but with the advancements in 3D printing technology, prosthetics with complex articulation can be manufactured for a fraction of the cost of myoelectric prosthetics. These advancements make affordable prosthetics at high quality much more feasible, and considering the questionable status of the ACA, affordable, high quality prosthetics will have an increasing social need that should be met.

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Selling Kidneys: an Ethical and Economical Approach

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As of November 21, 2018, 95,413 Americans with end-stage renal disease (ESRD) are waiting for a kidney transplant, according to the United Network for Organ Sharing (UNOS 2018). And with a median wait time of over three years - which can reach up to ten years in cities - an average of 13 people on the waitlist die per day (National Kidney Foundation 2016). It is clear the demand for kidneys far outweighs the supply. Economists have proposed that the shortage of kidneys available for donation could be alleviated, and thousands of lives could be extended and improved simply by allowing the sale of kidneys (Becker and Elias 2014). However, the sale of kidneys has been prohibited in the US since 1984 under the National Organ Transplant Act (NOTA). And not without reason; allowing a trade in kidneys would raise many ethical quandaries, primary among them issues of human dignity and exploitation of the socioeconomically disadvantaged. Yet, the current system is already fraught with ethical issues involving human trafficking and black market sale of kidneys (Carney 2011). For all the reasons legalization could be morally compromising, it is even more ethically unsound to miss the opportunity to improve and extend lives, reduce economic strain on the healthcare system, and potentially promote better palliative care in the process. If managed successfully, legalizing kidney sale could reduce exploitation by allowing for open communication of risks and regulation of the market. From both economic and ethical perspectives, the potential benefits of allowing a well-regulated trade in kidneys outweigh the bioethical concerns.

Most patients with ESRD on the renal transplant waitlist must undergo repeated hemodialysis to filter their blood, an onerous procedure which is less clinically effective and more costly both individually and systemically than kidney transplantation (Satel 2008). Those waiting for kidneys suffer from greatly reduced life expectancy and reduced quality of life. For instance, patients age 45 to 49 live on average 8 additional years on dialysis, whereas they live an additional 23 years with a kidney transplant (Becker and Elias 2014). Most of those on dialysis cannot work, and have to contend with exhaustion, edema, and nausea (NHS 2018). In contrast, the benefits of kidney transplantation are financial as well as personal. In the U.S., dialysis costs Medicare roughly \$120,000 a year per person, approximately 6% of all Medicare expenditures (Zimmerman 2017). That means that a single transplant would save taxpayers about \$300,000 in dialysis costs in the first five years. In 2014, Nobel Prize-winning economist Gary Becker and

colleague Julio Elias estimated that compensating kidney sellers \$15,000 would alleviate kidney shortages (Becker and Elias 2014). If the government paid the compensation to ensure equality, sufferers of ESRD would no longer have to endure extended dialysis, and public funds, if economic prognostications are to be believed, would be saved.

In her treatise making the case for compensating kidney donors, Dr. Sally Satel proposes a model in which the kidney trade could be regulated under a centralized market economy (Satel 2008). Under Satel's system, Organ Procurement Organizations (OPOs), which currently manage and coordinate donor organ procurement and organization, would extend their responsibilities to educating prospective kidney sellers about the transplantation process, risks of surgery, potential impact on future health, and performance of medical and psychological evaluations (Satel 2008). This proposal might indicate a conflict of interest, as OPOs have an incentive to collect increasing organs, so perhaps establishing an additional, independent organization providing counseling would be preferable. In Satel's model UNOS would apply their algorithm for matching current altruistic kidney donors to patients needing a new source of kidneys. Surgeries would take place at transplant centers which are officially registered, Medicare certified, and certified by UNOS in the performance of live-donor kidney transplant. Extending their current role in donor kidney transplants, these centers would be responsible for post-operative care. Satel proposes establishing a "National Provider Registry" under an oversight committee of relevant stakeholders as a centralized administrative agency under the US Department of Health and Human Services to regulate the kidney trade. The program would be implemented and evaluated in phases to ensure protection of participants. The funding for compensation would be derived from the savings accrued when patients get off dialysis (Satel 2008). To ensure long-term follow up after surgery, donors would receive 60% of their payment immediately after the procedure and the remaining 40% in installments over 5 years in which their health is closely monitored. Further monetary incentives would be offered to get participants to attend checkups and fill follow-up questionnaires biannually thereafter (Satel 2008). As a whole, this model seems promising, as it relies on modifying and working with existing bureaucratic structures, specifies a source of funding, and incorporates numerous measures to evaluate and maintain patient safety.

Since the only legalized market for kidney sale is in

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Iran, actual case studies of whether or not legalization has been effective are scarce. In Iran, within the first year of legalization of kidney sale in 1988, the number of transplants had almost doubled, and officials soon declared that kidney waiting lists had been cleared (Major 2008). However, there is no nationwide transplant registry in Iran, so the claim of cleared waiting lists has been questioned and the outcomes of transplants are difficult to track (Major 2008). Satel's model includes detailed registration, screening and follow-up criteria, so it would likely avoid similar regulation problems to those of the Iranian system. But as Satel's model is still untested and there are few instances of legalization from which to draw inspiration, so its implementation would have to be gradual - with pilot groups and careful oversight.

The primary arguments against kidney sale are rooted in concerns over the economic exploitation of would-be kidney sellers (Beauchamp 2003). It would clearly be unjust if a market for kidney transplants were systematically conceived so that the rich were able to buy kidneys from the poor and reap their benefits while the poor had no access to kidneys. In this scenario, the rich would cease to donate voluntarily to their relatives, while there would be scarcely a nephron available for the poor, and many of them could have donated a kidney already. Further, the poor within this system might feel that they had no other recourse to survival but to donate a kidney. If the rate of pay for kidneys were above a certain threshold, the payments could be disproportionately attractive to the desperate and impoverished (Beauchamp 2003). These ethical concerns should not be diminished, considering that in our current market, such forms of exploitation might very well come to pass. If we allowed the market to become increasingly libertarian, kidneys would likely grow curiously scarce among the poor. And if we allowed for black, private, and poorly regulated markets for kidneys to develop, the indigent would surely flock to these donation centers. Yet with a consistent and concerted effort to regulate the kidney trade, it may be possible to reduce the disproportionate burden of kidney donation on the poor that is likely to arise in such a situation.

In fact, the current lack of regulation surrounding kidney transplantation internationally encourages "transplant tourism" and a black market in kidneys, something which widespread legalization and regulation of kidneys could work to combat. Investigative journalist Scott Carney reports that the ample supply of kidneys available on the black market in socioeconomically disadvantaged regions coupled with the "excruciatingly long" wait times on organ donation registries makes organ brokering a profitable business enterprise (Carney 2011). Poor people worldwide, especially in India, Egypt, South Africa, Brazil and the Philippines, often view their kidneys as a "social safety net" of a sort - a final valuable to be pawned off (Carney 2011). Furthermore, illicit organ vendors are notorious for taking advantage of people at their most desperate. Many of these brokers will promise to pay a certain sum to organ sellers upfront with a greater sum

afterwards, but then refuse to pay the remaining money once the operation is completed (Carney 2011). The best practice of kidney excision is laparoscopic nephrectomy, a minimally invasive procedure where kidneys are removed with miniaturized surgical instruments (Mayfield-Hyperarts 2018). However, many kidney excision surgeons use the antiquated side-excision method, often in unsafe or unsanitary conditions and without providing appropriate care post-surgery, leaving kidney sellers debilitated long-term (Carney 2011). Because kidney sale is illegal, these victims are unable to receive medical treatment for fear of prosecution. Once harvested, kidneys are frequently sold to hospitals where transparency issues are rampant; the "transplant tourist" patients from first-world countries, are not told the true origins of their new organs under the pretext of "patient confidentiality" (Carney 2011). If a trade in kidneys were legal, prospective kidney sellers could have greater assurance of fair compensation and high-quality medical treatment, and it would be easier to ensure that kidneys worldwide are sourced from informed and consenting sellers.

Some critics have argued that legalizing the kidney trade would further stimulate a black market in kidneys, or that legalization would simply result in coercion in the current black market becoming more prevalent (Carney 2011). However, if we consider the motivations for people who currently seek kidneys on the black market, we can see why that will likely not be the case. The primary objectives for obtaining organs on a black market include gaining access to a commodity not available through legal means or seeking the commodity at a cheaper price (Satel 2008). Most patients who engage in "transplant tourism" would likely prefer to have access to legal transplants, as traveling to obtain kidneys under the brokerage of a human trafficker entails significant personal risk without protection against fraud or medical malpractice (Satel 2008). Legalizing kidney sales would increase legal access to kidney transplants, thus reducing individuals resorting to black market use (Becker and Elias 2014). Another potential issue with legalization is that some individuals who cannot afford health insurance might seek lower-cost alternatives for kidneys. The obvious way to drastically reduce this risk would be to ensure universal insurance coverage, making kidneys equally financially accessible to those who need them. As the US is quite resistant to adopting universal health insurance, this might prove a concern. However even under the current American healthcare system, the prohibitive costs associated with organ purchase, surgery, and immunosuppressant medication prevent uninsured individuals, who are disproportionately low-income, from undergoing surgery in the first place (Satel 2014). Legalizing a market in kidney sale would be unlikely to stimulate the black market, because the benefits of regulation would actually reduce the incentive for "transplant tourism," and the people who would be motivated to buy a kidney illicitly due to lower costs would be financially unable to do so.

A further ethical objection concerns assuring that

Selling Kidneys: an Ethical and Economical Approach

truly informed consent regarding risk factors of kidney extraction surgery is given for the sale of a kidney. It is ethically imperative that prospective kidney sellers should be fully informed of the medical risks to their future health and lifestyle. Short-term, United Network for Organ Sharing reports a surgical mortality rate among kidney donors of 3.1 per 10,000 donors, a small but not nonexistent risk of which potential sellers would need to be made aware (Wolters and Vorwinkel 2012). In the long-term, a nephrectomy follow-up study conducted with a large sample size, in which participants were tracked for 45 years, concluded that after a nearly full-life, nephrectomy had no adverse effect on survival (Wolters and Vorwinkel 2012). More significant is the risk of people having undergone nephrectomy eventually suffering from ESRD themselves. Recent long-term studies of kidney donors in Norway and the USA have shown that there is a small (approximately 0.3%) increase in absolute risk of developing ESRD after 15 years, as compared with a control population of similar health (Maggiore et al 2017). Quality of life changes are even more relevant to evaluating personal risk but are more difficult to study. A 2015 study found that patients' reports on various aspects of their well-being, including "functional capacity," pain, and "social function," still had not returned to pre-surgery levels after 30 days (Morales et al 2015). Hospital stays were typically between four to six days, and patients were able to resume their pre-donation activities "within a short time"; however, there was "no consensus" on exactly how short it was, as recovery time varied widely (Morales et al 2015). Much more long-term research is still necessary to provide patients with better information regarding how kidney transplant will likely affect their lifestyle, but current research generally supports the conclusion that kidney donation is relatively low-risk in both the long- and short-term. Nonetheless, prospective kidney sellers would need universal and comprehensive counseling about their personal risk factors and concerns before even being considered as candidates for kidney sale.

In an ideal world, obtaining informed consent would be as easy as simply telling the prospective kidney seller to read the previously cited medical literature, do their own personal cost-benefit analysis, and come back whenever they feel comfortable with their decision. However, that is not a realistic expectation; getting a potential volunteer, especially one who has not received education on medical procedures, to comprehend the risks and benefits of such a procedure can be a "formidable task" (Beauchamp 2003). Potential kidney sellers might not adequately appreciate the risk of health deterioration from nephrectomy, or how far the money they obtain from the procedure will go towards its intended use after factoring in the potential costs of post-operative recovery or reduced productivity. In order to combat impulsive decisions, Becker and Elias propose that prospective kidney sellers be required to wait a period of three months following counseling before undergoing surgery. Emphasizing these relevant factors to individuals desperate enough to sell a kidney might

prove challenging, but the alternative, in which desperate people continue to sell kidneys on the black market, is considerably worse for informed consent. In instances of illegal kidney harvesting, kidney sellers are not provided with information about the risks of a procedure, as brokers have no incentive to treat sellers ethically. In fact, in a 2001 study in India of 305 individuals who had sold a kidney illegally 6 years before the survey, 79% of participants said that they would not recommend selling their kidney (Goyal et al 2002). This suggests that if many people who had sold their kidneys under illegal circumstances had had more information about likely consequences, they would be less willing to sell (Beauchamp 2003). This is a further argument for legalization because, if legalized, it could at least be made mandatory that kidney sellers receive detailed and individualized counseling that presents the current medical data and assesses their personal risk factors before selling their kidneys. Though assuring that participants adequately appreciate risk is difficult, legalizing the kidney trade in order to better ascertain that information is being provided to would-be sellers, seems to be the more ethical option.

A further argument against the kidney trade is that it would be morally wrong to allow the commodification of the human body; the sale of kidneys amounts to a degradation of human dignity (Brecher 1990). By this logic, ESRD patients seeking a kidney transplant are responsible for a kind of vampiristic "neo-cannibalism," fueling their greedy desire for more lives by preying on the flesh of the indigent (Carney 2011). However, moral outrage is of limited utility in bioethical debates; the effects of a kidney trade on human dignity can be more effectively considered from the perspective of personal autonomy, human rights, and respect for persons.

As we have previously established, legalizing the kidney trade would open up an avenue for persons to make better-informed, comparatively safe, and personally autonomous decisions regarding their own bodies, as compared to the current situation where "transplant tourism" and human trafficking abound. Further, legalizing the trade in kidneys could promote human dignity by encouraging discussion regarding the downsides of buying a kidney. In the context of organ donation and illegal trade, doctors often use the privacy ethic to tamp down suspicion of exploitation along the supply chain (Carney 2011). With legalization of the kidney trade, there would be more incentive for transparency (Carney 2011). And the way transplants are often portrayed as a panacea to potential recipients is seriously flawed; while transplant is far preferable to being tethered to a dialysis machine, patients are merely "trading a fatal disease for a chronic one" (Carney 2011). After transplant, recipients must rely on a regiment of immunosuppressive anti rejection drugs, leaving their quality of life a shadow of what it once was (Carney 2011). Increased public discourse surrounding a trade in kidneys, as well as open discussion regarding the risks of kidney trade, could pave the way for a system that thinks more realistically about mortality. Potentially, the legalization

of a kidney trade could be accompanied by discussions surrounding the benefits and drawbacks of palliative care for ESRD, and a portion of the public funds saved through the process of getting people off dialysis could go towards better palliative care for sufferers. Rather than leading to a decrease in dignity, commodifying the kidney could allow greater information, safety, and agency for prospective sellers, greater transparency in the kidney trade, as well as more honest and matter-of-fact discussions surrounding chronic illness. It would therefore result in a net gain in dignity.

Legalizing a trade in kidneys could increase access to live-donated kidneys, extending and improving the quality of life for thousands of ESRD sufferers a year, while saving Medicare and Medicaid millions of dollars. Critics of commodification contend that it would lead to exploitation of the poor, as well as posing a threat to human dignity. However, by increasing market regulation, legalization of the kidney trade could decrease the incentives for a black market, thus increasing the levels of informed consent, safety, and transparency overall. Further, a well-regulated market in kidneys could increase open and honest discussions of risk factors both among prospective sellers and recipients, leading to a more honest evaluation of chronic illness and mortality in the transplant system. Paradoxically, commodifying kidneys could actually increase human dignity in kidney transplantation cases.

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Holistic Dissection: a Course in Empathy

Laurie Yousman*

Every year, a new class of medical students must proceed through the profession's most storied rite of passage: the gross anatomy course. As burgeoning physicians, medical school students must learn both distance from and empathy towards the patient from their first-year dissection. When presented with an opportunity to cut the human body into its component pieces, students require coping mechanisms to balance the objectifying nature of the dissection. Practices highlighting holistic identity as the basis of the student-cadaver relationship are vital in teaching students to embrace their desire to empathize as they take their first steps into an inherently fact-based field. In this paper, ceremonies and practices surrounding the dissection will be analyzed through two different perspectives on empathy and dissection.

The gross anatomy course as a way to teach students how to perform the tasks their profession requires without repressing their human emotion. If students gain "perspective and understanding by discussion and reflecting upon their emotions," it "enables them to do their work without denying an integral part of their being" (Rizzolo 2002). The methods of discussion and reflection vary across cultural lines, but the presence of these ceremonies is consistent in most medical schools. Being too objective towards the patient as a form of denial is further underscored by the idea that medical students "choose the profession as an expression of their compassionate, empathetic natures" (Rizzolo 2002). In effect, students have an inherent desire for an empathic connection with their cadaver, and practices that encourage this relationship are essential to any medical education.

Opposing the intuitive nature of doctor-patient empathy is the concept of reckoning scientific work, or "resolving a complex structure into less complex subunits, in order then to return to the complexity" (Rehkämper 2006). During the dissection, students take apart bodies, breaking down a whole organism into its parts. This scientific process challenges the view of the cadaver as a human individual, reducing it to a simple collection of body parts. However, the view of the cadaver as a complete being is vital to education, as "health and sickness are a phenomena of the whole organism" (Rehkämper 2006). A holistic view of the cadaver and empathizing with the cadaver go hand in hand. As a result, it can be concluded that empathy strengthening practices must be instituted into the dissection process to balance scientific thinking with an empathetic relationship.

In medical education, ceremonies celebrating the deceased cadaver have been increasingly implemented to

push the student towards acknowledging the cadaver's human value. In Thai *ajarn yai* ceremonies attended by students, families, and Buddhist monks, cadavers are offered ritual flower bouquets and the name of the cadaver is read out loud, bestowed the title of "great teacher" (Winkelmann and Güldner 2004). The ceremony both re-personifies the cadaver as a complete being in its role as a teacher while providing an outlet for students' empathetic desires that they may not normally be able to express in the dissection room.

Within states rooted in Judaic traditions, the matter of reconciling humanistic values and scientific ones is a particularly pressing issue for Israel's Sackler medical school. Religious procedures are followed in the dissection room to ensure full respect of the cadaver. In accordance with *tuma* (ritual impurity) laws, dead bodies must be immediately buried; one who comes in contact with a body is immediately tainted. Israeli dissection rooms are therefore classified as cemeteries and are physically separated from the rest of the medical school (Notzer 2006). The difference in location puts the student in a different mental state, transitioning from a mindset of mainly scientific thought to one that must take into holistic considerations. Seeing the cadaver outside of the scientific mindset, as more than just a set of tools, is essential to generating empathy within the student.

In the classroom, students must follow the Jewish tradition of keeping all bodily tissues, including blood and organs, together (Notzer 2006). When there is emphasis placed on keeping all tissues of the body together, it encourages students to allow the cadaver to retain its former identity as a living being by maintaining some semblance of its previous physical form. Following of Jewish burial practices shows that cadavers, despite their unorthodox post-mortem treatment, are still treated as human.

Taiwan's long history of body donation comes with specific religious practices as well. At Tzu Chi College, strict spiritual ceremonies are performed, and there is even a specific temple dedicated to housing ashes of the cadavers for families visit. Asian ceremonies on the whole are deeply connected spirituality, and remains are often returned to the families of the donors for grieving and spiritual purposes (Park 2011).

Following religious customs that honor the dead allows for students to relate to the cadaver in a religious context, outside of traditional scientific thought. Religion is a uniquely human concept, and when cadavers are given special religious accommodations, their values, and

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therefore human identity, are being honored. Retaining this holistic identity forges a relation of empathy for a donor.

As a result of this burgeoning relationship, there are lower levels of disgust and therefore more empathy present experienced in the relationship between the student and the cadaver. This is clearly exemplified in a direct comparison between two German and Ethiopian gross anatomy courses; the German medical students participated in a ceremony to honor the body, while the vast majority of the Ethiopian students did not. Later on, when surveyed about how they felt during the course, German students reported a much higher sense of “normal feeling” towards the cadaver, and upon initial contact with the cadaver, German students experienced much lower levels of disgust and discomfort towards the cadaver compared to Ethiopian students (Bekele 2011). It is possible that the presence of a ceremony to honor the holistic identity of the cadaver prevented a level of disgust towards the cadaver and promoted normalization of the body as a fellow human.

It follows that the lack of ceremony would yield the opposite effect. The unmodified state of a dissection is one that is rife with objective, medical fact, and yet is devoid of time for empathic reflection. Ethiopian students who did not experience holistic ceremonies were twice as likely to say that replacing the gross anatomy course was either tolerable or good compared to the German students who participated in a ceremony (Bekele 2011). Those who have gone through the emotional transformation of a donor ceremony are far more likely to deem the greater dissection experience as irreplaceable. While the process of scientific thinking that is necessary to learn medical fact may be replicated, the emotional experience that occurs when empathy based ceremonies are performed in relation to the dissection is unique.

Additionally, levels of disgust in Ethiopian students were not counteracted with normalization through empathy in the absence of a holistic ceremony (Bekele 2011). Desensitization from disgust and the establishment of normalcy is another important element of the dissection. In a study of the responses of medical school students to the cadaver dissection, two art projects were prompted, one in the early stages of the course and one in the late stages. The late-stage projects showed themes of desensitization and fewer themes of fear of violating the human body compared to the early projects (Shapiro 2006). Reflective activities allow for the student to experience an emotional transformation, turning an immediate visceral reaction into one that can facilitate learning.

This decrease in disgust is also generally correlated with a deeper understanding of the significance of the gross anatomy course. In a study wherein students were given three different surveys at different times during the course, a decrease in student responses of disgust saw a significant increase in their interest in the donor and reports that the course should not be replaced by instructional videos and models (Mulu and Tegabu 2012). Normalization of the

cadaver, often through reflection and ceremony, may lead to appreciation of the donor as an irreplaceable individual.

Even after normalization of a dissection, a holistic view of the cadaver is still closely tied to empathy. In a personal anecdote, one physician writes that as a result of imagining the cadaver’s identity as a living being, “it is impossible to hold someone’s hand with mere surgical intent; even the stiff grip of the cold fingers has an undeniable emotional effect” (Mahler 1995). She explains this as a lesson she took away from the course, showing that after completing the course and getting over the discomfort of cutting up a fellow human, the act of imagining the donor body as an individual caused her to empathize.

The gross anatomy course is a prime opportunity to cultivate empathy in future doctors, encouraged by practices that embrace a holistic view of the donor. Often, however, this purpose is overlooked, as dissection courses seem to be becoming less and less popular in the United States. Surveys of medical schools show that students spend as much as 80% less time in dissections as they did in the 50s. In some institutions, the trend away from a dedicated dissection course is even more extreme, students at the University of California at San Francisco don’t even perform the dissection themselves (Zuger 2004). The preservation of the gross anatomy course and associated holistic practices is vital to the education of young doctors as it provides medical students a first step towards learning to balance the purely scientific and objective tasks they must carry out as a physician while remaining empathetic towards their patients.

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Commentaries

Dissection, Empathy, and the Disposition of Our Bodies

Robert D. Hicks, PhD*

The essay argues, "... students have an inherent desire for an empathic connection with their cadaver, and practices that encourage this relationship are essential to any medical education." Further, the essay cites various cultural practices surrounding the disposition of the dead, noting that medical students may sometimes participate in or witness rituals or ceremonies that "honor the holistic identity of the cadaver," thus overcoming a student's "disgust towards the cadaver" by promoting "normalization of the body as a fellow human." The essay concludes by noting that the student's reflection about and participation in a ceremony "may lead to appreciation of the donor as an irreplaceable individual," again describing this engagement as "normalization of the cadaver."

I am responding to the essay not as a medical school professor but as director of a museum of medical pathology, Philadelphia's Mütter Museum. Medical museums are where those cadavers go, or parts of them, if not otherwise incinerated, after the students are done. Medical schools no longer maintain pathology museums. Some of our small museum staff have not participated in an autopsy, yet our working lives are constructed around the dead, their display, preservation, and in particular their evolving narratives. The essay seems timid in its academic distancing of the prospect of handling corpses and, indeed, describes students' reactions to dead humans as "disgusting." The word "cadaver" itself is a euphemism: the original Latin root meant, "to fall." The essay errs, however, in describing an empathetic approach as "normalizing." Empathy—also a euphemism in the context of the essay—is the wrong word. It refers to imagining what another person is thinking or feeling. Corpses do not think or feel. The "holistic identity" in the essay, though, hints at but does not make explicit a desire to absorb a narrative of a life, the life of the person now under the knife. Implicit to the essay is an "I-it" relationship; the correct relationship is "I-Thou/Us." The corpse's narrative, however, is not fixed nor has it concluded.

What does a medical museum have to contribute to this conversation? Medical museums were once domains exclusive to medical schools and provided lectures, study, and research. Sometime in the late 19th or early 20th century, physicians created a "clinical gaze" which effaced the identities of people whose bodies furnished the means for medical training and analysis. Now, enclosed by laws respecting privacy and the constraints placed on disclosure of personal data, medical schools that still have such collections cannot publicly identify their human remains even if the information exists. Museums not affiliated with medical schools, like the Mütter, are not subject to the same data privacy requirements. Simon Chaplin, former director

of the Hunterian Museum, Royal College of Surgeons of England, in London, one of the pre-eminent medical collections in the world, has thought deeply on this topic. He wrote that pathological specimens:

... speak, too, with a medical voice; in terms that are anatomical, pathological or histological, the lingua franca of the clinician or biomedical scientist. Most of all it is anonymous. Its accompanying case history may lay bare the most intimate details—reveal age and gender, health and habits, dissect a life with the same dispassion that has been brought to bear on the body—but the narrative is always impersonal, the patient is not named, and their voice has no place.

We are a cemetery for the unburied. Medical museums house us; they are our modern mementi mori. As institutions, medical museums are artifacts of their eras when specimen study formed a useful component of a physician's education: body parts sectioned and rendered almost transparent with toxic chemicals, cancerous tumors preserved in bottles, re-articulated skeletons in cases. These museums display us alongside simulacra intended to compete with and enhance the appearance of life or death, such as plaster models or moulages of wax that can sweat. Other preparations appear to have been arrested in death mid-sentence—the corrosion preparation of a human infant, mouth open, key nerves, arteries, and veins shown in muted blues and reds, most of the flesh gone, the skin a desiccated parchment, the expressive tiny face inarticulate. Vestiges of that clinical gaze remain, but that gaze has become something larger and multifaceted.

Our dialogue with the dead at the Mütter is personal, intimate, scientific, speculative, and faintly romantic. Drawn to our collections and captivated by the atmosphere of the museum and the specimens and medical tools, artists create fictional narratives surrounding the dead. Where the museum meets the arts, a dialogue takes place to rationalize the storytelling. Casual visitors sometimes label our specimens as weird or grotesque. Others who are more thoughtful, including artists, experience our anatomical specimens as the "pathological sublime" (Dery). The notion of sublimity takes its cue from Edmund Burke's 1756 essay, *A Philosophical Inquiry into the Origin of Our Ideas of the Sublime and Beautiful*. The sublime simultaneously astounds, mystifies, and enchants with an overwhelming, terrifying beauty. Far from finding dead humans disgusting, we at the museum find an intense aesthetic. Burke writes, "astonishment is that state of the soul in which all its motions are suspended, with some degree of horror." Is this a more

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accurate depiction of what happens when a medical student meets a dead human?

We recognize our collection of specimens as a biorepository. Technology now permits the extraction of DNA and the reconstruction of a genome for specimens preserved in fluids in the 19th century: we now offer this biorepository to the scientific world to extract genetic stories about the health of our forebears and, by extension our own. These are new narratives for corpses, inviting new relationships with the dead. The autopsy is not a concluding parenthesis to a life. Speculative fiction—whether via stories, poems, music, or other art media—augments the real lives represented in our collection. Historian Thomas Laquer embraces all, from the science to the art, as “humanitarian narrative.” This mode of narrative, which emerged during the late 19th century, provides intense clinical descriptions that undergird desperate behavior in which “the plight of the patient ... create[s] a ‘moral imperative’ for actions that appeared beyond the pale—harsh physic, radical surgery, and post-mortem dissection among them” (Gallagher and Laqueur). If the meeting of medical student and corpse is a threshold moment, a rite of passage, then why not enlarge it to include readings in (and discussion of) the humanitarian narratives of our mortal illnesses and death. Why not prepare the medical student as one actor in a continuing narrative of a life? That corpse might inspire art, reveal a health history of great relevance to descendants, or provide clues to public health in an early era. At our museum, we respect our dead, care for them, place them within new narratives, and meet the dead at a horizon of sublimity, Shakespeare’s “undiscovered country,” not as a “disgusting” phase between life and dissection. Playwright

Samuel Beckett, in his most famous play, *Waiting for Godot*, includes this meditation on the dead:

Estragon: All the dead voices.
Vladimir: They make a noise like wings.
Estragon: Like leaves.
Vladimir: Like sand.
Estragon: Like leaves.
(Silence)
Vladimir: They all speak at once.
Estragon: Each one to itself.
(Silence)
Vladimir: Rather they whisper.
Estragon: They rustle.
Vladimir: They murmur.
(Silence)
Vladimir: What do they say?
Estragon: They talk about their lives.

The bodies in medical museums and on the dissection table rustle, whisper, and murmur, and we ought to hear their voices.

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In Memory of My First Patient

Samuel Aidan Kelly, MD, MBE*

We said goodbye today. I thought it only fitting that I shave. I had planned to dress up, but found myself wearing the same old beat-up boots. Humility, I told myself, though convenience was more likely.

I put my headphones in as I walked to the lab, but couldn’t think of anything to play. My go-to for such occasions, Ave Maria, seemed ... heavy handed. I tried flipping through some practice questions instead, but soon gave up and simply listened to the December wind whipping past my ears. I felt I really ought to take my headphones out and appreciate the sounds of life around me, but the wind sounded just fine. Beautiful weather for the circumstances.

I had expected to be happy when anatomy lab was over. Not that I was sad, just internally quiet in a way that felt unfamiliar. The moment of silence was a nice idea, albeit somewhat lost amid the fray of a lab session. He had been lying face-down when they called the moment. Was that

all? Feeling something left unfinished, I tried to organize a moment of our own once others had left. After we flipped him, and I unveiled what remained of his face, I should have realized the fallacy of my plan. Instead I felt that now familiar need to defend him, probably more accurate to say possessiveness, when I saw the hollow eyelid. Someone had removed his right eye, the one we had intentionally left intact, without our knowledge. Or so I thought, only to learn that it had simply sunken to the back of the socket due to dehydration. Still, it looked hollow in a way I could not repair. Just as I could not realign his skull where we had split it, or the skin of his cheeks where we had flayed them to expose the muscles below. Feebly I grasped the various parts together as one empty eye looked back at me. I wanted only to show him an act of respect, and for some reason that meant putting him back together. I like to think he knew better.

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