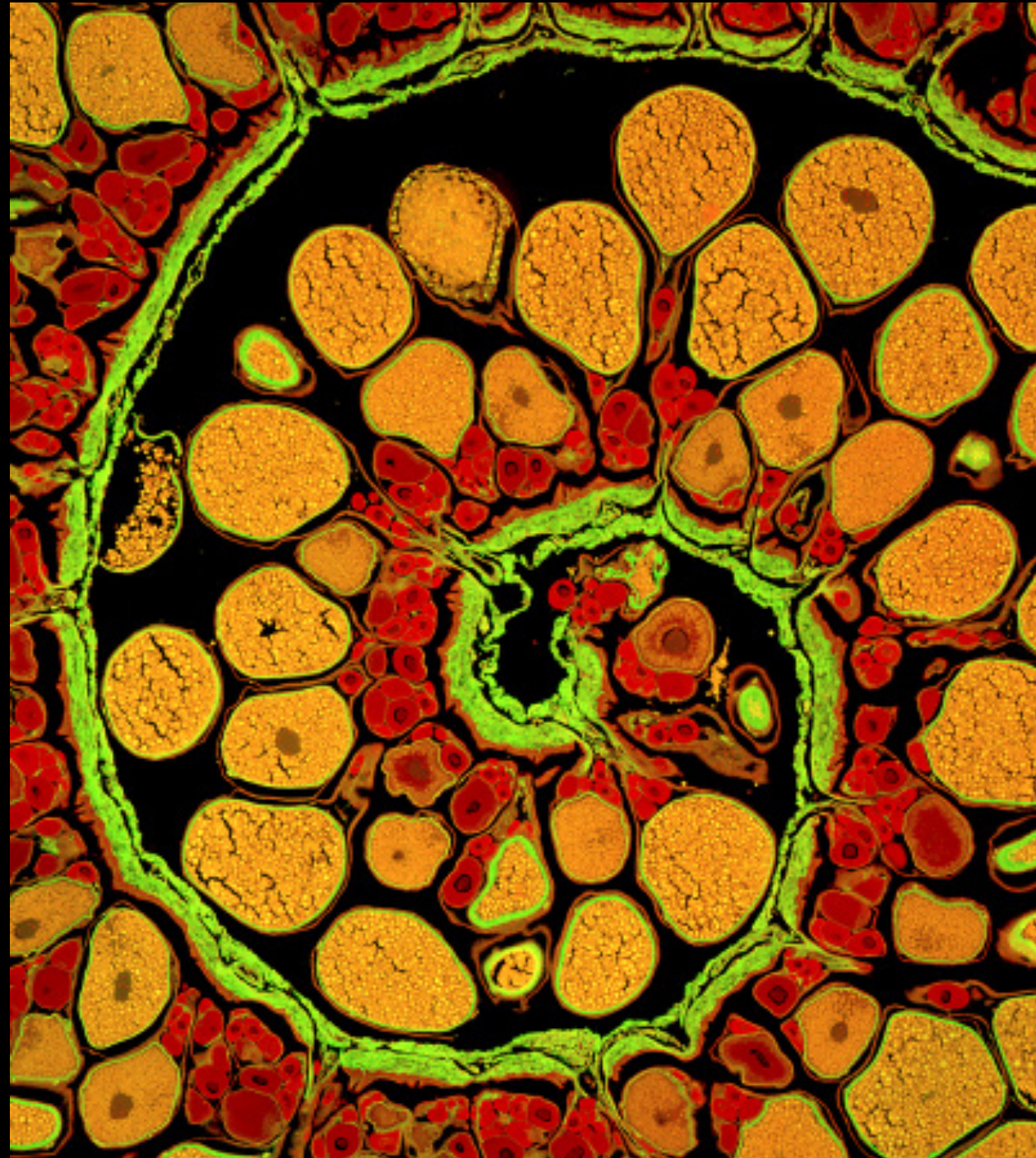


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THE RUTGERS JOURNAL OF BIOETHICS

VOLUME X, SPRING 2019

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The Rutgers Journal of Bioethics is an undergraduate journal exploring the intersection of ethics, biology, society, and public policy. It has been published each year since 2009. While the Journal solicits articles from all persons wishing to participate in the open discussion on bioethics, it is managed by students at Rutgers, the State University of New Jersey. The Journal is published by Premier Graphics (500 Central Avenue, Atlantic Highlands, NJ 07716) and funded through generous contributions from the Rutgers University Student Assembly Allocations Board. The Journal welcomes all unsolicited original essays, book reviews, editorials, and art. To submit, please e-mail a copy of your paper or a high-resolution image of your work of art to <rubioethics.journ@gmail.com>.

©2019 *The Rutgers Journal of Bioethics*. All copyrights to art or essays belong to their respective authors. All other copyrights belong to *The Rutgers Journal of Bioethics*. Please send all questions and comments to the above email address. Our sister organization, the Bioethics Society of Rutgers University, meets every other Wednesday during the academic year at 9:00 PM in Scott Hall on the College Ave. Campus at Rutgers-New Brunswick (43 College Avenue, New Brunswick, NJ 08901). All are welcome to attend. Sometimes we have pizza. Meeting details are available at <<https://www.facebook.com/bioethics.ru>>. We would like to thank Dr. Eric Singer and Dr. Michael Solomon of Robert Wood Johnson University Hospital for their advice and support.

Letter from the Editor

In the realm of bioethics, it sometimes seems like we speak in hypotheticals—what would be the appropriate response *if* a situation with no clear-cut answer were to come about? However, events inevitably crop up that serve as poignant reminders of the importance and practicality of such discussions. In November 2018, one such event made international headlines when a Chinese researcher claimed to have genetically altered two baby girls in an attempt to confer innate immunity to HIV-1. While it is fruitless to attempt to suppress our desire to push the limits of nature, we can prepare ourselves for the future now, in the present, by deciding how to direct our moral compass. Expanding upon our wealth of knowledge and human capability is the cornerstone of the legacy of our species, but we must strive to do so responsibly.

I am excited to launch the 10th volume of our Journal, which presents a number of issues ranging from policy analysis to case studies. Together we will explore financial incentives involved in kidney donation, concierge medicine, and cancer care in the United States. Furthermore, we will take a step back and explore global issues with an article on cross-cultural bioethics and an analysis of the medical student's role in international health. It is my hope that this body of work sheds light on topics previously kept in the shadows. Literacy in science is exceedingly important in a world where reliable sources are difficult to come by and where social media often muddles the facts.

This publication is made possible with the help of our sister organization, the Bioethics Society of Rutgers University, which has worked tirelessly to organize our annual symposium to celebrate the launch of this year's publication. I would like to thank our authors, editors, and design team for their hard work in creating this diverse and insightful addition to our collection.

Lastly, as a graduating senior, I would like to express my gratitude for all the people I have met and the skills I have accrued as a result my time spent with the Journal. I joined this organization three years ago at the suggestion of my predecessor; at the time, I could not have imagined how great a role Rutgers Bioethics would play in my growth as a leader and public health student.

Meredith Giovanelli

Editor-in-Chief, *The Rutgers Journal of Bioethics*

Letter from the Society

The Bioethics Society of Rutgers University aims to raise awareness of bioethical issues from the past and in the present. In our bi-weekly meetings, students analyze bioethical issues or case studies and discuss potential solutions. We focus on issues in healthcare (such as the ethics of aborting a fetus after prenatal testing has revealed genetic abnormalities), policy (such as the ethics of religiously-affiliated hospitals refusing certain treatments), biomedical research (such as the use of CRISPR to create babies who are resistant to certain diseases), and public health (such as organ allocation and vaccination). It is important to discuss these matters thoroughly since the “correct” answer in biology and related fields is not always clear. Our students pursue careers in healthcare, research, public health, and law, and it is essential they are able to analyze ethical dilemmas and make informed ethical decisions.

Apart from our general body meetings, we host two large speaker events each year, the first of which is held during the fall semester. This academic year, Dr. Eric Singer, a urologic oncologist at the Rutgers Cancer Institute of New Jersey and a member of the Robert Wood Johnson University Hospital Ethics Committee, presented at our event, “Bioethics with Dr. Singer.” He discussed the various ethical concerns related to clinical research trials and the development of disease treatments. This event was a great success and offered real-world examples of the importance of bioethics.

During the spring semester, we host the annual Rutgers Bioethics Symposium. This event is intended to shed light on current and pressing issues in health and medicine. This year, we welcome a panel of professionals who will speak about various aspects of the debate surrounding abortion. We hope our event will inspire students to think more deeply about ethical dilemmas.

We would like to express our gratitude to the members of the Rutgers Bioethics Society. The dedication and commitment of our students is admirable, and they are the main reason why this organization succeeds in its mission. As they progress in life, we hope our members carry forth the principles and ideals discussed at our meetings and events. Additionally, we would like to thank the executive boards of the Society and the *Journal* for helping to put together our programs over the course of the year. Their devotion to this organization and passion for bioethics are what make our meetings and events possible. The publication of Volume X of *The Rutgers Journal of Bioethics* is a manifestation of the hard work of the *Journal's* executive board, and we hope you benefit from reading this edition.

Kusuma Ananth & Muhammed Rahim
Presidents, Bioethics Society of Rutgers University



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Cover: James E. Hayden, Wistar Institute, Philadelphia, PA, *Anglerfish ovary cross-section*, cropped. "This image captures the spiral-shaped ovary of an anglerfish in cross-section. Once matured, these eggs will be released in a gelatinous, floating mass." Retrieved from <https://www.nigms.nih.gov/education/life-magnified/Pages/default.aspx>.

Addressing the Ethics of Removing the Financial Disincentive of Living Kidney Donation

by Emily Slome[†]

Some bioethicists have recently argued that the current legislation in the United States surrounding living kidney donation should be amended in order to remove the financial disincentive of donation. While the law allows for certain kinds of reimbursement, it makes it extremely difficult for living kidney donors to be completely reimbursed for their donation-related expenses. This lack of complete reimbursement can be a deterrent for those who wish to donate. In this paper, I argue that there is an ethical obligation to allow donors to be more fully reimbursed. In order to do so, I address what I take to be the best arguments in favor of leaving the legislation as is and explain why those arguments fail.

The issue of whether a regulated organ market should be legal in the United States remains highly controversial. A few bioethicists, however, have recently argued that what should not be controversial is amending the current legislation to allow for a more exhaustive reimbursement of living donors' donation-related costs. [2][6][12] Strict laws in the United States make it illegal to provide any sort of financial incentive for donating an organ. Although these laws allow donors to be reimbursed for certain donation-related expenses such as travel, lodging, and lost wages, they forbid financial compensation for other costs that may be seen as ethically problematic financial incentives or forms of payment.

According to proponents of changing the current legislation, living kidney donors face many financial burdens, and these burdens often present disincentives or barriers for potential donors. Many of these proponents argue that while we should continue to be careful not to allow ethically problematic financial incentives for kidney donation, we need a program or poli-

[†] **Emily Slome** is a philosophy PhD student at the University of Colorado, Boulder. Her main areas of interest are applied ethics and bioethics. She received her master's degree in bioethics from New York University.

cy in place to remove the financial disincentive or barrier faced by potential donors. In doing so, the hope is to increase the supply of kidneys and to therefore decrease the number of deaths caused by this shortage.

In this paper, I will, in agreement with these bioethicists, argue that there is an ethical obligation to better reimburse living kidney donors in the United States for their donation-related costs. I will first explain the kidney shortage problem and current organ donation legislation in more detail. Next, I will outline some of the recent literature supporting better reimbursement of living kidney donors. I will then present some possible ethical and practical issues someone opposed to such changes might bring up. Finally, I will address each of these possible issues, and with them in mind, I will propose a method for establishing a policy of better reimbursing living kidney donors that is least ethically problematic.

BACKGROUND

Although there are many different opinions on how to improve kidney supply in the United States, it is clear that some change needs to be made in order to alleviate the crisis. In the United States, there are currently over 120,000 people waiting for lifesaving organ transplants. The vast majority of that number is people waiting for kidney transplants. The median wait time for a kidney transplant is approximately three and a half years. In 2014, over 4,700 patients died while waiting for a kidney transplant, while over 3,600 patients became too sick to receive a transplant. Every month, around 3,000 new patients are added to the list of people waiting for kidney transplants. In the U.S in 2014, around 17,000 kidney transplants occurred. [14] The key takeaway from these statistics is that there is a substantial disparity between the number of people waiting for kidney transplants and the number of people receiving them.

Moreover, a majority of transplants come from deceased donors. Of the approximately 17,000 kidney transplants in 2014, approximately 11,500 came from deceased donors and approximately 5,500 came from living donors. [14] This statistic remains despite the strict conditions under which kidneys from potential deceased donors can be transplanted. Typically, a viable deceased kidney donor is someone aged sixty or below with a heartbeat, who is declared brain dead in a hospital, and does not have any of several specified medical conditions. This criterion disqualifies an extremely large percentage of the people who die each year from becoming deceased donors. [5] According to Cook and Krawiec, because only a small percentage of kidneys from deceased people are eligible to be transplanted, and because some of the eligible kidneys do not end up being transplanted for various reasons, even if everyone in the United States consented to be a deceased donor, a vast gap between those waiting for a kidney and those receiving

kidney transplants would remain. [5] Therefore, it is likely that the more effective or efficient method for alleviating the organ shortage problem is increasing the number of living donors.

Understanding the relatively low rates of living kidney donation, and how best to increase those rates, requires understanding the current legislation surrounding living kidney donation. One of the most important pieces of United States legislation related to living organ donation and transplantation is the National Organ Transplantation Act (NOTA) of 1984. A key aspect of NOTA is that it prohibits any form of financial incentivizing for organ donation. In other words, it not only prohibits the buying and selling of organs in the United States but also prohibits any sort of “valuable consideration” or financial compensation for living donors including, for example, tax breaks. Implicit in NOTA is a distinction between what counts as an illegal financial incentive or payment for an organ donation, and what counts as a legal financial reimbursement of some of the living donors’ donation-related expenses. While NOTA does not specifically state examples of illegal financial incentives or “valuable considerations” for an organ, it does explicitly state that living donors may be reimbursed for donation-related expenses including travel, accommodations, and lost income. [10]

While NOTA makes it illegal to financially compensate or financially incentivize individuals to donate organs in any way that is reminiscent of an organ market, many states have already implemented some policies that attempt to encourage or facilitate living organ donation by partially removing the financial barriers involved with living donation. Some of these policies include paid leave from employment during donation-related activities, and recovery and tax benefits for donors, which are meant to be equal to the monetary amount lost by donors from donation-related costs. [2] For example, some states (e.g., New York) have a paid leave policy, which allows up to thirty days of paid leave to serve as an organ donor. Other states (e.g., Iowa) have a similar paid leave policy as well as a tax deduction policy, which dictates that a taxpayer who donates an organ may receive up to \$10,000 in tax deductions for unreimbursed donation-related expenses, including travel, lodging, and lost wages. [1]

Currently, the National Living Donor Assistance Center provides financial assistance for living donors. Although this program does provide some aid to living donors, in order to comply with federal law it has strict rules for what expenses can be reimbursed and who can be reimbursed for those expenses. The expenses that can be reimbursed are travel, lodging, and meals, as well as expenses incurred by the donor that are related to evaluation, hospitalization for the surgery, and medical or surgical follow-up for up to two years after the surgery. However, these expenses can be reimbursed only if the donor is unable to receive reimbursement for any expenses through any

state reimbursement program, an insurance policy, a federal or state health benefits program, or from the recipient of the organ. [13]

REVIEW OF RELEVANT RECENT LITERATURE

While the policies implemented by some states to remove some financial barriers of donation seem promising, evidence shows that these actions have only a minimal effect on increasing the number of living organ donations. According to Chatterjee et al., who conducted a study on the effect of state policies aimed at increasing organ donations and transplants from both living and deceased donors, these efforts have had little to no effect on the rate of organ donation and transplantation in the United States from 1988 to 2010. [2] The authors of the study concluded that state policies aimed at removing financial disincentives seem to be insufficient in motivating potential living donors. In the development of this conclusion, Chatterjee et al. cite a study conducted by Venkataramani et al., which focused on the impact of tax policies on living organ donations in the United States from 2000 to 2010. The study examined policies in several states that offered tax deductions to defray potential donation-related costs. According to Venkataramani et al., the state tax policies had no significant effect on the rate of living donation. [12]

The authors of both studies suggest that a reason for the lack of effectiveness of state policies on donation rates is that the policies do not make a large enough dent in reimbursing the financial costs associated with living organ donation. [2][12] Venkataramani et al. state that a tax deduction of \$10,000 on donation-related costs translates to only about \$600 in actual cash value. [12] This cash value is small compared to the estimated average financial burden faced by living kidney donors in the United States for costs such as transportation, lodging, lost wages, and medical costs. Depending on the case, these costs can range from \$907 to \$3089. [3] Based on these numbers and the ineffectiveness of state legislation, Venkataramani et al. suggest that state policies would likely be more effective in encouraging or facilitating living donations if they increased the value of tax deductions or instead offered tax credits. [12] More recent numbers suggest living kidney donors face a financial burden of, on average, \$3650, and up to more than \$7500. [8] Chatterjee et al. suggest that future policies should offer more complete reimbursement of living donation-related costs. [2]

In addition to the above study-based arguments for more complete reimbursement, some bioethicists have advocated for the same solution by citing more personal experiences and real world observations. For example, Sigrid Fry-Revere, president and co-founder of the Center for Ethical Solutions and the American Living Organ Donor Network, is a vocal proponent of enacting policies to better reimburse living donors. She speaks

from experience both as someone considering living kidney donation and speaking with other potential and actual living kidney donors. According to Fry-Revere, many potential living kidney donors are denied the chance to donate because they do not have the financial means. In her own experience, Fry-Revere was denied the opportunity to donate an organ to a friend in need in part because under NOTA she was legally forbidden from receiving financial aid from her friend or anyone else for certain expenses she would need covered. For example, she required an estimated \$8,000 in order to hire someone to look after her farm during her six week recovery. [6]

According to Fry-Revere, there are two main components to removing the financial disincentive associated with living kidney donation. The first is creating a system that will allow us to better reimburse living donors for their expenses. The second is changing the guidelines for reimbursement in the United States to allow donors' expenses to be covered up front, before they donate, instead of having to wait to be reimbursed after the fact. One proposal put forth by Fry-Revere is to amend the current law to allow for giving living donors cash upfront in amounts up to \$14,000 depending on predicted donation-related expenses. Fry-Revere believes that receiving reimbursement after the fact, rather than upfront, is an additional disincentive because most people do not have the financial means to spend the money first and then wait for reimbursement. She states that the money on such a card could be used for donation-related costs including lost income and transportation, as well as additional costs such as childcare. [6]

ETHICAL ANALYSIS

What is missing from much of the recent literature on this topic is an in-depth analysis of the ethical principles involved. My main goal in the remainder of this paper is to fill in this space in the literature. In doing so, I will outline and address the most plausible ethical worries about removing the financial disincentive to living kidney donation.

One primary concern of someone who supports the restriction of financial reimbursement for living kidney donors might be for the health and psychosocial well being of potential living donors. Although people can typically live relatively normal lives with one kidney, there are still risks involved with donating a kidney. As we have seen, the hope of enacting policies and laws that would allow for more complete reimbursement of living kidney donors is to persuade more potential living donors in to going ahead with donation. Although this change, if effective, would have the benefit of saving the lives of many people with kidney disease, one might question whether we really want to support law and policy changes that may encourage more people to put their health at risk. According to the Organ Procurement and Transplantation Network, some of the recognized potential health and psychosocial

risks associated with living kidney donation include death, decreased kidney function, kidney failure, the need for dialysis or transplant, body image issues, post-surgery depression or anxiety, and a general impact on the donor's lifestyle. [15] Considering all of these risks associated with living kidney donation, perhaps a financial disincentive or barrier is beneficial because it will deter some people from taking on these risks if they are unsure about donating. At least, it forces potential donors to stop and seriously consider taking on the risks of donating before making the choice to do so.

There are several ways of responding to the concern that donation will negatively affect donors' health and psychosocial well-being. Primarily, the fact that there is concern for the health and well-being of living kidney donation is all the more reason to allow donors to be fully reimbursed so that they are better financially prepared to handle the risks associated with it or to keep the level of risk very low through proper follow-up medical care. Further, even though there are some health and psychosocial risks, there is evidence to show that health problems for living kidney donors are fairly uncommon and living donors do not usually regret their choice to donate. For example, there is less than a 0.5 percent increase in incidences of end stage renal disease for living kidney donors at 15 years after the transplant. [9] For these reasons, it seems that ensuring that potential living donors have made a fully informed choice to consent to donation, including that they understand all of the risks involved, is enough to ensure that living donors have spent an adequate amount of time fully considering the choice to donate. If we ensure that this is the case, we do not need a financial barrier to make sure donors are weighing this decision carefully. Finally, it seems that someone who does not support fully reimbursing living donors due to a concern for the health and psychosocial well-being of the donor is not really opposed to fully reimbursing donors. Rather, they are opposed to the idea of living kidney donation itself. However, the policy and law changes I am suggesting are contingent upon the legality of living donation and the basis that living donation is morally permissible.

A second concern with laws and policies that allow for more complete reimbursement is that they may open the door for more societal or familial pressure to donate on people who do not want to donate because they no longer have a financial excuse not to. For example, a potential donor who chooses not to donate because he, understandably, fears the health risks associated with living donation may feel more pressure to donate than he otherwise would have if there were a financial barrier to donation.

We can respond to this concern with a reply similar to the one given above. Unless you have reason to believe that living donation is, in itself, a wrong thing to do, there is no reason to be concerned that people will no longer have an excuse not to donate if there is no longer a financial disin-

centive. If someone does not want to donate his kidney, there is little reason to believe that the lack of a financial barrier would put undue pressure on him to do so. Even if this were the case, the fact that removing the financial disincentive will likely allow many more people who would like to donate to do so seems significantly more important than some amount of added pressure to donate because there is no longer a financial barrier. Although it is important to consider that a small number of people who do not want to donate may feel some extra societal pressure, this concern is secondary and can perhaps be alleviated with open conversation within families and guidance or counseling from doctors and medical personnel.

Yet another concern with removing the financial disincentive is that it does not alleviate the issue that people living in poverty are likely to feel the negative health effects of living kidney donation to a higher degree due to things such as labor-intensive jobs, poor nutrition, and a higher rate of violence and infectious diseases. Not only does removing the financial disincentive by better reimbursing donors not alleviate this issue, it may, in fact, exacerbate the issue by creating the illusion that because there is something like a financial safety net, living kidney donation is not risky.

The above concern is both plausible and important. One reply to this concern is that regardless of whether we remove the financial barrier by fully reimbursing living donors or not, there will continue to be people living in poverty who want to donate or do, in fact, actually donate. These incidences in which people living in poverty donate despite a financial barrier will be especially likely to occur for people with a relative, spouse, or other loved one in need of a transplant. Thus, these people will already face extra financial burdens. If people living in poverty are going to donate either way, it is best to at least ensure that they do not face extra financial hardships by providing them with full reimbursement for their donation-related costs. As long as we do our best to ensure through careful policy choice that we are not encouraging anyone in living poverty to donate through extra financial incentives, we should not run into any extra problem here. In several countries, receipts for each particular expense must be provided in order to receive reimbursement. [11] This type of policy is one way to ensure we do not go beyond removing the disincentive and enter into the category of providing financial incentive. Another possible way of addressing this issue is to enact additional regulations that ensure those people living in poverty are fully aware of the extra risks they may face and perhaps providing additional medical resources or reimbursement to protect them from those risks. We could implement such regulations in conjunction with formulating policies or enacting laws that allow for more complete reimbursement of all living donors.

One final concern with removing the financial disincentive is that the

line between removing the financial disincentive and creating an ethically problematic financial incentive or payment may, in fact, be quite blurry. If we cannot draw a distinct line between removing the financial disincentive and creating a financial incentive, we run the risk of facing similar ethical issues to those associated with a kidney market, which allows for the buying and selling of kidneys. The most prominent ethical issue associated with a kidney market is the exploitation of people living in poverty. Those who hold this view argue that a system that allows people to buy organs allows rich people to take advantage of the poor. It is claimed that a rational person would sell an organ only if he or she were in great economic need. [7] Someone who decides to sell an organ out of economic desperation is not truly making an autonomous choice but rather, is in a sense being influenced by his economic situation. If this is the case, it might call to question whether someone can truly give informed consent to selling a kidney. [7]

In order to ensure that we are not crossing the line into the territory of financial incentives for donation, we would need to answer several very difficult questions. First, we would need to decide exactly which costs faced by a donor would or should count as donation-related expenses, which should be completely reimbursed. For example, donation-related costs such as medical expenses, the donor's travel and lodging expenses, paid leave for the donor, travel and lodging expenses for a spouse or family member to accompany the donor, and childcare each seem like fair candidates for reimbursement. However, reimbursement payments to the donor to cover the costs he might face during weeks of recovery such as hiring someone to clean his home, walk his dog, mow his lawn, tend to his garden, or cook meals for him and his family may seem to some to be extraneous costs that should not be reimbursed. A second difficult question to address is when we should stop reimbursing a living kidney donor's expenses, particularly, his medical expenses. While it seems relatively uncontroversial that a living kidney donor should be allowed reimbursement for the cost of the surgery to remove his kidney and any medical costs associated with the initial recovery immediately following the surgery, reimbursing some other medical costs is more controversial. For example, we would need to decide which of the donor's medical costs further down the line should be reimbursed, such as if a donor later develops disease in his or her remaining kidney. The last ethically difficult question associated with enacting laws or policies to better reimburse living donors is about how we could ensure that any reimbursement payments made to a donor would actually go to covering the donor's donation-related costs and not instead to some entirely unrelated cost.

While there is no concrete way to answer these questions, one possible method is examining the policies implemented in other countries and reviewing their successes and failures or ethical pros and cons. For exam-

ple, an article published in 2009 presented the first comprehensive review of global policies and programs for reimbursing live organ donors for their non-medical expenses. [11] According to this article, many nations have recently established programs, differing in operation and scope, which aid living donors with their financial expenses. More specifically, as of 2009, donor reimbursement programs exist in 21 countries. In 17 of those countries, lost income is reimbursed, while in 12 to 19 countries, travel, accommodation, meals, and childcare costs are reimbursed. Finally, 10 countries have comprehensive programs, where all major cost categories are reimbursed to some extent, including costs such as eldercare and parking. Further, each program varies widely in its method for determining what extent to reimburse donors, how to supply the donor with the reimbursement, and how to ensure reimbursement goes towards donation-related costs. For example, some countries have programs in which reimbursement is determined, in part, based upon income levels, while other countries such as Norway place no maximum amount on reimbursement as long as expenses are documented and reasonable. This information on policies and programs in other countries is useful. However, more extensive research needs to be done to evaluate the success of these programs. Success should be based on whether they increase rates of donation as well as whether or not they have shown to be ethically problematic in terms of providing unwanted financial incentives.

Moreover, even if a policy were implemented in the United States that erred on the side of more generous rather than cautious reimbursement, additional regulations could be created to help protect against negative effects such as undue influence in case unwanted financial incentives were inadvertently created through such a policy. For example, as discussed earlier, it is important to draw the line carefully between which costs can and cannot be reimbursed and for how long those costs can be reimbursed. Careful research needs to be done in order to come to an agreement about where to draw the line that will work for a broad variety of living donation cases. Again, it is possible that reimbursing costs such as homecare and cooking, or offering the donor a health insurance plan for many years post transplant surgery, might be viewed as a financial incentive, which goes beyond simply removing the financial barrier. However, if policy makers did choose to reimburse each of these costs and reimburse them for long periods of time in order to maximally remove any financial disincentive, they might also create strict guidelines for psychologically evaluating donors. These psychological evaluations would ensure, for example, that donors were not being coerced to donate due to a difficult financial situation. This type of regulation has been proposed by those in favor of regulated organ markets in order to reduce concerns usually associated with organ markets, such as the worry of coercion. [4] One might argue that such regulations may not be strong or

easily enforceable enough to reduce risks of coercion. However, such regulations may be effective if used as something like a safety net to ensure that we do not cross the line from removing a financial disincentive into the ethically risky and problematic territory of creating a financial incentive.

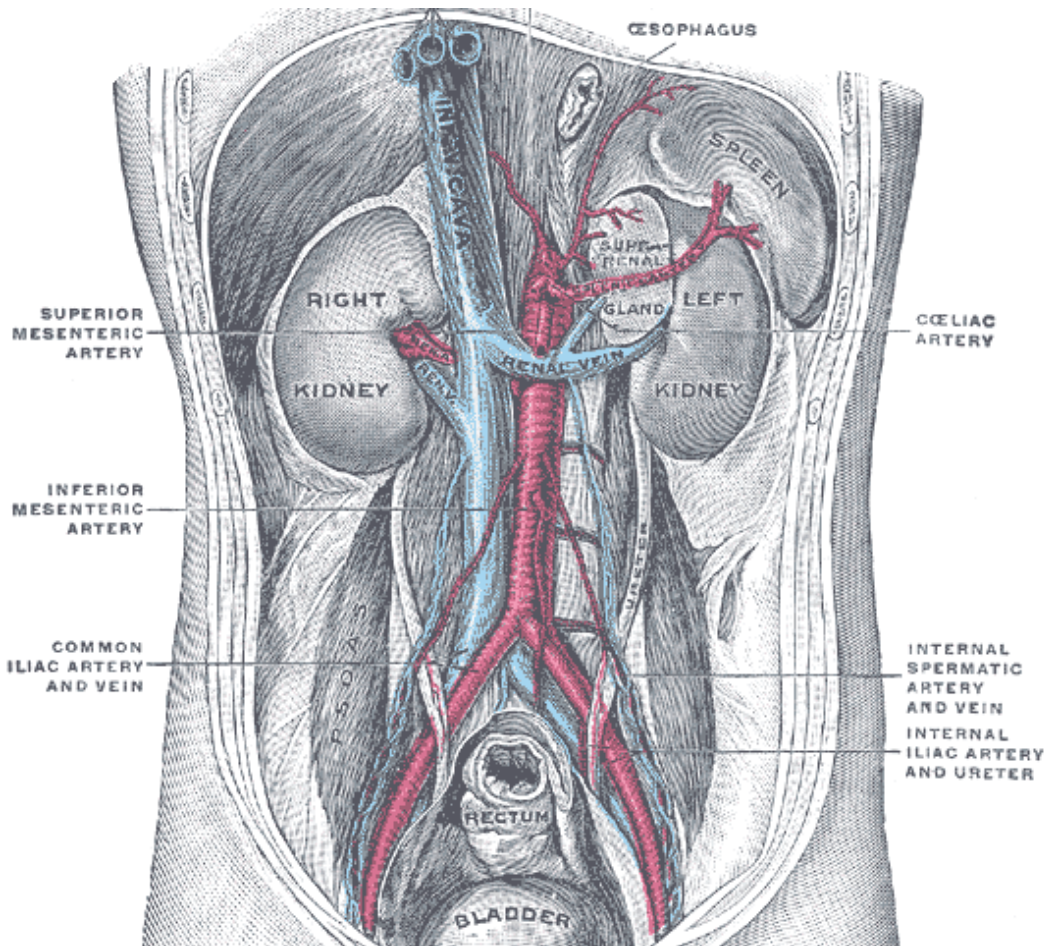
CONCLUSION

Many bioethicists support the idea that the United States needs to change its policies and laws to allow for more complete reimbursement of expenses in order to remove the financial disincentive associated with living kidney donation. In this paper, I have addressed several ethical concerns regarding removing the financial disincentive. While these concerns are important, they are outweighed by the importance and urgency of solving the kidney shortage crisis and can be mediated through careful development of policies and regulations. There are extremely weighty reasons to amend policies in order to remove the financial disincentive of living kidney donation, and a lack of strong enough ethical reasons to not do so. Thus, it is clear that the current legislation needs to undergo serious change.

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Henry Vandyke Carter, circa 1858, *Plate 1121*. “Posterior abdominal wall, after removal of the peritoneum, showing kidneys, suprarenal capsules, and great vessels.” Published in *Anatomy of the Human Body*, Henry Gray, 1918. Licensed under public domain.

Ethical Concerns of Concierge Medicine in America

by Emily Sayegh[†]

Concierge medicine has grown in practice, partly as a result of the increasing issues within the American healthcare system. This system allows physicians to limit the number of patients seen by charging an annual fee, which buys the patient unique and exclusive services from an “on-call” physician. However, this practice negates the ethical principles of healthcare as it discriminates against those unable to pay. In this paper, I argue that concierge medicine is not the solution to healthcare issues like “physician burnout” and overpacked clinics. Rather, concierge medicine is unethical, compromises the healthcare of poor communities, and disproportionately redistributes much needed medical expertise in favor of the elite.

Concierge medicine, especially within the last few years, has certainly made an impact on the healthcare system. However, its growth has caught the attention of many, as it manipulates the boundary of what is considered ethical medical practice. In this article, I argue that concierge medicine is indeed unethical in that it is a classist and discriminatory solution that further perpetuates health inequalities, especially across income levels. First, I provide a brief background on the nature of concierge medicine and why it has captured the interest of so many physicians and patients in America. Then, I make the case as to why it is an unethical, discriminatory, and classist form of medical practice. Finally, I propose the most important considerations when attempting to reform healthcare and to ensure the most vulnerable populations are provided the resources needed to maintain their health.

For the past several years, the American healthcare system has seen ever-increasing disparities in access to basic primary healthcare between

[†] **Emily Sayegh** is a senior at Fordham University majoring in biology and minoring in bioethics. Sayegh has done bioethical research on conscience clauses as well as the topic of concierge medicine. She also worked on clinical research that was focused on women’s preventative healthcare. She is currently on the pre-medical track and hopes to become a physician, keeping a strong focus on the inequalities within the healthcare system.

low-income and high-income patients. [1] The disparities in healthcare access between these two groups exist for many reasons, two being the inadequate distribution of physicians to low-income communities and the decreasing number of medical school graduates electing to enter primary care specialties. Currently, “out of the 16,000 students who graduate... less than 600... per year plan on entering general internal medicine.” [2] This decrease in the number of physicians who aim to specialize in internal medicine is not without cause. Many young physicians turn away from primary care because of its incredibly long hours, high volume of patients, and relatively lower compensation, compared to more glamorous and lucrative specialty fields. Robert Berenson, a former member of the Medicare Payment Advisory Committee, wrote that although the public has “little sympathy for physicians who cry poor, the lower income of primary care physicians is a major factor leading U.S. medical students to reject primary care careers.”

Our current healthcare system’s setup has caused a large influx of patients at clinics and a gradual shift of physicians from primary care medicine into privatized speciality medicine. Insurance companies limit per-patient revenues for services provided, leaving providers no choice but to increase the number of patients they must see to earn an appropriate income. [4] The relatively small reimbursement per patient forces physicians to work long hours, leading to serious burnout. Concierge medicine is one approach some physicians are turning to in an attempt to increase wages while reducing physician burnout as practitioners of general medicine.

Concierge medicine is a private medical practice in which the physician charges each patient a retainer fee for services provided, typically in the range of \$1500 to \$1800 per patient, per year. This fee buys the patient near round-the-clock access to the physician’s care and time, and it allows physicians to limit the number of patients seen, thereby increasing patient-physician time and allowing for better quality of healthcare. In essence, these practices limit the number of patients seen by providers, who “have contractual agreements with their patients to cover costs of medical care,” [2] once the retainer fee is paid. Since the establishment of the first concierge practice in 1996 by Drs. Howard Moron and Scott Hall, its popularity has grown at a steady rate. [2] As of 2010, “there are more than 400 group practices and the total number of physicians participating may exceed 1,300.” [6] Many concierge medical groups have formed, setting up a coalition of concierge practices that abides by an “ethical” code and is held to certain standards.

For obvious reasons, concierge medicine appears to be an appealing solution to primary care physicians’ difficult working conditions. The system allows primary care physicians to see fewer patients and to avoid certain formalities, thereby allocating more time per patient, allowing for stronger patient-physician relationships, and raising physicians’ income somewhere

near to what a specialist might be paid. One concierge physician, Dr. Harlan Matles, explains that concierge medicine enables him “to give the time and energy each patient deserves,” and adds, “I wish I could have offered this to everyone in my old practice, but it just wasn’t feasible.”

Concierge medicine is especially attractive to recent graduates of medical school due, in part, to the burden of student debt. This form of medical practice grants new physicians economic stability without the unbearable hours and high patient load, and it allows new physicians to follow their own professional interests. Many have argued that physicians are justified in making the switch to concierge medicine because they have the right to pursue a career that offers the lifestyle they want—physicians have autonomy and should be able to choose their own path. Concierge medicine appeals not only to physicians but also to patients who are fortunate to afford such a high standard of care. It is a luxury that allows one to receive high quality care whenever it is needed, to participate in proactive preventative care with a physician, and to build a proper relationship with the individual overseeing one’s overall health.

Despite these obvious perks, where does that leave the patients unable or unwilling to pay the retention fee? Concierge medicine compromises the healthcare of patients unwilling or unable to afford the retainer fee by contributing to the exodus of physicians from primary care clinics, particularly in low income areas. This concern is of particular significance when we consider the grave statistical differences between the number of physicians of lower and higher income communities. In a 2010 study, the Bronx was recorded to have 654 primary care physicians, making the rate 47.1 physicians per 100,000 patients. Manhattan, on the other hand, had 2,083 primary care physicians making the rate 131.2 per 100,000. [9] These stark differences put communities like the Bronx at a higher risk of being harmed by the shortage and potential loss of physicians from their communities due to concierge medicine. A shortage of doctors increases the patient load for existing primary care practitioners, leaving lower-class patients with longer wait times and less individualized attention from the physician. This neglect worsens the experience of a physician visit and increases the risk of developing future health problems.

This effect that concierge medicine has on the healthcare of non-participating patients is a major reason as to why its practice is unethical. Many have attempted to justify this indirect consequence by comparing concierge medicine to the first-class-coach-seat debate. Anthony Demaria explains that while first class travel allows those financially successful to afford a better quality flying experience, it does not compromise the experience of traveling in coach. [3] First class indeed offers more attention and amenities and luxury seating, yet all passengers whether traveling first class or coach, arrive

at the same destination, at the same time, under the same pilot—the technicalities of the flight remain the same. With concierge medicine, however, those unable to afford this service do not receive the same standard of care as the “elite” patients—the technicalities of the “flight” are different.

When more physicians switch to concierge medicine and become unavailable to the patients who can’t afford this type of practice, the physicians are taking away from the healthcare experience of the lower class patients. Therefore, although some argue concierge medicine is fair in that it offers a luxury form of healthcare, it indirectly affects the quality of care of those not participating in this luxury.

Concierge medicine might address the problems of long wait time and minimal physician-patient relationship for some, but it worsens the stresses of the healthcare system for those unable to afford such luxuries. The provision of improved accessibility and the illusion of better quality care comes at the expense of decreased accessibility and lesser care for the other group. In all, concierge medicine further contributes to the ever-increasing healthcare disparities in our current healthcare system. One specific example was observed in a study that surveyed both concierge and traditional practices; it found that concierge doctors see significantly fewer African-American, Hispanic, and Medicaid patients than traditional physicians. [2] Concierge medicine stretches the divide between healthcare received by minority groups and low-income communities and the healthcare received by middle- and higher-income communities.

The impact on quality of care already brings concierge medicine into question, but the way in which it is marketed is also ethically inappropriate. Access to and quality of healthcare is one of the most central aspects of one’s quality of life. Given that everyone has the right to life, healthcare, too, is an inherent right held by all human beings. This differs from a privilege, whose possession depends on one’s social, political, or economic standing. If healthcare were to be considered a product to be sold, it would be reasonable to assume that its quality should increase as its cost increases. While it’s not unreasonable for certain elective procedures to bear a high price tag, the quality of the most basic care should not be a function of the price paid. Therefore, the promise of better healthcare and more attention from physicians in exchange for paying a higher price is unethical on the grounds that a person’s irrevocable human right is dwarfed by their social status and ability to pay.

Despite this, many argue that physicians still have a right, just like any other working professional, to make career decisions autonomously that fit the lifestyle of their choice. While this is true to some extent, the medical profession must abide by ethical boundaries that limit this autonomy due to the nature of the field. A physician’s duty, first and foremost, is to do no

harm while providing equal and quality healthcare to patients regardless of their race, gender, ethnicity, sexuality, or ability to pay. Therefore, medicine does not abide by the same ethical code as a financial firm or small business since “medicine is understood to be a profession characterized by fiduciary responsibilities not expected of entrepreneurs.” [5] The unique and critical aspects of a medical profession do not allow for the physician to act completely out of self-interest, as their own career decisions may affect the livelihood of their patients. When a physician leaves their position or patient population to practice a form of medicine that excludes patients from their original population, they are acting in a way that puts lower class patients at risk. This becomes a breach of their original vow they took as a physician to do no harm.

Concierge medicine is discriminatory against lower-income patients and indirectly harms the healthcare of those unable to afford the retainer fee. Unlike many other professions, the product, healthcare, holds an important place when it comes to social responsibility. Thus, physicians’ right to autonomy takes second-stage to their responsibility for ensuring equal, high-quality care to every patient. The health and well-being of the patients must outweigh any monetary benefits.

Many have suggested that concierge medicine may be a valid solution to America’s increasing healthcare issues. Concierge medicine in and of itself is not unethical; however, the indirect harm dealt to low-income groups and the perpetuation of health disparities makes the practice unethical. The benefits to concierge physicians and the relatively small group of patients they attend to do not outweigh the harm dealt to patients unable to afford the retainer fee. It is important when dealing with scenarios like this to prioritize, especially in healthcare, the most vulnerable. In this case, that would include the lower class patients who are unable to afford such luxuries as concierge medicine. Since this particular patient population is already experiencing difficulty in accessing healthcare and resources, physicians should do what they can to minimize this harm and to not exacerbate it.

Clark, Friedman, Crosson, and Fadus argue that concierge medicine, when it follows careful guidelines, does not harm those unable to pay and cannot be considered an abandonment of patients. They explain that concierge medicine is an ethical practice because physicians “have a plan of continuity of care... and do not leave patients in an unstable condition.” [2] They further claim that some concierge physicians offer scholarships to a limited number of patients unable to pay the retainer fee. The reality is, however, that these contractual guidelines attempting to maintain concierge medicine’s ethical standards only work on the small scale; they do not prevent the large-scale harm concierge medicine deals to low-income communities as a functioning unit. A study conducted by Gavirneni and Kulkarni found that

concierge medicine is more likely to be adopted in areas of high income and where the income variance is larger. [4] This finding alone sustains the argument against concierge medicine, but it also hints at the inefficacy of those scholarships provided to people unable to pay. Even if these scholarships are an effective means through which lower-class patients can afford concierge medicine, the practices themselves are often located outside their community, making ability to travel another serious consideration. Solutions to the growing inequalities in healthcare must involve better use of private and public resources. [8]. Those working in healthcare must recognize the socioeconomic factors that influence the opportunity structure and access to quality care. The solution to the healthcare crisis is not attained by providing further opportunities for care for the few but, rather, by mitigating the factors that limit the opportunities for the majority—limited accessibility, a shortage of physicians working at primary care clinics, unaffordable insurance costs, and external influences that take a toll on the patient's health.

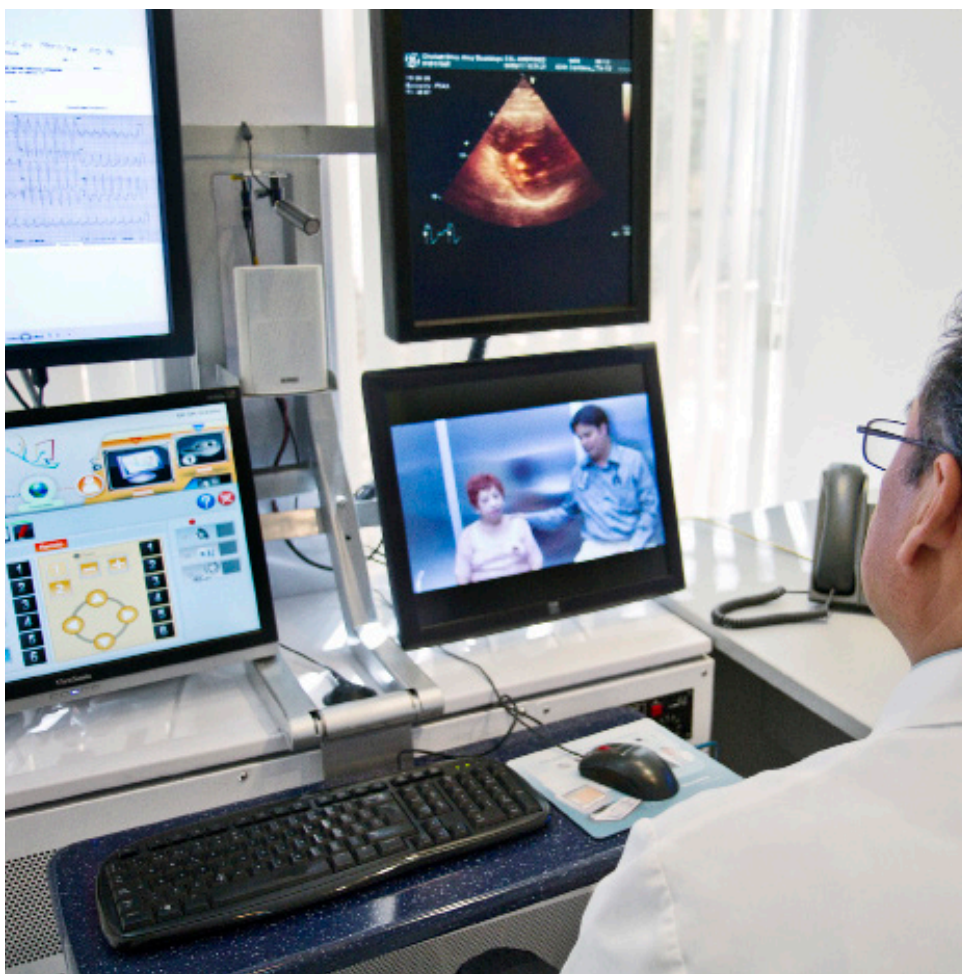
A single solution that addresses all these issues is nearly impossible, but the entrance of new physicians into underprivileged healthcare through incentive systems, increasing the physician-to-patient ratio, is a reasonable start. Increasing compensation for primary care physicians and implementing a preventative-care-based approach to healthcare that targets health problems prevalent in particular communities are other feasible strategies. Concierge medicine is unethical on the grounds that it discriminates against those unable to pay exorbitant costs and indirectly harms the healthcare of those who do not participate, especially in low-income communities. Concierge medicine, although bearing respectable intentions, further perpetuates the correlation between income and healthcare accessibility by redistributing needed resources to the middle- and upper-economic classes. The practice further stratifies the quality of care across race and class and, although it relieves some issues like physician burnout, it allows for a greater problem to persist in which individuals' health, well-being, and human rights are at risk.

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Employing Embodiment Bioethics: A Cancer Care Case Study

by Danielle C. Thor[†]

Holistic bioethical inquiry requires the understanding and utilization of several analytical techniques to contextualize and ultimately alleviate a variety of presented conflicts. Of these techniques, embodied ethics, or ethical exploration based on the process in which a body comes to know itself within a social context, may serve greater purpose to the aspiring bioethicist than initially imagined. Through a clinical cancer research case study, the three dominant embodiment types—body as a specimen, patient, and spectacle—are examined for their utility. The study also suggests new avenues for exploration in extensions of embodied ethics.

The pursuit of modern bioethical knowledge necessitates the need to develop tools that place bioethical dilemmas in the context of the lives actually affected by the resolution of such conflicts. Embodied ethics, or ethical exploration based on the process in which a body comes to know itself within society, serves as a metaphorical multi-tool to provide a more thorough, contextual analysis. In embodied ethics, the body is seen distinctly as a body reflexive of the self that is acting within a unique sociocultural environment, or a “Body-Self-in-Action” for short. This examination of the body and its constant fluctuation within an equally changing environment leads to three social constructions of theoretical “body types”: the Body as a Specimen, the Body as a Patient, and the Body as a Spectacle. Bioethicists tend to treat each “body” as a stand-alone theoretical approach to understanding the human experience of illness or disease. However, in a real-world clinical setting, this approach is arguably too narrow-minded to

[†] **Danielle C. Thor** is a graduate student in the M.A. in Urban Bioethics program at the Temple University Lewis Katz School of Medicine. Her experiences in health-care range from years of service in emergency medical services, to laboratory research in academic and industrial settings, to her current role as a clinical research coordinator at Fox Chase Cancer Center. She holds a B.S. in kinesiology and completed the ACHS Post-baccalaureate Program at Temple University and hopes to culminate these pursuits by becoming a physician.

suffice for such analysis. Within the experiences of clinical cancer research, it is illustrated that the body types of embodied ethics are best used synergistically in clinical practice to circumvent such parochial divisions of the body and encourage a contextually-sound approach. With examples of each body in action drawn from the same patient interacting with the same Clinical Research Coordinator during their clinical trial enrollment, the benefit of employing a multifaceted understanding of embodiment will be confirmed. Doing so not only enriches bioethical dialogues, but creates opportunity for the development of new, potentially useful bodies to expand the functionality of the “embodied ethics multi-tool.”

The first of the body types, titled “Body as a Specimen,” is generally regarded as the objectification of the body for the purpose of scientific study and/or mechanical repair. Throughout modern history, the rapid influx of medical technology alongside the surge of scientific dominance over medicine has increasingly reinforced the specimen viewpoint of patients, for better or for worse. Medical sociologist Marc Berg and health ethicist Paul Haternick observe the introduction of this objectification through the chronology of 20th century medicine:

“In the interrelation of proliferating techniques, patient-centered record, doctors, nurses, and the patient, a body emerged whose dimensions do not map the everyday sites and events on the ward or in the clinic. The body extends in an anatomical/pathophysiological space and time which is traveled by blood cells and growing tumors, and which is explored through urinalysis and endoscopies.” [1]

Sociological historians may utilize such a definition to outline the progression of the “technicalization” of a given population at a given time to paint medicine as systematic and separated from the subjective patient experience. Similarly, clinical cancer research enforces a “specimenization” of the patient, as the pressures placed on the research professionals demand a seemingly endless creation and collection of validated quantitative data. These pressures are best demonstrated through the following real patient example:

A 63-year-old male, to be referred to as Tim, has been diagnosed with recurrent Peripheral T-Cell Lymphoma (PTL), a rare form of non-Hodgkin’s Lymphoma (NHL) with no known cure despite its similar morphology and presentation to more common NHL subtypes. Having been diagnosed almost a decade prior, Tim had completed a plethora of standard of care treatments for NHL, including chemotherapy, immunotherapy, and an Autologous (Self-to-Self) Stem Cell Transplant, resulting in several collective years of remission. Despite these efforts, his cancer rapidly rebounded over the last several months, resulting in a high enough tumor burden in his legs that he had great difficulty walking and faced moderate to severe daily leg pain.

Having already completed so many treatments, with the recommendation of his treating physician, Tim and his wife sought out an appropriate clinical trial at a larger cancer center and found an industry-sponsored trial specifically for PTL. The experimental treatment itself was relatively simple: a bimonthly 30-minute infusion of a well-known immunotherapy with a limited side effect profile. Yet, virtually every other aspect of Tim's progression through the trial required his paired caretaker, the Clinical Research Coordinator (CRC), to utilize each embodied ethics "body type" to provide him with the best care while also maintaining the integrity of the research data.

As soon as Tim confirmed his interest in enrolling in the PTL clinical trial, he was instantly redrawn by the research enterprise as a specimen, or "specimenized." For every research participant, the first order of business following informed consent procedures is to determine the participant's eligibility based on a series of criteria pre-determined by the study sponsor; simply stating that the participant has the type of cancer the study is looking for will not do. Since Tim's study was run by a major pharmaceutical company, the multipage eligibility criteria provided in the study protocol mandated that Tim complete a myriad of repetitive, potentially harmful procedures, such as bone marrow biopsies and lumbar punctures, within a short time-frame to scientifically confirm his eligibility and/or rule out any confounding variables. Once Tim's eligibility was confirmed and he began his treatment, he would maintain his level of "specimenization" through constant surveillance for adverse events from the treatment and extra blood draws for pharmacokinetic testing (despite the experimental drug's pharmacokinetics already being well-understood by the NHL community). Lastly, the data manager associated with the study would be tasked with quantifying and imputing virtually his entire patient experience from first treatment to last five-year post-treatment follow-up, solidifying him in the eyes of those who care for him or his data as "Subject 00076." Without the ability to view Tim from the "Body as a Specimen" narrative, neither he nor his physicians may have found him a treatment option like this highly-specific PTL trial. However, an "over-specimenization" is equally possible, especially when engaging with a protocol as relentless as that from a pharmaceutical company. Both the patient and his providers benefit from an understanding of the "Body as a Specimen" embodiment in maintaining a balance between the utility of scientific inquiry about disease and the dehumanizing nature of data collection to advocate for and/or ensure that the best care is provided or received.

The second "body type," Body as a Patient, is typically viewed as a shift from the objectivity of the Body as a Specimen to a more subjective experience through patient illness narratives. Body-as-Patient thinkers, such as Good, apply phenomenology, or the study of people's perception of the world, to find meaning in stories shared by patients as they come to terms

with how their illness has reshaped their perception. Good divides his approach into two processes the body undergoes when ill: symbolization and narrativization. [2] Symbolization generally describes the patient's official recognition of their diseased state evoked through a concrete object or moment, whereas narrativization follows to guide the patient in addressing why they believe this illness befell upon them and reconstructing their story. Clinical researchers who work directly with the patients they study often bear witness to these patients as they reconstruct their narratives to reconcile their experiences as both a sick person and a research subject.

Regardless of a patient's previous experience with cancer treatment or trials, introduction of any new course of action forces the body to react and cope with the direction their disease is taking them in. Before our example patient Tim could consent to his clinical trial of choice, his "body type" had to be seen and understood as a patient with grave concerns about his disease progression and the undeniable unknown that experimental treatments present. As he began his treatment, his first infusion of the experimental drug served as a symbolization of his new state of being, noting his "new beginning" to himself and his wife. The two then worked together to reshape his illness narrative, often communicating their findings to their CRC. Not only was the CRC one of the few healthcare providers consistently available to listen, but the CRC who can act as a liaison between the patient and the physician could communicate important findings in this narrativization process. In Tim's case, his dominating concern about his chronic leg pain and perceived helplessness when attempting to ask for improved pain management during discussion of treatment could be a point of interjection for the observant CRC. As Tim navigated the confusion of abandoning his remission narrative to create relapsed disease and research narratives, having both patient and provider aware of the Body as Patient "body type" allows both sides to make use of his subjective story to maintain his humanity despite the dehumanizing but objectively necessary experimental treatment.

The third "body type," Body as a Spectacle, is rooted in the jarring nature of medical abnormalities; the "othering" of the ill or diseased body, be it from intrigue or disgust, entertainment or exclusion. Examples of this "sensationalization" of the body range from the worship of albino persons by indigenous peoples of South America, to the wonder cast by the members of circus "sideshows" of the 19th and 20th centuries, to the fear or disdain towards certain mental illnesses or disabilities perpetrated by the modern mainstream media. Irrespective of the varied tones set by these examples, the Body as a Spectacle reinforces an internal and external "other" or "abnormal" label, displacing the patient from society. Chronic changes to the body from disease or disability, such as those of malignant cancer, can sensationalize patients even within the confines of their own healthcare team.

As mentioned, our example patient Tim suffered from PTL, a rare form of NHL lymphoma, which his treating physician had seen very few cases of in her tenure. Additionally, he was the only patient to enroll in the PTL clinical trial at the cancer center, and the 10th patient out of 20 total patient slots available to over 50 participating facilities nationwide. Tim was quickly sensationalized by the treating physician amongst her colleagues, during physician grand rounds, etc., and the trial's external monitors eagerly awaited the collection of his equally sensationalized clinical data. Even after the PTL clinical trial was determined to be the best treatment plan for his cancer, his first whole-body scan following five cycles of treatment furthered his body into the spectacle domain; it demonstrated that the tumors in his upper body had improved from the treatment while the tumors in the lower body had worsened in a rare scenario called "pseudo-progression of disease." This new spectacle opened productive communication between hematologists, radiologist, and clinical research medical monitors to determine that he was just beyond the threshold for "pseudo-progression," should no longer receive the experimental treatment, and still had some more obscure treatment options left. Superficially, the "Body as a Specimen body type" constructed for Tim may have enforced an "other" label onto him as "the guy with the weird, rare cancer," that may have some privacy implications in the gossip that ensued. However, this "body type" also served some benefit, as a case with such uncertainty as Tim's demanded open dialogue and collaboration between healthcare providers inspired by the spectacle.

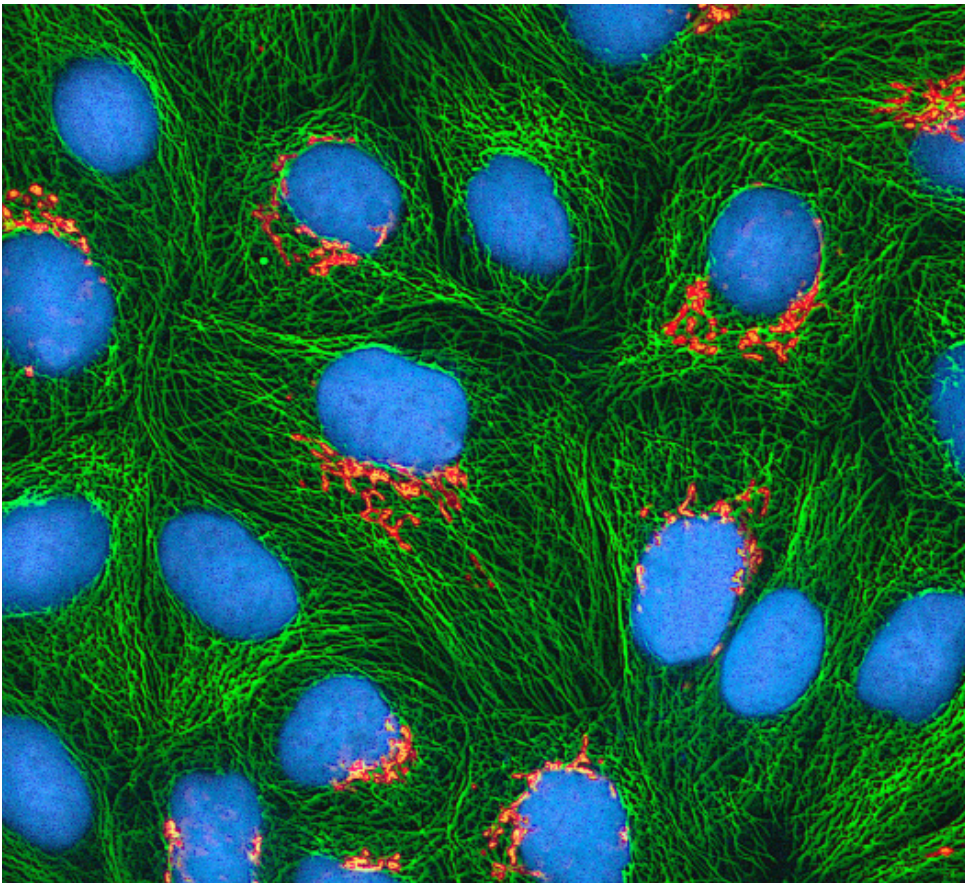
A comprehensive understanding of the three main "body types" of embodied ethics – Body as a Specimen, Patient, and Spectacle – have all provided equally diverse and productive ways of seeing patient disease or disability. From a bioethical viewpoint, embodied ethics serves as a valuable metaphorical multi-tool for performing context-driven examination of moral inquiry. It dives deeper into the realities of the given situation, providing greater insights from patient discourse to further validate a provider's course of action or a bioethicist's decision-making logic. Furthermore, by being cognisant of the Body or Bodies the individual patient identifies with, the provider can better visualize how a patient is coping with their illness and provide more expansive emotional support. Embodied ethics is demonstratively practical at the varying levels of patient interaction and ultimately worthy of greater utilization in the bioethical canon.

Through consistent use of complete embodied ethics, two more dimensions may emerge; Body as a Number and Body as a Participant. A body viewed as a number may describe a person's understanding of their individual role within maintaining the health of the collective or as "a living statistic," and may encourage novel incorporations of public health into the bioethical cannon. Somewhat similarly, a body viewed as a participant may describe

the embodiment of the “healthcare consumer” arguably either fighting or controlling the Westernized healthcare system with which they interact. Schools of thought like these (or others yet to be imagined) may already be topics of discussion, however, a more detailed investigation is necessary to determine the efficacy of either extension of embodiment. Ultimately, employing a holistic embodied ethics throughout healthcare will generate the demand for further inquiry, while encouraging a contextual understanding of illness experiences to benefit both patient and provider alike.

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Bioethical Implications of Medical Student Participation in Global Health Experiences

by Travis Kling[†]

Global Health Experiences are an increasingly popular activity for medical students, with thousands of students travelling internationally each year. Students stand to gain both personal and professional competencies from participation. However, their involvement raises a number of ethical considerations in regard to patient safety and health. Nonetheless, with adequate oversight and institutional interventions, medical student integration into international health can be realized both ethically and practically.

International medical missions serve to excite practitioners and medical students alike, and often provide the latter with a glimpse of clinical practice amidst the toil of undergraduate medical education. Global health is the understanding of population and individual health in a global context and the appreciation of factors which influence healthcare disparities. Thus, a Global Health Experience (GHE) can serve to integrate students into clinical care, engender cultural competencies, and incite passion for working with the underserved.

GHEs have become a popular activity for medical students to pursue. In fact, 27.1% of 2017 graduating US medical students had participated in a GHE during their medical education, a figure which has grown considerably from a rate of 6.4% in 1984. [1] This represents approximately 5,215 US medical students participating in at least one GHE between 2013-2017, not counting other health professions students or medical students from other high-income countries (HIC). [1]

[†] **Travis Kling** is a senior medical student at **Rutgers Robert Wood Johnson Medical School**. After graduating with his medical degree, Mr. Kling will complete a residency in emergency medicine at The University of California, Davis. Mr. Kling holds a special interest in international medicine and the ethics of healthcare delivery and has a desire to practice medicine in an international setting. As a member of the United States Air Force, he plans to continue interacting with health systems around the world as a military physician.

GHEs afford medical students the opportunity to learn about different healthcare systems. They also allow students to develop cross-cultural competencies, which leads to better care of diverse patient populations in an increasingly globalized society. Medical students who participated in a GHE during preclinical years demonstrated increased levels of cultural competencies such as acceptance of complementary medicine practices and understanding of culturally-bounded behaviors; these competencies persisted into those same students' clinical years. [2][3] Additionally, GHEs allow students to learn about healthcare inequity as well as to work with vulnerable patient populations. Students who participated in GHEs are more likely to enter primary care specialties and work with underserved populations. [3][6]

OBJECTIVE OF MEDICAL SERVICE TRIPS

In a broad sense, medical service trips (MST) in the international setting aim to fulfill the unmet health needs of target populations, often in low and middle income countries (LMIC). These unmet needs are substantial. Health practitioners; defined as physicians, nurses, and midwives; per capita is as low as 0.107 per 1000 population in Rwanda, far below the World Health Organization (WHO)-identified 2.3 per 1000 population density of practitioners necessary to meet the primary health needs of a population. There are approximately 80 nations which fail to meet this standard, with most being in Sub-Saharan Africa and Central America. For reference, the United States has 12.45 practitioners per 1000 population. [7] The target populations of MSTs often correspond with the nations with the greatest need for physicians, with the largest receiving regions estimated to be Latin America followed by Africa, regions which, as a whole, have large healthcare disparities. [7][8]

On many MSTs, there is also an educational component, with many MSTs serving as experiences for medical students and resident physicians from HICs. [6][9][10] In one review, 43% of medical missions also included an educational component for local practitioners in the target community, though these educational interventions were often lacking a detailed description in the literature. [5] Most medical service missions are short-term endeavors, with the mean participation duration based on survey data being 11.8 days for physicians and approximately 4 weeks for medical students. [3] [8] As short-term trips, many MSTs do not contribute to the establishment of lasting healthcare infrastructure, nor do many LMICs have resources in place to ensure adequate patient follow-up. [11][12][13] Survey data has indicated that physician participants in MSTs perform over 220,000 surgical procedures each year and provide countless other medical services, with conservative estimates indicating that over 250 million USD from the USA alone is spent on MSTs to LMICs. [5] Though the expenditure on MSTs to

LMICs is significant, there is a relative lack of published data collection or quantitative evidence pertaining to mission outcomes in the current literature. There is often also a lack of standardized institutional oversight for medical missions, with no governmental or professional agency responsible for ensuring quality standards. While some MSTs include cost-benefit analysis of their interventions, many do not, raising questions about economic sustainability. [14][15]

ETHICAL IMPLICATIONS

Autonomy

Respect for a patient's right to make informed decisions about their health-care should be paramount when working with any population. However, patients that are being treated as part of an MST that includes medical students from HICs may not be able to make completely autonomous decisions. Patients may not feel that they can refuse treatment by a foreign student or, due to cultural and language barriers, may not be properly informed about the student's participation in their care before they consent. [16] Furthermore, given the power differential between practitioner and patient that exists in some societies, there may exist a real or perceived implication that refusal of student involvement may lead to adverse repercussions. [17][18] While a more contemporary view of medical ethics often trades purely paternalistic practice of medicine for a model based on shared decision making, there are still many areas throughout the world where this is not put into practice. For example, the physician-patient relationship in India remains largely paternalistic, most likely due to culturally and religiously-informed holding of healers in high esteem. [19] In these populations, a more paternalistic medical model may infringe on patient autonomy to refuse medical student participation in health delivery. Additionally, societal views of the medical profession may lead to the patient wanting to please the physician, and thus they may not be fully autonomous in their decisions. [16] These types of real or perceived coercion can limit patients' abilities to make fully-informed, autonomous decisions.

Beneficence & Non-maleficence

Students without an appropriate level of training commensurate to tasks being performed can harm patients if there is a lack of adequate supervision, especially when medical students are working at understaffed GHE sites. In resource-poor areas, students may be asked to perform tasks that they are not proficient in and which would not be permitted in their home countries based on their current level of training. [23][24] Cultural and language barriers as well as power differential between physicians and students may limit the student's ability to seek adequate training.

It may be argued that medical students must be trained and learn their clinical skills in some capacity and that students could just as easily harm patients during training in HICs. However, medical training in many HICs is highly regulated and subject to rules and guidelines governing student practice. Training also includes supervision that aims to protect patients while also allowing for student learning. [25] There have been a number of studies where surveyed students express concerns that they or fellow medical students participating in GHEs provided unsupervised medical care or performed tasks beyond their level of training. [23][24][26] Several students shared similar accounts.

One reported, “During my trip, I was basically given free range to practice things such as suturing, placing IVs, and even intubation before surgery. The problem was, I had never learned these skills. Where I was in India, the physician thought I was already a doctor.” Another conveyed, “As a fourth year, I was used to having a fair degree of autonomy. However, at my site, due to there not being enough physicians, I was often left to diagnose and treat on my own. There was more than a few times where I felt I could have hurt a patient.”

It may be asserted that any form of medical care, though it may not be at the standard expected in HICs, is better than a patient not receiving any care at all. This is not necessarily the case; medical students from HICs have a greater potential to do harm in GHE settings given a variety of potential factors: less supervision, language deficiencies, cultural and ethnomedical differences, and lack of advanced diagnostic resources. Furthermore, there is the potential for harm given that patients may mistake the wearing of medical paraphernalia as conveyances of medical qualifications, thus elevating students’ medical advice in patients’ eyes. [27] Additionally, medical student incorporation may lead to poor resource allocation at GHE sites, as they will require physician supervision and medical equipment that could be better utilized for direct patient benefit.

Justice

GHEs can cultivate cultural sensitivity and a desire to work with underserved populations amongst students who participate in them. However, should disadvantaged foreign populations face the burden of cultivating these competencies in medical students from HICs? Given that these medical students are unlikely to practice in the LMIC where they attended an MST when they complete their training, foreign populations are unlikely to directly benefit from the competencies, and thus would not be justly compensated for their role in helping to foster these competencies. While there is no reliable data on United States emigration statistics as they apply to US-trained physicians, migration patterns appear to be quite low. Conversely,

it is a well-recognized phenomenon that those medically trained in LMICs often immigrate to HICs to practice; [20][21] for example, nearly 20% of Sub-Saharan Africa-born physicians currently practice in the US and UK alone. [21]

One may argue that medical students from all nations must by necessity be trained somewhere, and that this training is central to the future furnishing of competent healthcare. However, the populations served by those medical students participating in GHEs are unlikely to directly benefit from these students' competence in the future while concurrently assuming the risk of these same students' participation. While these risks conferred by students in their home countries are acceptable given the future population benefit, the ethical responsibility to provide just care commensurate to assumed risk has not been met in the setting of GHEs involving medical students. Though this responsibility could be considered met if the number of students exchanged from HICs to LMICs and vice versa was equivalent, it remains a fact that far more students from HICs participate in MSTs to LMICs than the converse. [22]

Even in resource-poor areas, allowing individuals with student-level training to provide care to patients without adequate supervision or as a substitute for the availability of more highly trained practitioners perpetuates a cycle of ignoring the broader societal factors related to healthcare inequity. To be sure, when other healthcare options do not exist in these populations, MSTs with medical students from HICs may fulfill the immediate fiduciary responsibility to provide just care; however, they fail the larger responsibility to ensure a sustainable health delivery system in that population.

Virtue

As medical professionals, our affirmation via the Hippocratic Oath to use our knowledge and skills to serve the sick makes GHEs seemingly appropriate opportunities in which a medical student may participate. Medical students may serve a vulnerable population and apply their skills for the betterment of others. However, the medical student's participation should be an exercise in virtue, in that they must acknowledge when they have the necessary knowledge and skills to help and when they do not. Just as the virtuous physician applies humility and consults his colleagues when he lacks the necessary skills to best serve his patient, so too should the medical student acknowledge the limits to his abilities. All too often, it is inexperienced first- and second-year medical students who participate in GHEs, who may not be in the best position to competently serve the target population. [8][13]

While medical student education may be viewed as virtuous in and of itself in that it eventually will lead to a competent physician who is able to treat his patients, I would argue that the pursuit of knowledge for the future appli-

cation of virtue does not supplant the responsibility to apply virtue in every patient encounter. While one may argue that patients treated in teaching hospitals in the US also bear a disproportionate burden of students' training, patients in US teaching hospitals come from all socioeconomic backgrounds while patients treated at GHE sites are assumed to be economically disadvantaged, even by their own nation's standard. [28][29] Additionally, while US teaching hospitals often record better outcomes than their non-teaching counterparts, there is a relative lack of outcome data for patients treated at GHE sites. [29][30][31][32]

PROPOSED SOLUTIONS

Medical schools should develop and foster responsible GHEs for students that meet standards of medical ethics. This could be realized via the establishment of Global Health Institutes which would develop frameworks for acceptable student conduct, such as appropriate levels of patient care involvement and levels of supervision needed based on experience level. Furthermore, these bodies should establish reasonable models for just compensation of patients seen by students at GHE sites that take into account a risk assessment of student involvement. Analysis of medical school websites in 2018 reveals that 106 of the 151 Liaison Committee on Medical Education (LCME)-accredited institutions, or 70.2%, had a dedicated office or tract governing global health. This compares to 47% in 2008. [33] While educational institutions are improving oversight of GHEs, more schools need to establish Global Health Institutes or similar bodies to govern student involvement in GHEs.

All medical students participating in GHEs should receive country and site-specific training which would serve to both enhance patient care and augment their own experience. Only approximately 60% of medical students who participate in GHEs have some form of pre-departure training, and only 40% of those who received training found it to be adequate. [23][34] Additionally, the LCME and other accrediting bodies should incorporate global health education into required curricular standards for medical institutions, as they already acknowledge the need to prepare students for the contemporary practice of medicine as well as require institutions to maintain ethical standards during extramural student activities. [35][36]

Medical schools should establish review boards consisting of faculty, staff, and students familiar with global health ethics to review and approve GHEs in which students may participate. These boards should continuously solicit input from physicians and students who participate in GHEs to ensure that each school-sponsored site continues to uphold ethical standards and that any suspect occurrences are examined and promptly resolved. Professional organizations and accrediting agencies would also do well to utilize

oversight boards to govern the broader number of MSTs which do not involve medical students. They would provide much-needed oversight for this burgeoning area of healthcare delivery.

Lastly, there is a dearth of research in the field of global health education and international MSTs that is concerning given the magnitude of health-care they provide. In many cases, there is a lack of information as to the efficacy and outcomes of MSTs, nevermind the more distinctive question of outcomes when medical students are involved. The organizers of MSTs would do well to incorporate data collection efforts into their protocols to ensure that practices continuously improve and become more patient-centered.

CONCLUSION

While GHEs exist as valuable opportunities for medical students, there are a number of ethical considerations which should be considered by students, sending institutions, and regulatory bodies that are unique to the setting of MSTs. These experiences have been shown to include a number of benefits for medical students, but these benefits should be carefully weighed against the potential harms that may be caused in the global health setting. While research into the impact of MSTs and GHEs is an expanding endeavor, there are a number of interventions that should be presently considered to address the ethical quandaries posed by medical student involvement. Medical students stand to serve as integral parts of MSTs, and given the proper ethical framework, their incorporation can serve as valuable learning opportunities while also minimizing risk and improving patient outcomes in target populations.

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Which is Which and Why This: An Analysis of Ambiguous Genitalia and Cross-Cultural Bioethics

by Esther Antwiwaa-Bonsu[†]

In this paper, I blend narrative and bioethical principles about intersex disorders, first presented by Hugh Hampton Young, to examine a case study on the topic. I start by dissecting the difference between sex and gender in order to provide context for the principal case. By illustrating a clinic appointment, I begin to explain how intersex disorders oftentimes mix issues of gender identity, gender dysmorphia, and biology. I also discuss how the U.S. and the U.K. would approach a situation like this, while offering a recommendation to the patient in either of these countries.

The most prominent feature of human beings, in our society today, is one that does not differentiate us, or make us any more different than the next. It is a feature in which none of us had any say in. A feature that was assigned at, or prior to, birth: our male or female anatomy.

Tey Meadows, in a lecture on “Being a Gender,” notes that the sociological rendering of the term gender deals with the relationships between women and men, amongst women, and amongst men within their social groups. Gender is a “property that is intersubjective and mutable in many cases because it is also an institution, broken down into three categories,” she says. [1] The three categories—bodies, identities, and behavior—represent gender’s role in our world. As gender describes our bodies, defines our identities, and manipulates our behaviors, we risk assessments by others. For Meadows, gender is not an efficient descriptive word. Often those using the term “gender” do not understand that gender is an assignation of personal identity and that it is a feature of the self. The medical community’s and so-

[†] **Esther Antwiwaa-Bonsu** was born in Kumasi, Ghana but spent most of her youth in Alexandria, VA. While a student at the University of Virginia from 2013-2017, Esther pursued religious studies with a concentration in Christianity and Hinduism. Her interest in the humanities and science also led her to minor in biomedical ethics. This fall, Esther intends to learn more about biomedical sciences when she matriculates at Geisinger Commonwealth School of Medicine.

ciety's acknowledgement that the symbolic category of gender identity and the sense of self is not aligned with the body is relatively new.

As physicians wrestle with the psychosocial ramifications of intersex children, Heather Looy & Hessel III Bouma note that "doctors believed that they could surgically normalise the genitalia, allowing parents to rear their children in the corresponding gender, confident that their child would be physically and psychologically comfortable with their sex and gender." [2] They did not anticipate that the birth of an intersex child, prompts a long-term management strategy, which involves a myriad of professionals working with the family.

For families that fear having an intersex child, Archive of Disease in Childhood published a study about the management of intersex disorders. They estimated that the prevalence of newborns with genital anomalies is only about 1 in 4,500 births. [3] The terminology for intersex in the medical community, however, has changed over time. Intersex is a part of a class of disorders called disorders of sexual differentiation (DSD). [4] The designation of DSD considers "developments in molecular genetics, ethical issues, and the perception of existing terms as potentially pejorative." [5] The most studied DSD case, with regards to sexual differentiation or the lack thereof, is congenital adrenal hyperplasia (CAH). CAH is estimated to occur in "approximately 1 in 5,000 to 1 in 15,000 births in Europe and North America." [5] Since CAH is an autosomal, recessive disorder its prevalence is limited, but of those cases, about 95% of them resulted from a mutation in an enzyme. This enzyme is integral in regulating adrenal androgens, so female fetuses diagnosed with CAH are born with some degree of virilisation, or development of male physical characteristics. [5] Surgery for intersex infants was first developed in the late 1930s by Hugh Hampton Young, a surgeon at Johns Hopkins University. Later, Young partnered with Johns Hopkins's psychologist John Money to develop an "intersex management" protocol. [6]

As the medical community conducted research on genetic disorders that cause ambiguous genitalia, underlying ethical questions grew. Do parents have the moral right to provide informed consent to surgically alter the genitalia of their children born with disorders of sex development and differentiation? Moreover, if they do not, should they wait until the child has a proper sense of gender identity before any procedures?

Because DSD is so rare, I did not expect to have an intersex/ambiguous genitalia case unfold during my first couple of weeks at the Fatal Care Center. Angela Holloway, 41, was pregnant with her third child when her doctors noticed an anomaly in her ultrasound. Sometime during the first trimester, doctors typically recommend the mother get an ultrasound to first confirm her pregnancy is viable and then to determine the sex, if the family wishes. Mrs. Holloway's predicament was a bit peculiar. At eight weeks, Mrs.

Holloway underwent an abdominal ultrasound imaging, which produced standard results. Her ultrasound showed a twin gestation and fetal poles. Per the American Pregnancy Association, “fetal pole” is the term used for the developing fetus when it first becomes visible in the gestational sac on an early pregnancy ultrasound. [7] Although called a pole, the shape of the fetal pole has some curve to it, with the embryo’s head at one end and, what looks like a tail, at the other end. [7] Because a fetal pole is among the first signs of a viable pregnancy, the presence of a fetal pole in a second gestational sac is a good thing. Mrs. Holloway’s second ultrasounds two weeks later, however, showed no further development in one of the gestational sacs. Her doctors referred her to a genetic counselor, a professional who specializes in disclosing sensitive information pertaining to genetics to pregnant women. Nonetheless, Mrs. Holloway was rightly worried about the implications for her developing babies.

While waiting to hear her options, Mrs. Holloway sat in a room where the green color of the walls called to mind sickly images, while the symmetrically hung art did nothing to disguise the thick lump of anxiety forming in her throat. A pleasantly dressed woman sat in the chair directly in front of Mrs. Holloway, with a pen, poised to write. Underneath her hand was a blank sheet of paper, with Mrs. Holloway’s name, age, and number printed in the right-hand corner. At any moment, the pen would fly across the paper, filling with patient details about their family history of diseases, disguised as lines and squares and circles. These same lines, squares, and circles were integral to the genetic counselor profession because they denote a patient’s family tree or pedigree. Once a pedigree is drawn, “all decisions about genetic screening or genetic testing is made in the context of the patient’s full family history.” [8]

As Mrs. Holloway sat on a too comfortable blue couch, she began to answer the questions the genetic counselor asked, which grew in detail as they went on. Yes, her mother and father were alive. No, she did not have a history of Down Syndrome or Turner’s Syndrome in her family. No, she was not of Jewish descent and neither was her husband. Throughout the questioning, the counselor’s pen left no line or circle or square undrawn. She was efficient.

However, efficiency was the least of Mrs. Holloway’s worries because she still shifted uneasily on the couch, wondering how this pedigree would negatively impact her. Perhaps the reason she was at the Fetal Care Center in the Battle Building of the University of Virginia Health Systems was because of something more sinister than poorly developing fetal poles in two gestational sacs. She waited.

The genetic counselor smiled again, probably knowing that her words held the key to either absolving all of Mrs. Holloway’s fears or fueling them. Perhaps a smile would make the news that was about to come more easy to

swallow. Although Ms. Holloway remained unconvinced, she listened intently as the counselor laid out the facts.

The facts were that in Mrs. Holloway's first abdominal ultrasound, two gestational sacs were forming, but only one had a fetal pole. As a result of an inconclusive first ultrasound, another ultrasound was ordered. The second one, at ten weeks, showed that Mrs. Holloway no longer carried twins. The ultrasound detected remnants of the second sac, but it appeared to have been re-absorbed, suggesting the demise of the co-twin. Although the death of a co-twin occurs in about 4% of monochorionic placentations, or twins that share one amniotic sac, Mrs. Holloway's twins were dichorionic twins. [9] The risk of co-twin demises for monochorionic twins is higher than dichorionic ones, but research is inconclusive for why this happened for Mrs. Holloway's case. Researchers did know that there was a discrepancy between the findings from the non-invasive prenatal test and the ultrasound. The sex of the baby, however, was not determined in the second ultrasound because in place of genitalia, there were three little bumps. This would be troubling news for most parents, but the genetic counselor maneuvered Mrs. Holloway's fears expertly. A survey, published in *South Asian Journal of Cancer*, found that patients wanted more information about their illnesses and options, despite the common perception that telling patients about their options only serves to increase their anxiety and may even dissuade them from undergoing one of the treatments. [10] In an effort to assuage Mrs. Holloway's circling thoughts, the genetic counselor disclosed as much information as possible.

Typically available to patients in developed nations are the vast number of options modern medicine has provided. Choosing from these options, the genetic counselor suggested Mrs. Holloway undergo an amniocentesis, an invasive prenatal cytogenetic test for chromosome abnormalities, neural tube defects, and genetic disorders. [11][12] Some parents do not care to learn the sex of their babies, but inconclusive results presents one of the central problems in ambiguous genitalia case.

So how does Mrs. Holloway proceed, knowing that at 22 weeks she is about to hit the deadline on viable terminations and that her decision would, essentially, determine her baby's sex?

Before the 1990s, clinicians in the United States made the final decision on intersex infants. By running tests, they could determine which chromosome the child had. XY denoted a male and XX for female. Clinicians also examined the genitals of the infants, when chromosome tests were inconclusive results. Per Alice Dreger, when writing for the Intersex Society of North America and in the book "*Hermaphrodites and the Medical Invention of Sex*," historically there have been two models in which discussions about intersex infants occur. [13][14] The first is the concealment-centered model,

where DSD is viewed as a rare abnormality, thought to bring great distress for both the person with the intersex condition and the parents. [13] Pioneered by John Money, this model explained that gender is malleable in the first 18 months of life. He continued to postulate that “from very early in life children’s anatomy must match the “standard” anatomy for their gender and that boys primarily require “adequate” penises with no vagina, while girls primarily require a vagina with no easily noticeable phallus.” [13] Unfortunately for most intersex boys, the designation of female is placed on them because crafting a vagina—just a hole that a penis can fit into—is easier. [13] Money’s concealment-centered model advised parents and clinicians to shroud the patient’s condition in secrecy. The patient should know very little because knowledge would lead to gender confusion, a condition that the gender assignment surgeries tried to avoid.

Fortunately for medical science and social advocates for intersex cases, this model has largely been replaced in America with the patient-centered model. In the patient-centered model, intersex is defined as a relatively common anatomical variation from standard male and female types. Parents are encouraged to seek psychosocial support and as much information as possible. Children are also given choices when it comes to the medical response. Most clinicians of this model acknowledge that children are not as ignorant as some adults like to believe. They are aware when adults are lying to them, especially about something serious. They know when something is seriously wrong with them, and as cases of terminally ill children show, they can deal with the truth if presented in a way understandable to them.

Advocates for intersex children in North America champion informed consent. Informed consent refers to the conformity of social rules of consent. Informed consent requires professionals to obtain legally/institutionally valid agreements from patients before proceeding with diagnostic/therapeutic procedures. For consent to be informed and granted, patients must fully understand the procedure, by having the procedure clearly disclosed to them. Once those conditions are satisfied, the patients can give proper approval.

Along with informed consent, patients and parents of intersex children should have the right to informed refusal. Dr. Julie Cantor, in an article published in the *New England Journal of Medicine*, wrote that competent adult women’s rights should not be diminished just because they are pregnant. In the article, she details a situation where a mother’s right to refuse treatment was ignored by the attending physicians due to a court order. [15] The court order, argued that the state has a strong interest in fetal well-being and therefore women have special obligations to fetuses when they choose to carry them to term. Physicians should discuss and revisit the risks, benefits, and alternatives of recommended care and should adequately document an informed refusal. “Forced interventions undermine the liberty, privacy, and

equality of pregnant women.” [15]

Per the U.S.’s assessment on DSD, Mrs. Holloway has the right to refuse care in the hopes of allowing her child informed consent. Her clinicians, acting ethically, should offer as much information on her child’s condition as possible. Each interested party should feel that their wishes are being listened to. But how would another country evaluate Mrs. Holloway’s case?

Questions of what is medically and ethically appropriate for cases of DSD calls for delicacy, while inciting controversy. Catherine Minto, a United Kingdom based physician, conducted a study where she found that feminizing a child by doing clitoral surgery may lead to a lifetime of sexual problems. The current protocol is to raise the child female and using surgery to remove “excess tissue” or in some case crafting genitalia. [6] Following these protocols, however, leads to very little support, education, therapy, or counseling for parents, who often are not educated on what it means to have a child with intersex conditions.

Minto urges that parents should wait for the birth of the child before any decisions are made about the child’s genitalia. Waiting for puberty, at the earliest, S. Faisal Ahmed et al. reports, proves more ethically favorable. [16] As the child grows, their conception of gender identity develops so it is imperative that clinicians and parents allow them the time to nurture that concept. Along with time, clinicians and parents should always tell the truth to their parents and children, S. Faisal Ahmed et al. notes, especially during the initial evaluation of DSD.

Drawing upon Immanuel Kant when considering the issue of truth telling in cases of DSD, there is a “categorical imperative” from which our various moral duties derive. [17] The imperative expresses that reason, above all else, is what our moral principles should rely on, rather than the inclinations of social desires, status, etc., and that the duty of veracity, or the principle of truth telling, is unconditional. Violating a child’s self-determination, by electing surgeries in infancy, is to treat them as less than a person and infringe on their autonomy. David DeGrazia, Thomas Mappes, and Jane Zembaty describe three modes of autonomy in their book detailing biomedical ethics. In it they describe autonomy as freedom of choice, liberty of action, and effective deliberation. [18] Giving the full range of choices for the parents and the child would be the most ethical thing to do, according the U.K. and U.S. recommendations for intersex cases.

Gender identity haunts every facet of our lives, dictating the outcomes of our conversations, our relationships, and our workplaces. It even rears its head on our bath products, conveniently packaged as exclusively male or female. Most infants are assigned a sex based on the appearance of their external genitalia, long before they are named. These decisions are allocated in a typically binary fashion, with no expectations for ambiguity. While the

norm, has this simplicity led the medical and social communities astray? In Mrs. Holloway's case, and many other ambiguous genitalia cases, at what time is it appropriate for the relevant parties to decide on a course of action? Moreover, how would their decisions impact the baby and its future development?

These questions, among others, came up while discussing this topic with the genetic counselor during one of our clinic days. Showing her compassionate heart, she noted how these cases not only affect the parents, but also the clinicians who first discover the anomalies. Disclosure is a chief concern of clinicians in ambiguous genitalia cases. If a clinician discloses too much or not enough information, the pregnant woman may be negatively impacted. In a "well-controlled human study," researchers found "that pregnant women with high stress and anxiety levels are at [an] increased risk for spontaneous abortion and preterm labour and for having a malformed or growth-retarded baby (reduced head circumference)." [19] The possibility of having a baby with indistinguishable genitalia is one thing, but adding stress could cause other birth defects, that Mrs. Holloway most likely wanted to avoid.

Clinicians often inform parents that societal pressures may have to be considered in decision-making as well as the baby's wishes, especially when they can understand and exercise informed consent. Although it is impossible to discern how the baby will perceive their gender, the genetic counselor urges parents to wait until the baby is born. She advises that immediately after birth, the family should see a pediatric endocrinologist, who specializes in the diagnosis and treatment of children with diseases of the endocrine system, such as growth disorders or hormone deficiencies. [20] A pediatric endocrinologist would properly diagnosis the baby for any disorder of the endocrine system that may have caused the ambiguity of the genitalia.

Additionally, the genetic counselor recommends that the family seek psychiatric help if they feel troubled about the impending decisions. Undergoing gender assignment is not a one-time procedure, but a process involving multiple surgeries and hormone therapies. Gender reassignment surgeries are not the most pleasant of surgeries, especially since they persist as the child ages. As a result of this parents should consider the biomedical ethics principle of nonmaleficence in their decision-making. Nonmaleficence prohibits the infliction of harm, injury, or death upon others. [21] Sex reassignment surgeries have lasting consequences to the baby, both physical and emotional. No one can properly discern how, if at all, the child will be affected, but the best course of action would be to wait and assess when the child is of age, sometime during puberty.

Additionally, numerous cases of children feeling something wrong and that their assigned sex does not align with what they know to be true, have

been documented. In cases like this, the genetic counselor suggests the parents explore all their available options, but first should seek professional help. She advises that although talking to other families in similar predicaments can be cathartic, professional help is essential for good decision-making.

My conversation with the genetic counselor led me to think about how I would personally address an intersex case. Like Mrs. Holloway, I was troubled to hear about the ambiguous nature of her baby's genitalia, but I am not entirely convinced ultrasound imaging is a "catch-all" technology, on which decisions should hinge. Like the counselor, I would recommend that Mrs. Holloway have an amniocentesis and a rapid FISH, or Fluorescent in Situ Hybridisation test done. FISH "is a rapid method for counting the number of certain chromosomes within cell." [22] Rapid FISH results offer quick reassurance for parents, especially if there is anxiety due to an abnormal ultrasound. Hopefully these prenatal tests would assuage some of Mrs. Holloway's concerns.

After prenatal tests, there is not much clinicians can do apart from hormone therapies. Because of this, I would recommend Mrs. Holloway wait until the birth of her baby. If she wants to explore termination as an option, I would present her with all available information and options, but also notify her of UVA Health System's rules on the matter. If she decides after the 22-week mark of her pregnancy, I would refer her to a genetic counselor.

As a bioethicist, I would respect Mrs. Holloway's autonomy. Once the baby is born, I would present Mrs. Holloway with the following courses of action: wait until the child has established a semblance of gender identity and allow him/her to make their own choice on sex reassignment surgery, or visit a trusted endocrinologist who could better diagnosis the disease and offer choices. The key word is "trusted" because, per an intersex advocacy group online, "many endocrinologists press unnecessary—sometimes devastating—"normalizing" hormone treatments on patients who are otherwise healthy." [23] Intersex groups also believe that many "doctors continue constructing vaginas in infants and young children, despite arguments by many medical professionals that early vaginoplasties fail too often and are unnecessary to begin with." [23] Listening to the opinions of advocacy groups are important for making informed decisions because these groups are influential in focusing research on an issue of great concern and providing voices for those who are not being heard. If the ambiguous genitalia case turns out to be one where a sex reassignment surgery is recommended or hormone therapies are prescribed, I would recommend that Mrs. Holloway wait until her baby has aged and the decision becomes their own rather than a rash decision by grieving parents. Jennifer Lerner and George Lowenstein discuss in *Handbook of Affective Sciences*, that the emotions we feel at the time of deciding can impact us in direct and indirect ways. [24] They note that

although “people anticipate which decision will result in things like regret, emotional pain, happiness or pleasure, they still try to select the actions with the most positive emotional outcome.” [24] Grieving parents try to minimize negative emotions, but unknowingly put their wishes and happiness on their child’s sex determination. They want their child to have the easiest time assimilating into society, so they often do not give their child the chance to define their gender.

Additionally, I would consider the ethical principle of beneficence, when making recommendations. Because beneficence is about minimizing harm for all parties involved and maximizing the benefit, recommending that Mrs. Holloway wait for the birth of the baby would be in the interest of everyone. Once the child is born, preserving the well-being of the patient, not just the intersex baby, is the next obvious step. Kessler explains that chromosomes, gonads, hormones, clitoris, reproductive capacity, and penis size—all biological indices for managing intersex—are used based on “cultural understandings of gender.” [25] Because cultural understandings of gender are subjective at best and stereotypical at worst, it is recommended to wait for the baby to make their own decisions about their gender. Gender identification is integral to people’s identity and how they present to the world. Allowing the child a full range of choices would not only adhere to the ethical principle of beneficence but also respect their autonomy.

As gender continues to be deeply valued in our culture, it becomes more strictly defined, and less fluid. The need for the medical community, families, and society to “fix” ambiguities in genital development to appease conventional definitions of sex, result in a multitude of ethical issues. Mrs. Holloway’s situation provided a perfect study in which the ethical principles of informed consent, respect for autonomy, beneficence, and nonmaleficence could be explored. No one contests that the decision-making process is a difficult one, for both clinicians and patients. Those involved wish to make the best decision possible, but fear their decision would have bad, lasting consequences. Within this paper, I argue that the most appropriate decision, in the interest of the most affected party, is the one that corresponds closely to the child’s deepest sense of self as an adult. Therefore, whenever possible, it is important to wait at least until puberty so that the patient can decide for themselves about such essential qualities such as their gender assignment and the accompanying surgeries. Allowing an ample amount of time, in which the child can develop their own sense of identity, adheres to the biomedical ethics principles of informed consent, respect for autonomy, and nonmaleficence.

Since intersex cases present themselves as not only physiological or social issues, but as genetic abnormalities, it is important to offer patients and their families the option of psychiatric help. I reject Money’s claim that gen-

der is malleable and parents must, therefore “race the clock” to determine their infants’ sex. The studies described in this paper almost all show the benefits of delaying gender assignment surgeries and therapies.

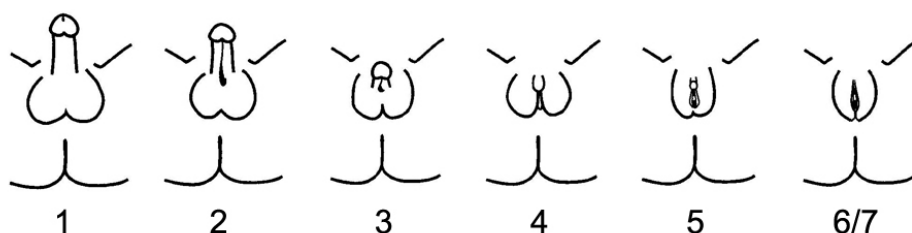
Clinicians and advocacy groups in the United States and in the United Kingdom acknowledge the complexity of DSD cases, but are hopeful for the future. Despite the U.S.’s past, in which gender assignment superseded meaningful dialogue, advocates of intersex self-determination have permitted the medical field, allowing for proper ethical considerations to take place. Failure to do so, could result in traumas and difficulties with familial relationships. Moreover, previous literature in the U.K. tended to place an emphasis on maintaining stable gender identity by accepting the medical team’s determination. As technology continues to advance, new avenues for diagnosing and treating patients with DSD become less about invasive surgical interventions and more about psychosocial understanding.

Lastly, because no other opinion matters more than that of the mother and the child, or what she perceived would be the child’s wishes, Mrs. Holloway must search deep, taking heed of the advice presented in this paper, and come up with the best solution for herself and her growing family.

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